Debate: Euthanasia — a physician's viewpoint

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Author's abstract

Discussion about euthanasia is often confused because of a failure to distinguish between deliberate death acceleration and letting nature take its course. There is a need to reiterate the traditional principles upon which the care of the dying should be based, including the need for the doctor to practise medicine in the knowledge that eventually all his patients will die. It follows that a doctor does not have a duty to preserve life at all costs.

The care of the patient with far-advanced cancer has improved considerably in many areas as a result of the establishment of hospices and domiciliary support teams. Treating the patient as a person is the key to a successful doctor-patient relationship. An analytical approach is necessary to control pain and other symptoms. Care of the relatives is also fundamental.

Voluntary euthanasia and 'assisted suicide' represent an extreme solution to a situation which demands a far more comprehensive and compassionate approach. The need is not for a change in the law but for a change of emphasis in medical education.

Editor's note: this paper is based on a lecture given to an international conference on voluntary euthanasia and suicide, sponsored by EXIT (formerly the Voluntary Euthanasia Society). A commentary follows by Nancy Ludmerer, attorney, legal writer and member of the New York bar.

Introduction

The scope of the debate concerning euthanasia has widened significantly over the last 50 years. In 1931, when Dr Killick Millard asserted that 'vast numbers of human beings are doomed to end their earthly existence by a lingering, painful and often agonising form of death' (1) discussion was largely confined to death from cancer. Today, proponents of voluntary euthanasia and/or assisted suicide express concern for a much wider circle of patients including those with severely disabling conditions such as quadriplegia (non-progressive) and multiple sclerosis and Huntington's chorea (both progressive) (2).

Concern is also expressed about the elderly invalid, the senile and those with chronic psychiatric disease.

Unfortunately, when discussing euthanasia, there is often failure to state clearly which group of patients is being referred to. From a clinical point of view, most of these categories are essentially disparate, not least because the implications of the illness for a young quadriplegic differ considerably from those for the patient with multiple sclerosis or senility. In other words, it is necessary to examine each group of patients separately in order to avoid gross over-simplification and sweeping generalisations, both of which serve simply to obscure rather than to clarify. Most of my remarks are, therefore, restricted intentionally to the care of patients with advanced cancer.

'Euthanasia' literally means death without suffering but is now generally defined as bringing about the death of a human being on purpose as part of the medical care being given him. In relation to the terminally ill, a more precise functional definition is helpful — the administration of a drug (or drugs) deliberately and specifically to precipitate or accelerate death in order to terminate suffering. Unfortunately, much that is said and written about euthanasia fails to distinguish between deliberate death acceleration and matters such as adequate pain relief and 'letting nature take its course'. I shall begin, therefore, by considering some of the principles on which clinical practice is traditionally based.

Ethical considerations

1) A DOCTOR PRACTISES MEDICINE IN THE KNOWLEDGE THAT EVENTUALLY ALL HIS PATIENTS WILL DIE

This implies that the doctor recognises that one day nature must be allowed to take its course. In other words, there comes a time when, because of the natural order, a patient ought to be allowed to die. This implies that the responsibility of the doctor in this circumstance is to do nothing that might unnecessarily prolong the process of dying. If you like, in certain situations, the patient has a 'right to be allowed to die'.

'There is nothing anyone can do', the old man whispered. 'Even without your gadgets, medic, you know what's wrong with me. You can't mend a whole body, not with all your skills and all your fancy instruments.'

The body wears out. . . . And even if you gave me a new body, you still couldn't help me, because down deep, where your knives can't reach and your instruments can't measure, is the me that is old beyond repair' (3).

2) A DOCTOR ALWAYS TREATS A PATIENT

It is important, however, to remember that medical care is a continuum, ranging from cure at one end to symptom control or 'comfort care' at the other. It is, therefore, never a matter of 'to treat or not to treat?' but of determining what is the most appropriate form of treatment for each individual patient.

The term 'passive euthanasia' is often used to describe the omission of certain forms of treatment which, if applied, would tend to prolong the lives of the terminally ill. In other words, doing nothing to prevent or delay the natural course of events. However, as it does not involve deliberate death acceleration it should not be described as euthanasia. Moreover the care of the dying should not be thought of as simply a passive pursuit, that is, simply a matter of omissions (1). The use of the term derives from a failure to distinguish between the aims of acute medicine and those of terminal care. Priorities change when a patient is expected to die within a few weeks or months; the primary aim is then not to preserve life but to make the life that remains as comfortable and as meaningful as possible. Thus, what may be appropriate treatment in an acutely ill patient may be inappropriate in the dying. Cardiac resuscitation, artificial respiration, intravenous infusions, nasogastric tubes, and antibiotics are all primary supportive measures for use in acute or acute-on-chronic illnesses to assist a patient through the initial period towards recovery of health. To use such measures in the terminally ill, with no expectancy of a return to health, is generally inappropriate and is therefore, by definition, bad medicine.

It is sometimes said that the ethical justification for 'letting nature take its course' relies on the doctrine of acts and omissions. This states that, in certain situations, failure to perform an act (*eg* prescribe an antibiotic for a patient with terminal cancer who develops pneumonia) is less bad than performing a different act (*eg* administering a lethal overdose) which has identical predictable consequences. That is, it is more reprehensible to kill someone than to allow a person to die. While this doctrine has a certain general validity, it is nevertheless irrelevant when discussing the care of the dying. Therapeutic recommendations are based on a consideration of the possible advantages and disadvantages that might accrue for the patient. Arguments in favour of a certain treatment revolve around the question of the expected effectiveness of intervention. Linked with this are considerations of the consequences or implications for the patient, his family and society as a whole. In other words, the doctor seeks, on the basis of the biological and social facts at his disposal, to offer the patient the most appropriate form of care.

