Euthanasia and Palliative Care - An Uneasy Partnership

J. E. ELLERSHAW

This paper explores the ethical and clinical aspects of the voluntary euthanasia debate. It is clear both from reading the literature and from clinical practice that some people view voluntary euthanasia as morally equivalent to killing, yet others regard it as a basic right of the individual, and think it should be incorporated into medical practice. Before further discussion of these issues, it is first necessary to define the term 'voluntary euthanasia'. For this purpose I will use the following definition: 'a deliberate intervention taken with the express intention of ending a life to relieve intractable suffering at a patient's request'.

When considering the issues of voluntary euthanasia it is necessary to consider the ethical principles of autonomy, beneficence, non-maleficence and justice. These principles have been well described and underpin many ethical issues in the clinical arena. It is often argued that respect for autonomy, that is an individual's right to self governance, should allow an individual the right to voluntary euthanasia. It can be further argued that the principle of beneficence, ie to do good, can also be used in the argument for voluntary euthanasia, as voluntary euthanasia relieves intractable suffering. However, the principle of non-maleficence, ie to do no harm, encompasses a societal rather than an individual perspective of voluntary euthanasia related to the vulnerable in society, who may consider voluntary euthanasia a duty rather than a choice. In terms of the principle of justice within society, it could be argued that allowing voluntary euthanasia may encourage the direction of resources away from caring for people with life-threatening diseases. These are some of the core arguments used by the pro and anti lobbies regarding voluntary euthanasia. It is of note however, that no one of these principles always takes precedence over the other. The way in which each is ranked varies according to different circumstances. I will now consider these ethical principles within the context of clinical practice in various countries including the Netherlands, the USA, Australia and the United Kingdom. In Western Europe, the Netherlands is seen as a society whose laws are more liberal than those of other countries. For example in the Netherlands it is legal to possess and use cannabis. It is therefore of interest that this country has the most liberal practice regarding voluntary euthanasia in Europe. A recent article in the British Medical Journal highlighted the incidence of voluntary euthanasia in the Netherlands. This paper reports that 0.2% of all deaths are accounted for by voluntary euthanasia, which includes 2.25% of all cancer deaths and 13.41% of all AIDS deaths.

In the United States there is on-going debate regarding the legalisation of voluntary euthanasia. The vote to legalise voluntary euthanasia was narrowly defeated in Washington and California State, but in 1994 Oregon State voted for legalisation. However, this decision has been contested in the courts and the procedure may continue for some time, and may reach the level of the United States Supreme Court.

In 1995 the Rights of the Terminally Ill Act by the Legislative Assembly of the Northern Territory of Australia created the first statute in the world to permit active voluntary euthanasia. The new law means that terminally ill patients can end their lives with medical help as long as strict guidelines are met, including diagnosis by two experienced doctors, one of whom has psychological qualifications.

It is of note that the proactive move towards the legalisation of voluntary euthanasia is often driven by experiences of friends and relatives of patients who have died in pain or distress. For example, one of the prime movers in the legalisation of voluntary euthanasia in Australia was Chief Minister Peron, who suffered through the distressingly painful death of his mother. Therefore we see the response of a number of countries towards the liberalisation of voluntary euthanasia based on respect for individual autonomy. The next question we must ask is, is there an alternative response to voluntary euthanasia for these patients?

It was also the experiences of friends and rel-
atives of patients who had died in pain or distress that inspired the development of the modern hospice movement. Instead of lobbying for voluntary euthanasia to be legalised, the modern hospice movement recognised that often people who have uncontrolled symptoms can have these symptoms controlled with the right medication. They also recognised that patients do not only have physical pain, but also psychological, social and spiritual pain and that they should not be treated as a single unit, but in conjunction with their family. Thus, the speciality of palliative care has evolved. The World Health Organisation defines palliative care as:

"The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms and of psychological, social and spiritual problems, is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with anticancer treatment."

There is an increasing body of specialised knowledge related to palliative care. Specialisation in palliative care has been undertaken by many healthcare professionals, including doctors, nurses, physiotherapists, occupational therapists and social workers. In the United Kingdom there are now over 200 inpatient hospice/palliative care units with 3,000 beds, and approximately 365 homecare teams supporting people in their own homes. There are increasing numbers of hospital palliative care teams who support and advise patients, carers and health care professionals in the hospital setting. There are also 220 day hospices. Palliative care services therefore encompass hospital, hospice and community and are also supported by research, education and audit (Fig 1)

A recent key report, 'A policy framework for commissioning cancer services', by the Department of Health in the United Kingdom regarding Cancer Services stated that 'palliative care should integrate in a seamless way with all cancer treatment services to provide the best quality of life for patients and their family'. Thus palliative care is now an established part of mainstream healthcare provision and is seen as a positive response to relieve intractable suffering in palliative care patients.

This very different response to the distress of dying patients and those with life threatening illnesses has not only occurred in the United Kingdom, but is now a world wide movement. With good symptom control, psychosocial support and spiritual care including support for the family, patients who feel their life has no value, often find meaning and value in their lives. This is the experience of many health care professionals working in the palliative care field.

