

SAYING GOODBYE IN A GOOD WAY: OBSERVATIONS ON PALLIATIVE CARE IN THE NETHERLANDS

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The modern hospice movement originated in the United Kingdom in response to the needs of patients with incurable cancer. The hospice model of palliative care has spread to many other countries, notably Canada, Australia and the United States. However, in the Netherlands, hospices have not played a significant part in the care of patients with advanced cancer, discussion about the care of these patients being dominated by the euthanasia debate. This paper seeks to examine three questions:

What is the current provision of palliative care services in the Netherlands? What are the concerns and attitudes of selected health care professionals in relation to their care of dying patients? Why has hospice care not flourished in the Netherlands?

This personal perspective is not intended to provide definitive answers to these questions but rather to contribute to the debate on the most effective ways of providing care for patients with cancer and their families.

Setting

A seven day visit was carried out to selected centres in the Netherlands. Interviews were conducted with two medical oncologists, an anaesthetist managing a Pain Clinic, a director of a Comprehensive Cancer Centre (CCC), a nursing director of education, a clinical psychologist, a leader of a home care nursing service, a general practitioner and a doctor involved in the care of patients in a 350 bed nursing home. These professionals were selected because of their particular interest in the care of patients with advanced cancer. Interviews were conducted on an individual basis and were tape recorded with the consent of the interviewees. The length of each interview varied from an hour to four hours.

PRESENT PROVISION OF PALLIATIVE CARE IN THE NETHERLANDS

Home care. As in the UK, the cornerstone of professional health care in the community is the partnership between the general practitioner (GP) and the district nurse. This team may be supplemented by private home care nursing organisations and home care assistants (home helps) who may become involved at the patient's request without GP involvement.

District nurses and home care assistants are not attached to practices but care for the patients of many different GPs. Many of the district nurses work part-time and continuity of care may be difficult to achieve.

Forty per cent of patients with advanced cancer in the Netherlands die at home. There was a strong feeling among all the professionals interviewed that patients prefer to die at home rather than in a hospital or nursing home.

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Hospital based home care. There is no defined specialty of palliative medicine in the Netherlands. Palliative care education does not form part of the medical undergraduate curriculum. Dutch doctors and nurses see palliative care as an integral part of their work and have not sought to create a specialty of the subject. Some oncologists feel that by creating a specialty of palliative medicine there is a risk of alienating general practitioners, surgeons and others whose work involves care of the dying. However in a few centres, oncologists are developing a community model of care. Patients are visited at home by specialist oncology nurses who can supervise treatments such as morphine infusions, blood transfusions and chemotherapy. Nurses and doctors work together to develop detailed protocols of care which are reviewed annually. Such close working acknowledges the skills of nursing colleagues who feel free to act as the patient's advocate. Initially some of the specialist nurses encountered resistance from the GPs when the service was set up. This was overcome once the GPs appreciated the considerable skills of these nurses.

Pain clinics

A visit was made to an innovative clinic which deals with difficult problems in the management of cancer related pain. Patients are given a tripartite assessment in which a radiotherapist reviews past treatments to ensure that all options have been covered, a nurse specialist assesses nursing and psycho-social care and an anaesthetist assesses pain and symptom control. The three professionals pool their expertise and evolve a treatment plan with the patient. This plan could involve referral to other specialists or to a clinical psychologist or psychiatrist with particular interests in care of patients with advanced cancer. The clinical psychologist attached to the clinic works full-time with cancer patients and their families and has links with a self help group which is described below.

In another centre a similar type of multidisciplinary clinic has been organised in a new way. A specialist nurse, psychologist and oncologist work together in the clinic. This organisation replaces the former pyramid-like structure with the doctor on top. The specialist nurses rotate through the out patient clinic, ward and day-centre thus gaining experience of patients at all stages of their disease. Experience shows that such variation in clinical tasks helps to reduce staff stress and burn-out.