3) A DOCTOR DOES NOT HAVE A DUTY TO PRESERVE LIFE AT ALL COSTS

This follows from point 1) but needs to be emphasised. Since Hippocrates, doctors have undertaken never to destroy life deliberately. This implies that they will endeavour to sustain life when, from a biological point of view, it is sustainable. On the other hand, a doctor has no legal, moral or ethical obligation to use drugs or apply treatments if their use can be described as prolonging the process or distress of dying. He does not have a duty to preserve life *at all costs*. For example, when pneumonia supervenes in terminal cancer, morphine and hyoscine are commonly prescribed to quieten the cough and reduce troublesome secretions; antibiotics are inappropriate in this situation.

When a person is within a few days of death, his interest in hydration and nutrition often becomes minimal. This is a situation in which it is wrong to force a patient to accept fluid and food if quite clearly he or she does not wish to. The lack of interest or positive disinclination should be seen as part of the process of 'letting go'. If, however, the distinction between acute and terminal illness is ignored, the situation will not be assessed in terms of what is biologically appropriate (and therefore in the patient's best interest) but will be seen as a question of 'to treat or not to treat?'. A failure to resolve what appears to be an ethical dilemma commonly results in additional, unnecessary suffering for the patient as essentially futile life-sustaining measures continue to be used.

4) A PERSON IS NOT OBLIGED TO ACCEPT MEDICAL TREATMENT EVEN IF REFUSAL MAY RESULT IN HIS EARLIER DEATH

Doctors often act as if patients have an obligation to accept the treatment that is recommended. It is salutary to recall that a doctor is laying himself open to legal censure if he forces treatment upon a patient, unless the latter is depressed, deranged, demented or a danger to other people. The doctor, therefore, has an obligation to discuss treatment options – and their implications – with his patients, particularly those who are frail and elderly or terminally ill.

5) ALL TREATMENT HAS AN INHERENT RISK

It is sometimes claimed that 'the lethal terminal dose' is already administered under the guise of relieving pain, so that a change in the law would 'tidy up' the present state of affairs and protect the doctor against the possibility of a charge of homicide. It is doubtful whether many, if any, doctors administer narcotic analgesics in such a way as to precipitate death deliberately. On the other hand, to relieve the pain of a dying patient is undoubtedly proper medical treatment, and to term such treatment as 'indirect euthanasia' is both misleading and incorrect. Giving drugs to relieve pain cannot be equated with giving a lethal dose deliberately to end life. Sometimes the use of a narcotic analgesic may marginally shorten the patient's life, but if given for

sound medical reasons and in an appropriate dose, the giving of such a drug plays no part in the legal causation of death. Nor is it the moral equivalent of killing the patient deliberately, as the drug is given for the relief of pain. If the patient dies as a result, it is considered from a moral viewpoint to be a secondary effect – foreseeable maybe, but not directly intended.

In practice, however, and contrary to popular belief, the use of morphine in the relief of cancer pain carries no greater risk than the use of aspirin *when used correctly*. It is my experience, and that of other hospice doctors, that morphine, given regularly every four hours by mouth, is a very safe drug provided the patient is not dying from exhaustion as a result of weeks or months of intolerable pain associated with insomnia and poor nutrition. In fact the correct use of morphine is more likely to prolong a patient's life rather than shorten it because he is more rested and pain-free.

'The duty of the physician consists more in striving to relieve pain than in prolonging as long as possible with every available means a life that is no longer fully human and that is naturally coming to its conclusion'.

Pope Paul VI (4).

It is, of course, axiomatic that even in extreme situations, the least drastic remedy should be employed. Many patients develop a number of confusional symptoms during the last few days or weeks of life, notably disorientation with respect to time and, sometimes, place. Misperceptions of external stimuli are also fairly common and some experience visual and/or auditory hallucinations. With explanation ('Many patients experience this', 'It is part of being very poorly', 'It does not mean that you are losing your mind'), most patients accept these disturbances of thought with little or no distress. A few, notably those who have not adjusted to their impending death, react with increasing agitation and, sometimes, with paranoia. It is not always possible to resolve their mental suffering even by skilled psychotherapy and the careful use of psychotropic drugs. When this is the case, it is necessary to ensure that the patient sleeps for one or more periods during the day as well as at night. Reducing the length of the day in this way sometimes leads to an improvement in a patient's mental state. If the distress persists, however, it is important to recognise that the patient almost certainly has an irreversible agitated terminal delirium. In this circumstance it may be necessary to sedate the patient so that he remains asleep until death ensues a few days later. In other words, if the patient's distress is considered to be both intolerable and intractable, even in this extreme situation, the least drastic remedy is to render the patient unconscious, not to kill him.

6) PROGNOSTICATION IS AN ART, NOT A SCIENCE

Every experienced clinician knows that it is usually extremely difficult, if not impossible, to give a firm prognosis. Comments such as 'I'd be surprised if Mr X

is still alive by Christmas' and 'It could be two weeks but, equally, it could be two months, or even more', serve to illustrate the fact that prognostication is certainly as much an art as a science. Studies have suggested that doctors tend to overestimate life expectancy in terminal cancer (5). On the other hand, there are many exceptions to this general rule.

