

## Euthanasia and palliative care: reflections from the Netherlands and the UK

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Euthanasia, though formally still illegal, is a broadly accepted practice in the Netherlands. In the UK it is widely discussed, but the background issues are radically different from those in the Netherlands. One difference is that care for the terminally ill in the UK has a long tradition, while this type of care is just emerging in the Netherlands. Is it the only difference? In this paper we explore experiences with people who request euthanasia but are cared for in a Dutch hospice. Is hospice an answer to the needs of terminally ill patients?

Holland is the subject of interest to many because, in 1984, the Royal Dutch Medical Association drew up guidelines on voluntary euthanasia which resulted in the non-prosecution of doctors who actively and intentionally terminated life at the patient's request. The guidelines stipulate that the patient's request must be voluntary; that the patient must be suffering 'unbearably' with no prospect of improvement; and that the doctor has sought the opinion of a colleague. Fifteen years' experience has provided some important quantitative and qualitative data on the practice of voluntary euthanasia.

Many patients admitted to hospices in the Netherlands have considered euthanasia. A review of their motivation provides useful qualitative information about euthanasia in the Netherlands, and also reveals that suffering in terminal illness is far more complex than simply distress from unrelieved symptoms.

Doctors are influenced by the society into which they are born and in which they are trained. They are members of the wider community in which they live and work. The Netherlands, sandwiched between other nations, has mastered the art of compromise to maintain peace on all sides, making a desire for consensus something of a national characteristic. Moreover, religious/spiritual life in Holland was dominated by Calvinism, whose emphasis on personal responsibility helps to account for the importance attached to self-determination in contemporary, secular Holland. Meantime, in the Western world, while religious observance has declined the goals of health and an improved 'quality

of life' are pursued with a quasi-religious fervour; suffering is widely seen as meaningless and social values are ostensibly increasingly utilitarian.

### THE HOUSE OF NEEDS

When a person is terminally ill, his or her vulnerability becomes evident. Emphasis on personal control and expectations give way to a sense of fear and helplessness. Patients' needs can be considered analogous to those of a house whose structure and foundations require maintenance to avoid disrepair. Similarly, maintenance is part of palliative care, where efforts are directed to prevent loss of dignity and the maintenance of the house's 'façade' to the rest of the world.

The doctor/patient relationship is interactive, involving much social interchange analogous to conversation in the living room of the house, where problems are defined in detail and solutions sought; this close and friendly exchange of information is at a 'living room' level.

Those requesting euthanasia have often very rapidly experienced a sense of loss, leaving them depressed and vulnerable<sup>1</sup>. The 'living room' level of consultation rarely encompasses problems associated with a sense of loss or with spiritual concerns. The emotional and spiritual part of a person is very private, analogous to the 'bedroom', where the most intimate events occur, rarely disclosed to others. However, it is from deeply within this inner spiritual, private part of a person that spiritual wounds can reopen as death approaches, with past experiences and fears impinging on the interpretation of current events<sup>2</sup>. Meticulous symptom control does not automatically heal these wounds or prevent other problems arising.

An example of this was a lady in her 60s with carcinoma of the pancreas who wanted to die. 40 years previously, her 19-year-old son, a Roman Catholic, had wanted to marry a Protestant girl, but had been dissuaded by his mother. He had hanged himself, and his mother (the patient) had found the body. Now, facing her own death, the deep pain of this spiritual wound emerged. Unable to face this spiritual pain, she saw euthanasia as a solution. However, her surviving sons had their own feelings which needed resolution, and they took the view that euthanasia would simply be a rerun of their previous experience and serve to aggravate their unresolved grief. Through a gentle natural death, mother

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and sons could finally grieve together and share deeply precious moments, which have subsequently sustained the survivors.

## DUTCH HEALTHCARE

Expenditure on healthcare in the Netherlands (population 15.5 million) is higher than in the UK. The Dutch approach to medicine is more 'high-tech', and symptom control is well developed. There are only four high-care hospices, with 50 beds in total, a further 20 specialist beds in nursing homes, and about 50 000 nursing home beds in total. These provide sophisticated geriatric services through the specialty of 'nursing home medicine', which is unique to Holland. 20% of all deaths in Holland occur in nursing homes, where the average age of residents is over 80.

Those requiring hospice admission are on average around 65 and represent a different population from those in nursing homes. Very small hospice units (with fewer than 6 beds) have increasingly developed but they are not true specialist centres. They provide inpatient nursing but cannot cope when complex cases require the multidisciplinary approach. When patients are terminally ill they are frequently discharged home by hospital to the care of a general practitioner (GP), who often takes a decision in relative isolation. The GP may have been told by the hospital that 'nothing more can be done'; hence death by euthanasia may appear the only option. The GP cannot access a multidisciplinary team approach and carries the full burden of decision-making alone. In recent years GPs have increasingly sought advice from specialists in palliative care. Palliative care, with academic reference centres, is developing in different parts of the country with government support. Thus the options available in the Netherlands seem to be increasing and euthanasia, which currently is often perceived as the only option, may be resorted to less often.