Hospital in-patient care

It was suggested that hospitals were oriented towards curative treatments and research trials rather than palliative care. One oncologist felt that palliative care was underdeveloped in the Netherlands and that patients did not know what palliation was so they did not know what to ask for. Since the shift from curative to palliative care may be gradual some doctors feel that the patient should be cared for by the same oncology or surgical team rather than developing specialist hospital support teams which only deal with palliative care.

Comprehensive cancer centres

There are nine Comprehensive Cancer Centres (CCC) in the Netherlands, each serving a population of between one and three million people. A CCC comprises hospitals, universities and radiotherapy units in a region. In some areas general practitioners and community health care organisations are also involved. The

CCCs facilitate a pooling of knowledge about cancer treatments and care and are responsible for distributing this information throughout their region. The aim of the system of CCCs is that every patient should receive the highest standards of care, provided locally as far as possible. To achieve this aim the CCCs are involved with: fostering expertise, consultative services, tumour working groups, home care, psychosocial care, clinical research, cancer registration and screening.

In order that patients may avoid travelling long distances for the best specialist care, senior consultants are attached to the CCC. These specialists are available to advise colleagues about individual cases to help with local treatment guidelines. CCCs are responsible for co-ordination and dissemination of guidelines and work with national tumour groups for the integration of regional guidelines into national guidelines.

The CCCs work to promote better communication between primary care and secondary care. They have an educational role for the district nurses, GPs, specialist nurses and home care assistants. The CCCs have training programmes to improve the communication skills of health care professionals. Information is available for cancer patients and their relatives, though direct counselling is not provided.

GPs may refer people for background information. Particular care needs to be taken so that patients relatives do not receive conflicting information from different professionals. Self-help groups are facilitated and provide an important resource to some patients. Funding problems have necessitated reductions in the provision of psycho-social services in recent months.

Self help groups

A clinical psychologist works in a patient group with a psycho-energetic therapist. Their objective is to give patients the opportunity to remain at home for as long as possible. Groups discuss problems like: How do you cope with distant relatives, friends, or colleagues coming to your home? They share the pressure of having to tell their story time after time.

Alternative therapies may be discussed; the group leader suggested that if it did not cost too much and it inspired them, why not, as long as they could still have conventional therapies? It is unethical to create problems of allegiance for patients.

Nursing homes

Nursing homes care for many dying patients. Although they do not have palliative care specialist nurses they do have specific nursing home doctors. GPs do not usually look after their own patients in the nursing home.

One hospital developed a ward for patients who were no longer curable and who were not well enough to live at home. The patients were under the care of a nursing home doctor and hospital staff. The ward was not equipped to cope with dying patients and the hospital staff were more accustomed to active curative therapies. The nursing home doctor did not consider that this model of care was a success.

Hospices

Two small hospices have been developed and were perceived by some oncologists to have a strong religious philosophy of care. Some doctors feel that this is inappropriate for patients who do not have any particular religious belief. One

general practitioner expressed reservations about the value of hospices in the Netherlands where people preferred to die in their own homes. Although hospice staff in the UK would claim that hospices were for the living, some Dutch doctors expressed doubts as to whether their patients would want to die in a hospice ward with other dying patients around them.

CURRENT ISSUES IN PALLIATIVE CARE IN THE NETHERLANDS

The health care professionals identified a number of difficulties which they encountered in their care of patients with advanced cancer.

Talking to patients at diagnosis and when the disease recurs

Patients may have different reactions at these two stages of their illness. A psychologist commented that at the time of first diagnosis they have a shock, their world collapses. They come back because the doctor has said that there are treatments which are likely to be successful. They cling to this hopeful perspective but if the disease recurs they lose their innocence.

One view however was that specialists were not all overoptimistic; some may be shockingly realistic. Patients need space so that they can grow into their truth. This view was also reflected in many of the conversations, indicating the desire in the health professions in the Netherlands to be honest with the patient.

When to stop active therapy?

