

UNRELIEVED SUFFERING IN PATIENTS WITH ADVANCED CANCER: A PERSONAL ETHICAL PERSPECTIVE

D. Jeffrey, Three Counties Cancer Centre, Cheltenham General Hospital*

One small step for man, one giant leap for mankind.

Neil Armstrong

The pioneering work of hospices has improved the care of patients with advanced cancer, and much of the basic philosophy and principles of such palliative treatment have now become incorporated into mainstream medical practice. Yet some patients who are dying suffer distress which is not relieved by medical treatment, and such instances present ethical dilemmas for the patients, their families, health-care professionals and society in general. Suffering is a subjective concept, familiar to each of us, but difficult to define accurately and succinctly in general terms. To ensure an effective response to it, it is helpful to explore the various factors which contribute to the distress experienced by the patient.

Two polarised broad approaches have evolved to deal with intractable suffering. Support for legalisation enabling active euthanasia is one approach, and the development of palliative care is the other. At the root of the argument of both the pro-euthanasia lobby and of those opposed to euthanasia is a genuine and heartfelt desire to relieve suffering. This paper seeks to review the arguments surrounding the advocacy of legalised euthanasia as a response to unrelieved suffering and, after a consideration of the issues involved, an ethical response that could meet this challenge will be suggested.

THE NATURE OF SUFFERING

Suffering has broad connotations for patients with advanced cancer and, among other matters, encompasses factors which diminish quality of life, a perception of distress, and ultimately an expression of a life not worth living.¹ Suffering includes in its ambit a threat to a patient's own autonomy and self-assuredness, which often does not remain limited to the patient but extends further to involve the family and the health-care professionals who are caring for that patient. It is not always directly related to the severity of symptoms but also depends on a number of other subtle and less easily measurable factors, such as whether a person has managed to come to terms with dying, the quality of the support which surrounds them and their pre-morbid personality. A strong need to be in control which cannot be achieved or fulfilled, for instance, may exacerbate a patient's suffering. The factors involved have been summarised by Cherny *et al*:

FACTORS INVOLVED IN THE PRODUCTION OF SUFFERING IN ADVANCED CANCER¹

Patient

- physical, e.g. unrelieved pain, breathlessness and other symptoms,
- psychological, e.g. depression, anxiety, loss of control, vulnerability, feeling of being a burden to others,
- spiritual/existential, e.g. hopelessness, meaninglessness, helplessness, endless distress,
- social, e.g. empathic distress of family, friends, health-care providers, isolation, loss.

* Macmillan Consultant in Palliative Medicine.

Family

- empathic suffering,
- anticipatory grief of bereavement,
- burden of care,
- conflicts between adequate relief of pain and fears of hastening death,
- conflicts of responsibility of care to patient and to other care-seeking dependants, e.g. children, elderly relatives,
- long trajectory of illness leading to emotional fatigue.

Professional

- empathic suffering,
- uncertainty of prognosis,
- increased awareness of own mortality,
- feelings of uselessness, failure, guilt.

WHY IS SUFFERING UNRELIEVED?

The word 'patient' is derived from the Latin '*patiens* = suffering'.² By definition, all patients are suffering, and it has long been acknowledged that not all such suffering is relievable. However, a first and essential step in assessing the situation is to ensure that all potentially reversible distress-causing factors have received attention. Thus some patients' suffering remains unrelieved because of inadequate prescribing by doctors, by lack of referral to specialist palliative care, or by a lack of awareness of palliative care services, all of which situations can be rectified.³

The medical model of patient care is certainly more useful, and more manageable and comprehensible when the goal of treatment is cure. When this goal is no longer achievable, the scope of the care should shift. Medicine may deal with suffering as a problem to manage, and the process of dying then may become a progression of problems to confront.³ Thus, a risk exists of a professional transformation of suffering into a series of medical complaints which distances the carers from the immediacy of the patient's experience.⁴ Medical language reflects our attitudes and reinforces remoteness and distance.⁵ Financial pressures and constraints of time both work against the humanisation of medical care.

Doctors have their own fears of death and dying, and these may lead them to distance themselves from dying patients in order to retain control of their own feelings.⁶ Such distancing may take the form of not making time available for these particular patients, and keeping the conversation with them limited to enquiries about symptoms rather than allowing the patient to speak and air his feelings on this subject, and anything else that really matters to him. Such emotionally-laden patient care of a non-technical nature may even be erroneously delegated to the least appropriately-trained. Paradoxically, technological advances which may prolong the dying process may inadvertently result in less care being available for a suffering patient today. Amongst patients is the fear of a lingering, undignified demise - one such patient felt she had to go to the courts to be assured of receiving 'standard' palliative care.⁷ It is this prospect of an undignified, prolonged, painful death that has generated fear in the minds of patients and rekindled interest in the possibility of legalising euthanasia.