A significant minority of one's patients far outlive one's initial estimate, usually by months but occasionally by years. Equally, it becomes apparent with some that the diagnosis of terminal cancer was incorrect, and that they do not have cancer after all. This means that the possibility of unexpected recovery must not be ignored. Accordingly, except when death is likely within a few hours or days, the potential for improvement should not be substantially lessened by the treatment prescribed.

7) MEDICAL CARE INCLUDES CONCERN FOR THE WHOLE PERSON

This means that those caring for a patient must be concerned about not only physical aspects but also psychological, spiritual and social ones. It follows from this that the patient *and his family* should be regarded as the 'unit of care'. Care, therefore, is a team concern. Nowhere is this more necessary than in the care of the patient with cancer.

Hospice care

In relation to far-advanced cancer, standards of care vary in different parts of the country. The situation has, however, improved considerably in many areas as a result of the impact of St Christopher's Hospice. Built by Dame Cicely Saunders and opened in 1967, St Christopher's stands as a protest against the shortcomings of modern high-technology medicine. Looking after patients mainly with far-advanced cancer, this modern hospice offers a type of care more appropriate to the needs of the dying – care which considers the person and his family as much as the disease and which provides an environment that enables the individual to adjust emotionally and spiritually to his approaching death.

In the 15 years since St Christopher's opened, many others have sought to offer a similar kind of care to those who are terminally ill. It has not always been possible to build a separate institution and today a variety of approaches is evident. The National Society for Cancer Relief has, since 1975, been responsible in part or in full for the establishment of more than 30 'continuing care units' and home-care programmes. The dissociation of this type of care from an inpatient facility, seen in home-care programmes and symptom control teams, emphasises the fundamental point that 'hospice' is a concept of care rather than a particular type of institution. Further, this concept is not new; it is as old as medicine itself. For, since time immemorial, doctors and nurses have sought 'to cure sometimes, to relieve often, to comfort always'.

Principles of hospice care

1) TREAT THE PATIENT AS A PERSON

All of us fear death; it is part of the survival instinct. We feel uneasy in life-threatening situations. We also feel uneasy in the presence of death. There is therefore a natural tendency to withdraw from the dying. Frequently the dying patient is not involved in discussions about his illness and symptoms tend to multiply or worsen. On the other hand, if the dying patient is treated as a person and not as someone to be feared and avoided, it is generally possible to maintain a patient's self-respect and morale (Table 1).

2) SYMPTOM CONTROL

Sixty per cent of patients with far-advanced cancer experience severe pain. The reported incidence of unrelieved pain varies considerably from as little as 1 per cent up to about 30 per cent (6). Reasons for inadequate relief are many (Table 2). However, in the majority of patients, it is not difficult to control pain provided certain basic principles are adhered to (7).

These include:

- careful evaluation of cause(s) of pain;
- realisation that pain is a 'somo-psycho' experience;
- use of an appropriate analgesic on a regular basis;
- recognition that the effective dose of a narcotic analgesic varies widely;
- adoption of a 'broad spectrum' approach, combining non-drug with drug measures, and
- continuing surveillance of all patients receiving narcotic analgesics

Table 1 Patients are people

Greet patient by name.

Introduce self by name at first meeting.

Non-verbal communication:

Shake patient by hand.

Sit down if possible.

Make eye-to-eye contact.

Visit patient regularly.

Attention to detail:

Ask about known specific symptoms.

Also ask about sleep, comfort, diet, mouth, bowels, micturition.

Verbal communication:

Generally, patients who want to know more about their condition will ask, if the way is opened to them.

Do not compromise your relationship with the patient by making unwise (and unethical) promises to the relatives about non-disclosure of information to the patient.

Truth has a broad spectrum with gentleness at one end and harshness at the other; patients always prefer gentle truth.

The doctor-patient relationship is founded on trust. It is fostered by honesty but poisoned by deceit.

The doctor's responsibility is to 'nudge' the patient in the direction of reality but not to force him.

Table 2 Common reasons for unrelieved pain

I Fault with patient and/or family

- Belief by patient that pain in cancer is inevitable and untreatable.
- Failure by patient to contact family practitioner.
- Patient misleads doctor by 'putting on a brave face'.
- Patient fails to accept or take prescribed medication as does not 'believe' in tablets.
- Belief that one should take analgesics only 'if absolutely necessary'.
- Non-compliance because patient or family fears 'addiction'.
- Non-compliance because of belief that tolerance will rapidly develop, leaving nothing 'for when things get really bad'.
- Patient stops medication because of side-effects and fails to notify doctor.