The need to widen care options is illustrated by a 56-year-old man who had malnutrition rickets as a child. Despite progressive deafness and blindness he managed to run his own cigar shop. Loss of confidence in his GP led him to stop his physiotherapy and analgesics, gradually becoming increasingly desperate and eventually requesting euthanasia because of physical deterioration and pain. After several weeks of physiotherapy in the hospice he returned to work. His loss of confidence in doctors was solved by finding him another GP, not by acceding to his request for death.

Patients provide a rich narrative of experience. Failure to listen adequately to the patients' stories and the reasons behind their actions or requests is responsible for inappropriate responses by doctors in many situations<sup>3</sup>.

A survey of thirty bereaved families, where euthanasia had been discussed previously, showed that all welcomed more open discussion. Twenty-nine families were glad that

they had not pursued the euthanasia option. The exception was a woman whose father had come to euthanasia 4 years previously: when her mother became ill she felt euthanasia would solve the problems of ongoing care.

## EUTHANASIA REQUESTS

Approximately one-quarter of Dutch patients receiving hospice care<sup>4</sup> will have requested or discussed euthanasia by the time of referral. Patients are made aware by the hospice that, although hospice policy is not to administer euthanasia, they are still welcome and the hospice will strive to make euthanasia unnecessary. However, patients retain their right to refuse hospice care and to undergo euthanasia at home or in the hospital.

An analysis of 200 consecutive cases yielded insight into these requests. The majority of patients considering euthanasia (80%) are afraid of something happening, seeking safety, through death, from the perceived threat. After appropriate care most of these patients abandon their request for euthanasia. The second group (4% of patients) are extremely ill, very close to death and feel 'emotionally dead'. Stress levels are very high in both patients and carers, who 'burn out'. Most of these patients have undergone radical life-prolonging treatments which have left them severely debilitated; specialist palliative care involvement has occurred very late. Several require sedative doses of drugs to relieve agitation, achieve symptom control and allow peaceful death.

The third group (less than 1% and rarely seen in hospices) tend to be young, in managerial or other senior positions, whose normal lifestyle involves being in control and taking complex decisions. They wish to arrange everything in practical terms, frequently neglecting the emotional needs of partner and children, with whom a balanced discussion of choices may be difficult to achieve. These patients are often pivotal or dominant figures in the family, to whose wishes others accede.

A fourth group of patients (14%) are profoundly depressed. Depression is a common feature in terminal disease and may be responsible for suicidal thoughts or acts<sup>5-7</sup> and the wish for euthanasia.

The fifth group (less than 1%) are those requiring complex interventions for extreme intractable pain. Their pain has not responded to conventional doses of opioids or other drugs and is often a manifestation of 'total pain'<sup>8</sup>. In these difficult situations escalating doses of drugs may be needed to obtain symptom control; the goal remains pain control, not the acceleration of death.

## THE EVOLUTION OF EUTHANASIA IN HOLLAND

Guidelines for the practice of voluntary euthanasia (and physician-assisted suicide) were laid down by the Royal

Dutch Medical Association in 1984. These guidelines approved euthanasia if the patient had made an explicit request; if there was no other way to alleviate the patient's 'unbearable suffering'; and if prior consultation with another doctor had occurred. The doctor performing euthanasia was also required to report his actions to the appropriate authorities. It was assumed that intractable suffering was an absolute state that could not be ameliorated and that euthanasia represented the only way of obtaining relief.

During the past decade the Dutch government's priority was to have all euthanasia cases reported. The aim of explicit rules around euthanasia was to make the process transparent to everybody. It was decided to leave reporting of the underlying motives for euthanasia to the discretion of the involved physician. There was concern that increased interest in the motives behind euthanasia, and in the psychological and medical details of the patients' condition, could compromise the doctor's readiness to report the case. This has had important consequences. First, the conditions of eligibility seem to have widened: 'unbearable' has been held to include non-malignant conditions, loss of dignity and even severe grief<sup>9</sup>. Second, euthanasia without an explicit request from the patient has become increasingly common and accepted practice.

Despite the open-reporting policy, 59% of the cases remain unreported<sup>10</sup>. Moreover, there is a growing concern that the low-threshold policy has increased the use of

euthanasia overall (Table 1)<sup>11</sup>. From material provided by Dutch investigators<sup>10,12</sup> it appears that voluntary euthanasia rose by 30% between 1990 and 1995<sup>13</sup>.

Although the Dutch government did not concur with this interpretation of the data, the potential implications seem to have made an impression. After publication of the data in 1996 a lot started to change in the Netherlands. First, there is a new proposal for the procedure of euthanasia. Each case of euthanasia will be now scrutinized by the regional commission composed of physicians, ethicists, lawyers and other professionals. Not only the procedure itself but also the motives will be subjects of interest. Again, investigation by peer professionals is expected to increase the readiness to report the case. Secondly, the government launched an extensive programme to develop palliative care in the Netherlands. This programme includes setting up six academic centres for training and teaching in palliative care, as well as integration of the existing hospices in the general healthcare network. Proponents of euthanasia expect less criticism from abroad about euthanasia in the light of poor palliative care. Opponents expect a decrease in the number of euthanasia cases through provision of good palliative care. Palliative care specialists from the UK may play an important role in teaching palliative care in the Netherlands.