EUTHANASIA - A FINAL SOLUTION?

A doctor who attempts to end the life of a suffering patient by what he administers to the patient intends active euthanasia. The arguments surrounding the adoption of

active euthanasia for those patients whose suffering is unrelieved may be summarised as follows:

Final respect for autonomy

Doctors have a professional duty to respect the autonomy of their patients and, with this aim fully in mind, it may surely be suggested that doctors should respond to a dying person's last wish. Such upholding of the patient's wish for autonomy does carry an important limitation, which is that the consequence of such respect for the self-determination of the patient does not infringe the autonomy of others. Thus a patient's request for euthanasia interferes with the autonomy of the doctor, with that of other family members and with society in general. The patient requesting euthanasia has to be aware of, and consider carefully, the effect of the demand for an end on family members, and that their personal choice might contribute to a more widespread use, and abuse, of euthanasia in society.⁸

If patients decide to take their own life, this might perhaps be construed as an act within the bounds of exercising their autonomy. However, once they involve a doctor, the ethical situation is different. Thus many doctors have, in general terms, rejected euthanasia.

A right to die?

A working party of the Institute of Medical Ethics suggested 'A patient's sustained wish to die is sufficient reason for a doctor to allow him to do so.'⁹ Patients may feel that the medical obligation to have their autonomy respected gives them a 'right to die'. However, the law prohibits actions causing intentional death, and ensures that any postulated right to die can never be equated with a doctor's right to kill.

Quicker relief from suffering: a duty of beneficence

Farsides postulates that euthanasia could be a logical extension of good palliative care: palliative care could be the first choice for dying patients, with euthanasia becoming available as a final option when the former appears to have failed to relieve suffering.¹⁰ Certainly doctors feel a strong duty of beneficence and that they should relieve suffering. However, this deeply felt sense of beneficent duty is to be balanced by one of non-maleficence which expressly states that the doctor must not deliberately and knowingly cause harm to his patients. Doctors are not qualified to judge that suffering always has a negative value. Since it is accepted that not all suffering is relievable and that suffering is subjective, it would thus be impossible to draw a line as to what level of suffering would justify euthanasia. In countries which have adopted euthanasia, palliative care services are scanty or non-existent. Thus it may be that, without the incentive to develop better ways of relieving suffering, euthanasia becomes an easier and logical option.

Rational use of scarce resources

In situations of economic constraint, it might even be tempting to identify euthanasia as a practical and less costly solution to the expensive problem of caring for the terminally ill. If palliative care for these patients comes to be perceived by society as a selfish and expensive choice, then funding of such services could be reduced. More resources are spent on cancer prevention and curative treatments than on palliative care, much of which is currently funded through charities. Indeed, the enactment of legalised euthanasia would be a powerful and disheartening signal to the terminally ill that the

remainder of society did not have a major interest in their need and in their care.¹¹

Killing and letting die are morally the same

It has been suggested that those doctors who refrain from treating a potentially remediable condition which eventually directly results in the death of a patient, are indeed employing passive euthanasia, e.g. withholding antibiotic treatment in a patient dying of widespread cancer who develops a bronchopneumonia. Although there are philosophical examples which suggest that 'killing' and 'letting die' may be morally equivalent, they are not inevitably the same. Withholding futile elaborate life-prolonging treatments in patients who have expressed a wish not to receive heroic treatments is morally fully justified; insisting on such treatment on all occasions would be an abuse of patient autonomy. It is this notion of futility, which is important in end-of-life decisions in palliative care.

The arguments surrounding killing and letting die make the assumption that doctors have powers to control fatal diseases indefinitely, and thus there needs to be a humble acknowledgement of the inexorably lethal power of many cancers and other conditions. Intentions are important in moral analysis. Some doctors are anxious about giving adequate amounts of opioid analgesics lest they are accused of killing the patient. The principle of 'double effect' clearly distinguishes intention, i.e. the relief of pain, from potential side-effects, such as an earlier death from acute respiratory depression. It should be noted that the appropriate use of opioids to relieve pain does not necessarily hasten death, as many members of the public may believe.

Public opinion favours euthanasia

In the UK, polls suggest a rising support for active euthanasia with 82% of the public sampled in 1994 agreeing that doctors should be allowed by law to end the life of a patient with a painful incurable disease.¹² Morality, however, is not a matter decided by an opinion poll. Seale speculates on the reasons for the rise in support for euthanasia:¹³

- Distrust of medical authority.
- The use of inappropriate life-sustaining technology.
- Decline in religious faith, more personal control.
- Individualistic approach to problems: 'I did it my way'.
- Ageing population, more lingering suffering.