II Fault with doctor

- Doctor ignores patient's pain because he believes that it is inevitable and intractable.
- Doctor does not appreciate the intensity of patient's pain; fails to get behind the 'brave face'.
- Doctor prescribes an analgesic that is too weak to relieve much or any of the pain.
- Prescription of an analgesic to be taken 'as required'.
- Failure by doctor to appreciate that standard doses (derived from post-operative studies) have no relevance in the management of cancer pain.
- Doctor fails to give patient adequate instructions about optimal use of the analgesic prescribed.
- Due to lack of knowledge about relative analgesic potency, doctor either reduces or fails to increase the absolute analgesic dose when transferring from one preparation to another.
- Doctor fears that patient will become 'addicted' if a narcotic analgesic is prescribed.
- Doctor regards morphine/diamorphine as drugs to be reserved until the patient is 'really terminal' (moribund), and continues to prescribe inadequate doses of less efficacious drugs.
- Failure by doctor to institute adequate follow-up arrangements in order to monitor patient's progress.
- Lack of knowledge of 'co-analgesics' and other drugs that are of value in situations where narcotics are only partially effective.
- Failure by doctor to use non-drug measures when appropriate.
- Failure by doctor to give adequate emotional support to the patient and family.

Attention must be paid to factors that modulate pain threshold, such as anxiety, depression, and fatigue. Much can be done to alleviate pain by explaining the mechanism underlying the pain (this reduces anxiety) and by continuing concern for the patient (this raises morale).

It is perhaps in cancer pain that the interaction of the physical and the psychological is most apparent.

Whatever the patient may know and have accepted about diagnosis and prognosis, the course of the illness – loss of appetite and weight, less energy, more symptoms, more time off work, increasing visits to hospital, and more frequent periods of inpatient treatment – means that any pain will be seen not as a useful (positive) warning but as a (negative) threat both to his way of life and to his very existence. The lack of positive meaning tends to intensify the patient's pain.

Most patients fear the process of dying ('Will it hurt?', 'Will I suffocate?') and many fear death itself. These fears remain unspoken unless the patient is given the opportunity to express them and to talk about his progress or lack of it. Then, as the true diagnosis of the patient's pain becomes clear and the patient is helped to deal with the pain of dying, less medication is needed.

In addition to obviously pressing symptoms such as pain, vomiting and dyspnoea, patients may experience discomfort from a variety of other symptoms such as dry mouth, altered taste, anorexia, constipation, pruritis, insomnia. As patients tend to be reluctant to bother their doctor about such symptoms, it is necessary to enquire about them from time to time rather than wait for spontaneous complaint. Good symptom control requires clearly-defined medical leadership. Attendance at several different out-patient clinics should be discouraged. Both patient and family should be able to identify one particular hospital doctor (or group of doctors) as their doctor(s), just as they can their general practitioner.

In cancer patients, symptoms are not necessarily caused by the malignant process. Even when they are, different mechanisms may be operative and treatment for the same symptom may vary considerably from patient to patient, *eg* vomiting associated with raised intracranial pressure and that associated with intestinal obstruction. Most symptoms are multifactorial in aetiology. Thus it is a case of recognising the various underlying factors and then 'chipping away' at them. In this way, although the underlying pathological process remains unaltered, it is generally possible to relieve the patient's symptoms either completely or to a considerable extent.

3) CARE OF THE RELATIVES

During a terminal illness the patient's relatives experience a variety of emotions. These will vary according to the depth of relationship between the patient and his family as well as to the duration of the illness and mode of death. Some people feel so repelled by the thought of death that they cannot face the one who is dying and retreat into a world of their own. In consequence, they reassure the patient that all is well, that he is getting better and there is nothing to worry about. This sort of behaviour not only isolates the patient but is ultimately harmful to those who indulge in it. The reaction to bereavement is frequently more prolonged and more guilt-ridden in those who have not faced the impending death realistically than in those who have.

When talking with relatives, one learns a lot about family relationships. Sometimes it is possible to encourage reconciliation between patient and estranged spouse or other member of the family. Financial problems or need for support in other ways, require the help of the medical social worker who should be kept informed even in situations that appear ideal. Patients often improve generally following admission as a result of the control of pain and other symptoms. They become physically independent again and no longer need to be in hospital. Because they remember what it was like before the patient was admitted for pain control, many relatives fear what might happen if the patient is discharged. A trial day out or weekend at home does much to allay their fears – or confirms that discharge is, after all, impractical.

Improving standards of care

Caring for the dying is not easy. There is no such thing as 'a typical dying patient'. Equally, no two families are ever alike. On the other hand, there is no doubt in my mind that the type of care offered by a hospice corresponds closely to the many and varied needs of the dying person and his family. Repeatedly, those who thought that the choice lay between dying in agony and being killed have found an alternative in the hospice to which they have turned with enthusiasm. This is well illustrated in the letter below (8).

The Producer,
'World in Action',
Granada Television,
Manchester.

4 August, 1980

Dear Sir,

'World in Action' 28 7 80.

Having taken part in the making of the above programme I write to register my displeasure with the final product, which proved to be a biased and sensational platform for the pro-euthanasia lobby but gave little or no insight into the real plight of cancer patients, such as myself, and the viable alternatives to euthanasia which exist.

My cancer was diagnosed in November 1979 and my health deteriorated rapidly thereafter. By January of this year I was bedbound by pain and weakness, having been able to drink only water for six weeks. My wife had been told by our family doctor that I 'would die a painful death within three months'. I felt desperate, isolated and frightened and at that time I truly wished that euthanasia could have been administered. I now know that only my death is inevitable and since coming under the care of the Macmillan Service my pain has been relieved completely, my ability to enjoy life restored and my fears of an agonising end allayed. As you can see, I'm still alive today. My weight and strength have increased since treatment made it possible to eat normally and I feel that I'm living a full life, worth living. My wife and I have come to accept that I'm dying and we can now discuss it openly between

ourselves and with the staff of the Macmillan Service, which does much to ease our anxieties.