We therefore need to look at the palliative care development in the countries that have moved towards liberalising voluntary euthanasia. In the Netherlands, unlike the United Kingdom there are less than a handful of hospices. Reports from the Netherlands suggest that patients often see the hospice as a place of safety. It is not only elderly people who feel vulnerable, but often young people who are diagnosed with incurable diseases. They too feel pressured by society to opt for voluntary euthanasia as the "proper" way to die and are keen to look for the care and support that is offered by palliative care. It is of note that in the Netherlands medical students are trained in voluntary euthanasia but do not have formal training in palliative care.

The Remmelink report was published in the Netherlands in 1991. This reviewed the practice of voluntary euthanasia in the Netherlands. Interestingly, this in depth analysis of the true cause of death of patients in the Netherlands, not only identified voluntary euthanasia but also identified non-voluntary euthanasia. That is, situations where voluntary euthanasia was being performed on patients without their explicit consent. This had occurred in 1% of people dying in the Netherlands. This shift from voluntary to non-voluntary euthanasia provides evidence of the difficulty of securing firm boundaries in the practice of voluntary euthanasia.

In Australia, hospice care has been available in major cities for some years. However, in the Northern Territory where voluntary euthanasia has been legalised, palliative care services are in their infancy and facilities such as radiotherapy are only available by travelling south to Adelaide in South Australia. Therefore, patients in the Northern Territory requesting voluntary euthanasia do not have ready access to specialist palliative care expertise. Educational develop-
ments are now underway to support the development of domiciliary palliative care teams and isolated General Practitioners.

In 1994 in the United Kingdom the House of Lords Select Committee on Medical Ethics took evidence over an eighteen month period from both sides of the argument regarding voluntary euthanasia and it’s possible legalisation. A subgroup of the Committee visited the Netherlands and reported that they were greatly troubled by what they had witnessed. Following consideration of all the evidence, the Committee recommended to the Government that there should be no change to the law. They recommended that voluntary euthanasia should remain illegal in the United Kingdom. Their main concerns included the difficulties involved in setting secure limits on voluntary euthanasia, and their concern that vulnerable people would feel pressure to request an early death. Their recommendations included:

* High quality palliative care should be made more widely available by improving public support for the existing hospice movement, ensuring that all general practitioners and hospital doctors have access to specialist advice, and providing more support for relevant training at all levels.
* Research into new and improved methods of pain relief and symptom control should be adequately supported and the results effectively disseminated.
* Training of health-care professionals should do more to prepare them for the weighty ethical responsibilities which they carry, by giving greater priority to health-care ethics and counselling and communication skills.
* More formal and regular consideration of health care ethics at national level would be helpful.
* Long term care of those whose disability or dementia makes them dependent should have special regard to the need to maintain the dignity of the individual to the highest possible degree.

In making these recommendations the committee acknowledged that if adequate care for such individuals in society was to be provided, there would be resource implications. In the Report they said that 'The rejection of voluntary euthanasia as an option for the individual in the interest of our wider social good entails a compelling social responsibility to care adequately for those who are elderly, dying or disabled. Such a responsibility is costly to discharge.'

How then should society respond to patients who request voluntary euthanasia because of intractable suffering? It is my belief and experience that patients requesting voluntary euthanasia are often seeking help at a very vulnerable time in their life. This may be due to their physical symptoms, for example pain; psychological distress, for example the fear of death; social problems, for example their separation from their family, or spiritual problems, for example a struggle to understand the meaning of life. For some this may include religious questioning. I believe that in this situation society’s response should be to acknowledge the distress of the patient and to respond to it by providing a multi-professional team who can provide care and support for the patient, whether this be in a hospital, a hospice or the community. The risks of allowing voluntary euthanasia are great. We have seen this demonstrated in the Netherlands where pressure has been brought to bear on the vulnerable in society and the practice of non-voluntary euthanasia has emphasised the difficulties in putting boundaries around voluntary euthanasia. We have also seen that in countries where voluntary euthanasia is performed there has been poor development of palliative care services. It would be a great tragedy for society if voluntary euthanasia was allowed in order that resources be directed elsewhere.

In conclusion I have discussed how some countries including the Netherlands and the Northern Territory of Australia now allow voluntary euthanasia in response to arguments led by respect for autonomy and beneficence, that is relief of intractable suffering. However, the response by other countries to alleviate the distress of dying patients and those with life threatening disease has been the development of palliative care, an holistic approach to the specialised care of the patient and support of their family. It is of note that those countries where voluntary euthanasia is allowed are yet to develop a readily accessible specialist palliative care service. There are also genuine concerns supported by evidence from the Netherlands that suggest consideration of the ethical principles of non-maleficence and justice may outrank that of
autonomy with respect to allowing voluntary euthanasia. This includes arguments that the vulnerable may consider voluntary euthanasia as a duty and not as a choice, and the difficulties of defining the boundaries of voluntary euthanasia to avoid the “slippery slope” which may lead to the practice of non-voluntary euthanasia.

I would advocate that voluntary euthanasia and palliative care is an uneasy partnership. Patients requesting voluntary euthanasia often feel vulnerable and that they are a burden to society. As a result they do not feel safe. I feel that our duty of care is to make these people feel safe, unburden them and, most important of all, make them feel valued.

References

3. Van Der Wal G, Onwuteaka-Philipsen B. Cases of voluntary euthanasia and assisted suicide reported to the public prosecutor in North Holland over 10 years. BMJ 1996;312:612-3