WHY ARE PALLIATIVE CARE SPECIALISTS OPPOSED TO EUTHANASIA?

In practice, when struggling with a particularly difficult case of unrelieved suffering, most health care professionals involved in palliative care have, at some time or other, carefully reflected on the possibility of euthanasia. Yet they have made a clear statement of their collective opposition to this solution to suffering in a submission to the Select Committee on Medical Ethics.^{11,14}

Respect for autonomy

The possibility of personal growth and change exists, even at the very end of life. This is one of the practical reasons why those working in palliative care specialty are opposed to actively ending the life of patients. This potential for change is expressed in the patient's autonomy; euthanasia extinguishes this autonomy and denies possibilities of change or any future choices.

Slippery slopes

Whilst death may at times seem to come as a relief to patients, relatives and professionals, it is morally unacceptable to use 'premature' death as a means of bringing about such relief. Indeed, in relation to death at the other extreme of life, a vivid example in this country is in the matter of termination of pregnancy: the law has been shown to be a clumsy tool in regulating matters of morality. The intention of those who drafted the initial legislation on abortion was to restrict it to the 'hard cases'; this has proved to be impossible and there is little to suggest that euthanasia would be any different.

Going Dutch

Evidence from Holland, a country that has a more liberal attitude to euthanasia, shows that as doctors gained experience of carrying out euthanasia they became more permissive and less discriminatory in their attitudes towards euthanasia requests.¹⁵ Physicians in Holland have spoken of the frequency of the euthanasia request occurring early in the course of an illness;¹⁶ however, as the disease progressed, the request is often not repeated. Three main areas of particular concern are:^{13,17}

- involuntary euthanasia, i.e. carried out without patient consent,
- non-reporting of cases where euthanasia has been carried out,
- euthanasia in non-terminal illness.

A cry for help

The request for euthanasia may be a 'cry for help' and, although one may not relieve all suffering, one can always help the patient substantially - this might simply entail making a commitment to stay with the patient until the end. The request may sometimes be a symptom of depression which can be therapeutically assisted.

The doctor-patient relationship

Logically, the goals and principles of palliative care are incompatible with euthanasia. An important reason for this is the need for trust between both doctors and patients. This precious relationship is under threat in many spheres of medicine, perhaps confirmed by the increasing numbers of cases of litigation and complaints against doctors. Why is it that many patients no longer trust their doctors? Perhaps the explicit market forces that have been brought into health care have contributed to the patient's sense of uncertainty. Some patients are now suspicious that doctors are not acting solely in their best interests, and are concerned that clinical decisions are being taken on purely financial grounds.

AN ETHICAL RESPONSE TO UNRELIEVED SUFFERING

An ethical response acknowledges the value of the individual's life and the complexity of the concept of suffering. Suffering may not be relieved in the sense that doctors can alleviate all distress but an ethical response can be made:

Care

Recognition of a natural dying process is central to the ethics and practice of palliative care. The focus of control of suffering is with the patient, not with professionals. Suffering is an experience which may be helped by others who may provide a safe environment that allows a patient to come to terms with their suffering situation,

rather than a symptom which must be 'controlled'. Understanding, empathy, and compassion are ethical alternatives to control.

Careful assessment and attention to reversible causes of suffering needs time and competence in palliative care. Education in clinical assessment skills and in communication is required for all who work with the dying and their families. Only minorities of patients who need specialist palliative care have access to these services. The public, politicians and our colleagues all need to be made fully aware of what can be achieved by palliative care. If we are truly concerned about the quality of dying, then palliative care services need appropriate resources.

Compassion

To 'suffer with' is the root meaning of the word compassion. Suffering enforces isolation: people are severed from familial and social relationships. The presence of a doctor or nurse represents an opportunity for the patient to share the vulnerability and suffering being experienced. Health-care professionals need time to discover the inner resources available to the patient and to evaluate the patient's coping mechanisms. Time is needed to follow up and to listen carefully to the patient's view and anxieties. Such time spent needs to be valued by both the purchasers and providers of care as much as it is by patients.

Such periods spent with distressed patients may be uncomfortable for the doctor who needs to acknowledge uncertainty and vulnerability. Decisions require practical wisdom rather than algorithms or protocols.¹⁸ Doctors need to develop ways of achieving empathy, to look at the world through the eyes of the patient. Doctors need the chance to discuss difficult issues with their colleagues.