My experiences have served to convince me that euthanasia, even if voluntary, is fundamentally wrong and I'm now staunchly against it on religious, moral, intellectual and spiritual grounds. My wife's views have changed similarly. I'm no longer in such misery that her love for me would make her want me to be dead. And after I've gone she will not have to fear the burden of guilt which would have been upon her had she wished for my early death. None of these feelings of mine were made clear to the viewing public in your programme which did nothing to shake the accepted view of cancer as a lingering, painful death, which can be avoided only by euthanasia. This lack of clarity was brought home to me when I was stopped in the street, by an inquisitor after the programme and asked 'was I for or against, after all?'.

I agreed to take part in the making of your programme to show why I was against euthanasia; why it is wrong and how groups like the Macmillan Service can make it completely redundant. Truly I feel misrepresented and abused; and I am concerned that euthanasia, if fuelled by the media with sensation-seeking programmes such as yours, will become a reality and a final and irrevocable, ill-informed choice of frightened sufferers, who really need help to live, not to die.

Yours faithfully,
Sidney Cohen

Consequently, as a practising physician, I find the very existence of EXIT anomalous. If a society to help the homeless was founded solely to campaign for the right of those without a home to opt for 'assisted suicide', few would consider it worthy of support, and many would seek to proscribe it on the ground that it would encourage some of the homeless to accept the option during a spell of transient depression or despair. Moreover, to limit a campaign to such an extreme solution would rightly be seen as casting a doubt on the wisdom, though not the sincerity, of the campaigners. As far as I am aware, no agency that is actively involved in caring for the disabled, the elderly or the terminally ill includes voluntary euthanasia among its aims.

I am reminded of the story told by Tolstoy of the death of Nicholas from tuberculosis in his novel *Anna Karenina*. Towards the end Nicholas is visited by his brother, Levin, and sister-in-law Kitty. The former is revolted by what he sees and finds himself powerless to do anything; but Kitty, with instinctive insight for what is needed, rolls up her sleeves and proceeds to wash, re-clothe, make comfortable and feed the dying man.

For 45 years EXIT has sought to legalise voluntary euthanasia. One wonders what would have happened had its founder, Dr Killick Millard, been like Kitty. One thing is certain, thousands of patients with

terminal cancer would have had better care and pain relief than has been the case.

Having said that, however, I am the first to admit that there are still far too many examples of abysmally poor care of patients dying of cancer. By means of post-bereavement visits to the surviving spouses of patients under 65 years of age, Parkes (9) concluded that 20 per cent of cancer patients dying in hospital and almost a third of those dying at home do so with their 'severe and mostly continuous pain' unrelieved. In patients cared for at home, the main reason for poor pain control appeared to be a failure on the part of the general practitioner to ensure that regular doses of an appropriate analgesic were given in sufficient quantity to alleviate the pain.

However, the real reason is almost certainly more fundamental than this – a doctor who has not come to terms with the fact of his own future death will find it difficult to support the dying. One man of 54 became totally demoralised and for several months spent much of the time crying. He was so frightened that he clung to his wife and became 'hysterical' whenever she left the room. He received an injection *each week* and apparently was not able to go into hospital because a bed was not available. Similar accounts given by other respondents suggested that neurotic exaggeration was not the explanation. Several patients put up with their pain without complaint on the supposition that nothing could be done to relieve it or that their chances of recovery would be enhanced if they refrained from taking powerful analgesics.

A change in the law will not correct current deficiencies in care. In fact, it is likely to make matters worse as it will remove the incentive for improvement. It would make it more likely that patients would be offered the false choice of only two options – dying in agony and being killed. It would further reinforce negative attitudes towards dying and death and perpetuate the belief that death from cancer is inevitably a painful, sordid business. Although seemingly compassionate, in practice it would not be so. What is needed is not a change in the law, but a change in emphasis in medical education, a greater realisation by doctors of what can be done and a parallel determination to do it. Accordingly, I conclude with an 18-point manifesto, the implementation of which would significantly improve the lot of those with recurrent and terminal cancer.

Manifesto for improvement in the care of patients with incurable cancer

What is needed is:

- 1) A recognition by doctors that much can be done, both physically and psychologically, to enable those with cancer to *live* better with their disease.
- 2) A recognition that the doctor's own fears concerning his, or her, own future death frequently prevents the adequate care of patients with recurrent cancer.