The achievements of British colleagues and the hospice movement should not be underestimated. However, even in the UK, where the debate on euthanasia continues<sup>14</sup>, there is

Table 1 End-of-life decisions by doctors in the Netherlands 1990-1995 (from Ref. 11)

|  | 1990           | 1995           |
|--|----------------|----------------|
| Deaths in the Netherlands  | 129 000 (100%) | 135 500 (100%) |
| Requests for euthanasia  | 8900 (7%)      | 9700 (7.1%)    |
| Euthanasia   | 2300 (1.8%)    | 3200 (2.4%)    |
| Assisted suicide   | 400 (0.3%)     | 400 (0.3%)     |
| Life-terminating acts without explicit request   | 1000 (0.8%)    | 900 (0.7%)     |
| Intensification of pain and symptom treatment  | 22 500 (17.5%) | 20 000 (14.8%) |
| (a) Explicitly intended to shorten life  | 1350 (1%)      | 2000 (1.5%)    |
| (b) Partly intended to shorten life  | 6750 (5.2%)    | 3850 (2.1%)    |
| (c) Taking into account the probability that life will be shortened                                | 14 400 (11.3%) | 15 150 (11.1%) |
| Withdrawal/withholding of treatment (including tube feeding)                                       | 22 500 (17.5%) | 27 300 (20.1%) |
| (a) At the explicit request of the patient   | 5800 (4.5%)    | 5200 (3.8%)    |
| (b) Without the explicit request of the patient  |                |                |
| (b1) Explicitly intended to shorten life   | 2670 (2.1%)    | 14 200 (10.5%) |
| (b2) Partly intended to shorten life   | 3170 (2.5%)    | —              |
| (b3) Taking into account the probability that life will be shortened                               | 10 850 (8.4%)  | 7900 (5.8%)    |
| Intentional termination of neonates  |                |                |
| (a) Without withholding/withdrawing treatment  | —              | 10             |
| (b) Withholding/withdrawing treatment plus administration of medication explicitly to shorten life | —              | 80             |
| Assisted suicide of psychiatric patients   | —              | 2-5            |

evidence that poor knowledge of symptom control persists amongst non-specialists<sup>15,16</sup>. There is no room for complacency about the quality and availability of palliative care.

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**REFERENCES**

- 1 Kissane DW, Street A, Nitschke P. Seven deaths in Darwin: case studies under the Rights of the Terminally Ill Act, Northern Territory, Australia. *Lancet* 1998;352:1097-102
- 2 Kearney M. *Mortally Wounded: Stories of Soul Pain, Death and Healing*. Cork: Marino Books, 1996
- 3 Greenhalgh T. Narrative based medicine: narrative based medicine in an evidence based world. *BMJ* 1999;318:323-5
- 4 Zyllicz Z, Janssens MJPA. Options in palliative care; dealing with those who want to die. In: Zenz M, ed. *Cancer Pain* (Baillière Clinics of Anaesthesiology, Vol. 12). London: 1998;1231-31
- 5 Grzybowska P, Finlay IG. Suicide in hospice patients. *Palliat Med* 1997;11:313-16
- 6 Chochinov HM, Wilson KG, Enns M, et al. Desire for death in the terminally ill. *Am J Psychiatry* 1995;152:1185-91
- 7 Hendin H. Assisted suicide, euthanasia and suicide prevention: the implications of the Dutch experience. *Suicide Life Threat Behav* 1995;25:193-204
- 8 Saunders CM, Baines M, Dunlop R. *Living with Dying: A Guide to Palliative Care*. Oxford: Oxford University Press, 1995
- 9 Ogilvie AD, Potts SG. Assisted suicide for depression: the slippery slope in action? *BMJ* 1994;309:492-3
- 10 van der Wal G, van der Maas PJ, Bosma JM, et al. Evaluation of the notification procedure for physician-assisted death in the Netherlands. *N Engl J Med* 1996;335:1706-11
- 11 Jochemsen H, Keown J. Voluntary euthanasia under control? Further empirical evidence from the Netherlands. *J Med Ethics* 1999;25: 16-21
- 12 van der Maas PJ, van der Wal G, Haverkate I, et al. Euthanasia, physician-assisted suicide, and other medical practices involving the end of life in the Netherlands, 1990-1995. *N Engl J Med* 1996; 335:1699-705
- 13 Hendin H, Rutefrans C, Zyllicz Z. Physician assisted suicide and euthanasia in the Netherlands. Lessons from the Dutch. *JAMA* 1997;278:817-18
- 14 BMA Medical Ethics Department. *Euthanasia and Physician Assisted Suicide: Do the Moral Arguments Differ?* London: BMA, 1997
- 15 Addington-Hall J, Altmann D, McCarthy M. Which terminally ill cancer patients receive hospice in-patient care? *Soc Sci Med* 1998;46:1011-16
- 16 Grande GE, Barclay SI, Todd CJ. Difficulty of symptom control and general practitioners' knowledge of patients' symptoms. *Palliat Med* 1997;11:399-406