Commitment

Patient involvement is crucial if we are to reduce the sense of helplessness and to enhance the feeling of control and personal worth. The specific treatment of the cancer may have ceased but the care of the patient has to continue to the moment of death. The goal is to make life more meaningful and satisfactory, even if the advances made in terms of palliation appear to be very small in the carer's eyes. In the patient's eyes these small steps matter greatly. There has to be a clarity of vision as to whose suffering we are dealing with: is it the patient's, his family's or our own?¹⁹

For example, a patient who requests euthanasia may be motivated to do so by a belief that they have become a burden to their family.¹³ Sometimes this belief may be articulated in terms of unrelieved pain. The existence of a prohibition of euthanasia gives the doctor an opportunity to address these important concerns. 'I acknowledge that you feel you want to die, but that is something I cannot do anything about. Let's look at the issues I might be able to help you with.' The feelings of low self-worth, helplessness and hopelessness can now be addressed and often the 'pain' is alleviated.

When suffering persists, our continued commitment necessitates acting without certainty. If one's commitment is subordinated to some allegiance to a detached professional demeanour some suffering will remain untouched.³ We need to appreciate that doubt is not to be feared but welcomed; as Feynman says, 'Doubt is not a blemish upon our ability to know but the essence of knowing.'²⁰

CONCLUSION

The arguments presented defend the maintenance of a barrier against euthanasia and allowing the lack of any scope for any erosion of this rule. A moral difference does

exist between carrying out euthanasia and withdrawing or withholding futile measures at the end of life. The broad prohibition of euthanasia, may seem to preclude moral change in future, but it is because the debate is being linked to one of rationing of resources that it is imperative to draw a line beyond which doctors will not go.

The existence of a prohibition of euthanasia has many advantages for patients. For the patient with cancer and their family the world may be perceived as an uncertain and frightening place. They need doctors and nurses whom they can trust to work with them, to ensure the best possible quality of life, acknowledging that much suffering is unrelievable but that they will still give both competent and compassionate care.

REFERENCES

- ¹ Cherny NI, Coyle C, Foley KM. Suffering in the advanced cancer patient: a definition and taxonomy. *J Palliat Care* 1994; 10:57-70.
- ² Gregory D. The myth of control: suffering in palliative care. *J Palliat Care* 1994; 10:18-22
- ³ Byock IR. When suffering persists. *J Palliat Care* 1994; 10:8-13.
- ⁴ Das V. Anthropology of pain. Chapter 7 In: Critical events. Delhi:OUP, 1996; 173-96.
- ⁵ MacDonald N. The interface between palliative medicine and other hospital services. *Proc R Coll Physicians Edinb* 1995; 25:558-68.
- ⁶ Klagsburn SC. Patient family and staff suffering. *J Palliat Care* 1994; 2:14-7.
- ⁷ Dyer C. Court confirms right to palliative treatment for mental distress. *BMJ* 1997; 315:1178.
- ⁸ Randall F. Two lawyers and a technician. *Palliat Med* 1993; 7:193-8.
- ⁹ Institute of Medical Ethics working party on the ethics of prolonging life and assisting death. Assisted death. *Lancet* 1990; 336:610-13.
- ¹⁰ Farsides B. Palliative care - a euthanasia free zone? *J Med Ethics* 1998; 24:149-50.
- ¹¹ Jeffrey D. Active euthanasia - time for a decision. *Br J Gen Pract* 1994; 44:136-8.
- ¹² Donnison D, Bryson C. Matters of life and death: attitudes to euthanasia. In: Jowell R, Curtice J, *et al.* British social attitudes; the thirteenth report. Dartmouth: Aldershot, 1997; 161-84.
- ¹³ Seale C. Social and ethical aspects of euthanasia: a review. *Progress in Palliative Care* 1997; 5:141-6.
- ¹⁴ Select Committee on Medical Ethics. House of Lords Report. London:HMSO, 1994.
- ¹⁵ Maas PJ, Pijnenborg L, Delden JJM. Changes in Dutch opinions on active euthanasia 1966 through 1991. *JAMA* 1995; 273:1411-4.
- ¹⁶ Jeffrey DI. Saying goodbye in a good way: observations on palliative care in the Netherlands. *Proc R Coll Physicians Edinb* 1996; 26:216-23. .
- ¹⁷ *Economist* (Leader). The right to choose to die. June 21 1997, 13-14.
- ¹⁸ Roy DJ. Those days are long gone now. *J Palliat Care* 1994; 10:4-6.
- ¹⁹ Dunlop R. Commentaries. When palliative care fails to relieve suffering. *J Palliat Care* 1994; 10:27-30.
- ²⁰ Feynman R. Character of physical laws. Cited in: Weschler L. Mr Wilson's cabinet of wonder. New York: Vintage Books, 1996; 90.