- 3) A recognition that doctors have much to learn about the art of sympathetic communication with both patients and their families.
- 4) A recognition that medical education is seriously biased in favour of diagnosis and cure, rather than in training future doctors to care for those with debilitating and progressive diseases.
- 5) A recognition that 95 per cent of doctors understand only poorly the nature of cancer pain and its management.
- 6) A parallel recognition that the control of pain and the relief of other symptoms (such as vomiting, breathlessness and insomnia) needs to be central to medical training and expertise.
- 7) A recognition that cancer pain can be relieved – either completely or considerably – provided the patient is given adequate psychosocial support and early rather than delayed analgesic treatment.
- 8) A recognition that there is far more to the relief of pain than the mere administration of analgesics.
- 9) A recognition that the two extremes of dying in agony and being killed (or committing suicide) do not exhaust the options open to the stricken person.
- 10) A recognition that the phrase ‘dying with dignity’ is too vague, too ambiguous, to be of any real value.
- 11) A parallel recognition that the emphasis in care should be on maintaining a person’s self-respect – a concept which is more easily analysed and applied, resulting in an improved relationship between the patient and those who care.
- 12) A recognition that the so-called ‘conspiracy of silence’ between the doctor and the family is unethical, inhumane and causes increased mental, and often physical, suffering for the patient.
- 13) A recognition that nothing does more to damage a person’s self-respect than the assumption by the family of the role of guardian, allowing the patient no say in the continuing management of his disease.
- 14) A recognition that 15-minute outpatient appointments at two- or three-monthly intervals are no way to monitor and control symptoms associated with far-advanced cancer.
- 15) A recognition that family doctors must take the initiative in monitoring the progress of the patient with cancer and in offering psychological support to both patient and family throughout the disease.
- 16) A recognition that, because many doctors still regard death as a failure, there is a tendency to pursue specific anti-cancer therapies even when they are obviously futile and reduce the quality of a patient’s life.
- 17) A recognition that a doctor does not have the right or duty to prescribe a lingering death by mindless, inappropriate interventions.
- 18) A recognition that talk about the ‘soft’ options of suicide and euthanasia serves simply to weaken the resilience and resolve of those who are ill, and of those who care for them, damaging morale and heightening both physical and mental suffering.

Acknowledgements

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Commentary

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I must say that Dr Twycross’s paper never really addresses the more recent thinking of advocates of voluntary euthanasia or assisted suicide at all. He defends ‘letting nature take its course’ (explaining that it is *not* euthanasia), speaks about the difficulty of prognosis, describes the advantages of hospice care (including some very valuable recommendations for dealing with pain in dying patients), and then, at the end of his discussion, states that euthanasia – and implicitly, assisted suicide, to which he makes only passing reference – is a bad choice because it is a ‘hopeless’ one, and will lead doctors to abandon efforts at controlling pain and developing hospice programmes. If that’s true – and he gives absolutely no evidence that it is – then the fault lies with doctors, and not with the choice of suicide by a dying patient, who sees suicide as a valid way of regaining some measure of autonomy and dignity in his or her final days.

The belief that for such patients – as few as they may be – suicide is an option which should not be denied was behind the most recent parliamentary bill dealing with the rights of terminally ill patients, the Incurable Patients Bill of 1976, which was defeated in the House of Lords in February of that year. Although I will devote the first part of my commentary to the topics Dr Twycross has emphasised in his paper, I will refer from time to time to relevant portions of the 1976 bill (1),

and close by trying to show how the authors of that bill sought to accommodate the needs of patients *and* doctors – and where I think they went wrong.

Once a physician undertakes to care for a patient, he has what is legally termed a 'duty of care' to the patient as a result of the special doctor-patient relationship involved. He must then seek to preserve the patient's life and health unless absolved from that duty in a particular instance – for example, by the patient's refusal to accept prescribed treatment or nourishment.

Early in his article Dr Twycross asserts that 'in certain situations the patient has a right to be allowed to die'. But what he fails to see is that the exercise of that right must be initiated by the terminally ill patient, not by the doctor's deciding what is 'appropriate' or 'in the patient's best interest' or even in the '(course) of nature'. Dr Twycross states that 'priorities change when a patient is expected to die within a few weeks or months; the primary aim then is not to preserve life but to make the life that remains as comfortable and as meaningful as possible'. Priorities change for whom? The doctor? Society? Dr Twycross states that there is 'no legal, moral or ethical obligation' to use drugs or apply treatments that 'can be described as prolonging the process' of dying. But who is describing them that way? I feel certain that there are some terminally ill patients who would choose even the merest chance of life that artificial respiration or antibiotics could give them; for these individuals, the first priority remains the preservation of life, even for a few extra days or weeks. I believe a doctor would be remiss in his legal 'duty of care' to such patients in failing to provide at least some of the supportive measures he enumerates. To say that using such measures is, by definition, 'bad medicine', points up how much medicine has come to focus on doctors and their professionally-generated standards, rather than on the needs and wishes of the individual patient.

It would be foolish to say that a doctor has no input into a patient's decision-making in the sick-room. What troubles me is that throughout much of his article, Dr Twycross has failed to recognise that there are limits to the doctor's role as decision-maker in treating the dying patient. On the other hand, there is no question that the diagnosis and prognosis of a disease are two judgments only medical experts can make. In his statement about the differing goals and types of treatment for the acutely ill and the dying patient, it's clear that Dr Twycross and other doctors make a great many *crucial* decisions all the time on the basis of their prognostication. Calling prognostication an art rather than a science doesn't change this fact.

During the debates on the 1976 Incurable Patients Bill in the House of Lords (2), its chief proponent recommended that, before a patient be afforded any rights under the bill, there would have to be substantiation by another medical opinion that the patient was indeed 'without any reasonable prospect of cure'. Although still not absolutely foolproof, this requirement would ensure that the patient was making *his*

decision based on information which was as accurate and complete as possible.

During his discussion of hospice care, Dr Twycross shows great awareness of the importance of treating a patient as an individual. In his description of ways of controlling pain in the hospice setting, as well as his table delineating the mistakes that doctors, nurses and patients make in their approach to pain, he has made a truly valuable and compassionate contribution. Where I disagree with him about methods of controlling pain is in his insistence that legislation in this area 'will remove the incentive for improvement'. Clause I of the 1976 bill stated that an incurable patient was 'entitled to receive whatever quantity of drugs may be required to give him full relief from pain and physical distress, and to be rendered unconscious if no other treatment is effective to give such relief'.

The legal basis for permitting the life-shortening drugs to be administered is not simply 'sound medical reasons' but the common law concept of *necessity*, which refers to 'a choice between competing values, where the ordinary value [not to shorten life] is to be departed from in order to avert some great evil [unrelieved pain]' (3). However confident Dr Twycross is that properly trained doctors will learn to assuage pain, suffering patients should not have to wait for the re-education of doctors for relief. As Dr Twycross's own statistics inform us, many doctors currently treating dying patients have no knowledge of, or interest in, controlling pain. It seems clear that in this area, help from outside the medical profession is needed by patients as well.

Doctors continue to wield a great deal of control over their patients in areas that are not strictly medical. Many doctors don't want this to change. As Dr Twycross observes, they help create a conspiracy of silence around the patient; in the debates surrounding the 1969 euthanasia proposal, for example, one doctor who opposed the bill objected most strenuously because the bill would have required her to tell a patient 'that he is doomed' (4). Ian Kennedy has written persuasively about how easily the lack of consent to life-saving procedures may be overridden in English law (5).

While Dr Twycross is far more sensitive than many doctors in his awareness of the legal deterrents to forcing treatment on an unwilling patient, I'm not sure if he himself ever really acknowledges the terminally ill patient's right to die *on his own terms*. What he has posited instead is the patient's right 'to be allowed' to die – on Dr Twycross's terms, in a hospice or other supportive setting acceptable to Dr Twycross.

But let us suppose for a moment that there are patients who do not choose the route of a hospice-like environment. And let us suppose that we are willing to allow that such a patient does have a right to make a private decision about his own death, a right which derives from the principle of self-determination – that a person is 'entitled to make his own decisions concerning himself, within tolerable limits, free from the interference of others' (6). Is there any way of implementing

such a right so as to make it acceptable to doctors? And is there any way of dealing with what Mary Rose Barrington, a solicitor and former chairperson of EXIT, correctly sees as 'the fundamental problem' at the heart of any proposed euthanasia legislation: determining the 'authenticity' of the patient's wishes (7).

In the Incurable Patients Bill of 1976, the bill's authors sought to achieve these goals by rather different means than in two prior proposals (in 1936 and 1969). In each of the parliamentary bills, it is true, 'tolerable [and necessary] limits' to the patient's autonomy were set by specifically providing for interference by other decision-makers, whose determinations – of the incurable or fatal nature of the patient's disease, for example – permitted or precluded the patient's exercise of his right to die. Thus, the patient's initial choice was actually only one in a series of decisions to be made. The earlier bills, however, included far more complicated procedures for doctors to follow. The 1936 proposal (8) even provided for intervention by a 'euthanasia referee' who would determine that the patient fully understood 'the nature and purpose of his application', prompting critics of that and like proposals to complain that the suffering patient would be subjected to 'the intolerable suspense of delay'.

In contrast, the 1976 bill ostensibly required very little of doctors or other caretakers. Quite simply, it stated:

'No person shall be under a duty to interfere with any course of action taken by an incurable patient to relieve his suffering in a manner likely to cause his own death, and any interference intentionally undertaken contrary to the known wishes of the patient shall be unlawful'.

The clause establishing the scope of the bill limited it to a patient

'suffering without any reasonable prospect of cure from a distressing physical illness or disability that he finds intolerable'.

By yoking the doctor's judgment of incurability (which was to be supported by a second medical opinion) to the patient's own judgment that *he* finds his illness intolerable, the authors of the bill apparently sought to make certain that the doctor's determination alone would never initiate the procedure under the bill; rather, the bill would only be triggered where the patient made known to the doctor that he could no longer tolerate the distress he was experiencing.

Clearly in other ways, too, the bill's authors tried to demand as little as possible from doctors – and as little change as possible in the existing law. Most important, there was to be no voluntary euthanasia, which doctors had long objected to as turning them into licensed murderers. There was not even to be assisted suicide, which currently constitutes a crime (by the assisting person) under the Suicide Act of 1961, and which subjects a doctor or other person convicted of aiding, abetting, counselling or procuring a suicide to up to 14

years' imprisonment (9). Under the Suicide Act, providing the instrumentality of the suicide is also unlawful – but 'mere presence' at the commission of a suicide where no duty of care remained would not be (10), and this seems to have been the legal premise the bill's authors hoped would apply.

In the debates surrounding this 1976 bill, Baroness Wootton, who had introduced it, emphasised that the non-intervention-in-suicide clause pertained to 'a patient who has taken a course of action, not someone who is proposing to take it or to attempt it'. Doctors, I think, would be the first to point out that serious practical problems in implementation are involved. As long as a patient spoke about wanting to die or to kill himself or otherwise gave reason to believe he would attempt to take 'a course of action likely to cause his own death', doctors and other professionals upon whose care the patient depended would be charged with protecting the patient and guarding him from such acts. It could be difficult to ascertain that the line drawn by this clause of the bill had in fact been crossed, and that the 'course of action' had already been undertaken and was drawing inexorably to its conclusion.

Once it was plain that the 'course of action' had been taken, then it would have to be equally plain that the patient had absolved the physician, hospital, or other caretaker of the duty of care which is imposed by law as a result of the special relationship involved. That raises the issue of the content of the patient's 'known wishes'. One imagines a doctor or other person walking in on an 'emergency' and having to determine right then and there if the patient's prior statement amounted to the requisite standard of 'known wishes'. What is it that the patient needs to have decided before someone else can decide not to try to save him? How specific and fully articulated must the patient's wishes be? These questions remained unanswered in the bill and the surrounding debates.

From looking closely at this bill's non-intervention clause, it seems quite likely that it was adopted by the bill's authors in an attempt to appease a medical community horrified at the notion of being labelled 'executioners'. I would ask that the medical community – and EXIT – take another look. For I'm convinced that assisted suicide would be more acceptable to doctors than non-intervention, and that it may be the only way to implement this right of the dying patient. Legislated carefully, a right to assisted suicide would be far more clearly and unambiguously the patient's choice. First, there would have to be an unsolicited statement of intent to commit suicide in writing from the patient, followed by a period of reflection, and then re-affirmed through a patient-initiated request for assistance. The doctor would be able to respond, providing means or simply advice, with greater certainty that the patient was seriously resolved to die than if confronted with a possibly ambiguous suicidal act. He would be less likely to be charged with having misconstrued the patient's wishes, since he would at no time be acting – or failing to act – without the patient's direction, left to

rely on what he knew of the patient's wishes from past encounters or conversations.

It might be more reasonable to expect a doctor to assist a patient *before* the patient was placed in an emergency situation. Certainly the patient would find it easier to get information and assistance where needed, while still retaining the responsibility for his own death. In contrast, the non-intervention clause would in some cases not really have helped the patient whose weakness and physical incapacity made his need for such legislation the greatest.

The terminally ill patient's decision to accelerate his own death is not always a result of 'transient depression or despair', as Dr Twycross would have us believe. Essentially this is not a medical decision. Rather it is one which must be made and carried out by the patient himself. But with appropriate legislation enacted – which could only happen with the support of the medical community – a doctor would be able to offer assistance, as well as his honest prognosis and advice, to a patient who sought it.

References

- (1) *British medical journal* 1976 January 17: 165.
- (2) 368 Parl deb HL 1976: 196–214, 226–229, 249–285.
- (3) Williams G. *The sanctity of life and the criminal law*. Knopf, 1957: 322.
- (4) 300 Parl deb HL 1969: 1229.
- (5) Kennedy I. The legal effect of requests by the terminally ill and aged not to receive further treatment from doctors. *Criminal law review* 1976 Apr: 222.
- (6) See reference (5): 219.
- (7) Barrington M. Voluntary euthanasia act 198–?. (Sic) In: Cole M, ed. *Beneficent euthanasia*. Buffalo, New York: Prometheus Books, 1975: 209–210.
- (8) *British medical journal* 1935 Nov 2: 856–857.
- (9) Suicide Act 1961, s. 2.
- (10) Principles of criminal liability. In: *Halsbury's laws of England*. 17.
- (11) 368 Parl Deb HL 1976: 235.

Response

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I have read with interest Nancy Ludmerer's comments in response to my paper. Unfortunately, she completely misunderstands my intention. I did not set out to address current thinking within the euthanasia lobby. Rather, I sought first and foremost to describe the principles of medical care in relation to the dying.

Those discussed are in the tradition of Hippocrates and of Judaeo-Christianity. I was not seeking to establish anything new; merely to re-state the time-honoured.

Ludmerer is wrong when she states that the physician's 'duty of care' implies, even when a patient is clearly dying from an incurable, irreversible and progressive disease, that it is the patient alone who may cry, 'Stop!' in relation to life sustaining (death prolonging?) measures. When deciding *any* treatment the doctor considers, among other things, the patient's 'biological potential'. There comes a point when life supporting measures become biologically futile. In such circumstances, it is part of the doctor's responsibility gently to dissuade the patient who remains eager to cling to life despite being irreversibly at death's door. As always, the treatment finally decided on, and put into effect, depends on a subtle ongoing process of negotiation between doctor and patient.

Ludmerer accepts, seemingly without question, that men and women have an ultimate right of self-determination and, therefore, of self-deliverance. This of course, presupposes a universe that has evolved through chance alone. Once God is introduced, unless he is a disinterested landlord, Man cannot claim an inalienable right to choose the moment of his death. For many, including myself, God is a vital basic presupposition without which nothing can have ultimate meaning or purpose. Ludmerer's stance is, therefore, fundamentally false.

After the presentation of my paper at the international conference organised by EXIT, Oxford 1980, several of those present said to me: 'If all doctors practised as you do, I should not need to be a member of this society'. There is, therefore, a continuing need to re-state traditional medical principles so that the public may not be misled into supporting a radical alternative which will be difficult to implement, to monitor and to prevent from abuse. That the dying are frequently ambivalent as to what they want is well known to those who work with them. Also well recognised are the emotional conflicts within the family. The longer I work with the terminally ill, the more I realise that the final solution of the euthanasia lobby just does not match the complexities of real life. It is simplistic and naive – at least in relation to cancer patients. And if it is so for these, I have no doubt that the same is true for people dying from other forms of incurable, progressive disease. It is difficult to document this conviction.

Perhaps Ludmerer should spend a year or two on the staff of a hospice. If she does, she will see what I mean. Certainly, there can be no compromise: hospice care and euthanasia/assisted suicide are mutually exclusive.