One oncologist stated that generally, doctors were very clear as to whether the goal of treatment was curative or palliative. Some patients want hope. Most patients are also clear about the intention of treatment. There was a need to discuss the options with patient and relatives and to have a nurse present as well. Another oncologist remarked that palliative care included active treatment, surgery, radiotherapy and chemotherapy but these were being used to relieve symptoms. There was always the obligation to relieve symptoms even during curative measures. Fear of rejection by the doctor may prompt patients to continue chemotherapy. It may be difficult to avoid paternalism. Sometimes the doctor becomes so involved with a patient that a personal feeling develops that treatment must be continued. The patient has to be told if their goal is unrealistic. The therapist is obliged to stay with the patient.

EUTHANASIA

There is a problem in definition. There is a difference between giving analgesia to relieve pain and giving euthanasia with the intention of killing.

One oncologist described the case of a young woman with a head and neck tumour who requested euthanasia when her suffering became too bad. A few days later her condition deteriorated and she became comatose. She did not die quickly and as time progressed her nursing problems of nutrition and skin care were considerable. The nurses who had been closest to the patient felt that euthanasia should be carried out as she had requested. The suffering was not of the patient but of the carers. The doctors did not carry out euthanasia but set up a team meeting to allow the nurses to ventilate their feelings. There is a risk of burn out. It was remarked that the doctors should take care to only get involved with the issues that they can cope with. Not every problem is the doctor's problem.

WHY DO PATIENTS ASK FOR EUTHANASIA?

Poor symptom control

That everybody fears pain was a psychologist's perspective; he went on to state that one may not be aware of all the problems a patient may have. There is a general feeling in the population that there is no use in suffering. Symptom control does not abolish suffering. Facilitators of the self-help group have observed that patients do not get that desperate when they share their fear. With improvements in care the demand for euthanasia may be less but it will not disappear.

Losing control

A view from the psycho-social support staff was that when pain is relieved and psychosocial support provided there are not many euthanasia requests. Most requests come from patients who cannot accept their deterioration.

As for living wills—patients want to give direction to their lives and are afraid that doctors will not listen unless it is written down. Patients have an idea that the medical profession will not listen.

The request for euthanasia changes during the course of the disease. It was considered that there is a need to differentiate the euthanasia thought and the euthanasia request. In between the two, people learn to deal with the consequences of their illness when the options are reduced. When the change is from being in bed to being dead, most prefer to stay in bed. They can live with the reality but not with the fantasy.

One GP, reflecting on the difference between suicide and euthanasia, remembered a young man paralysed from spinal metastases who asked his doctor for a lethal injection. The GP wondered, if the patient could move his arms, why did he not inject himself?

Abuses of euthanasia. Doctors had no evidence of any abuses in relation to euthanasia. They confirmed that strict guidelines had to be followed if euthanasia was contemplated. However there were comments which indicated some unease about the current situation amongst both professionals and the public. For example it was remarked that a doctor visited a patient at home and shortly afterwards the patient died. The wife was afraid that the doctor had done something. Nobody knew. Maybe the doctor had done nothing, but euthanasia practice raises the possibility. Doctors also may have deep seated uncertainty: When the patient said to one doctor 'Now is the time', he gave the drug as pills in case she changed her mind in which case she could have her stomach contents pumped out.

Legal aspects. In the Netherlands euthanasia legally remains murder. The doctor who performs it must notify the coroner of an unnatural death. The coroner then checks whether the guidelines have been obeyed.

The guidelines are:

1. The request must be persistent, conscious and free.
2. Doctor and patient must agree that the distress suffered is unacceptable and beyond relief.
3. Another physician, not involved in the case must be consulted.
4. The attending physician himself must perform the euthanasia.

5. All other options for care must have been exhausted or refused.
6. Everything leading to this decision must be documented clearly.

If this is the case then no prosecution will follow.

One oncologist wrote that a procedure may seem simple on paper, but living through can be a very trying experience. In his opinion euthanasia was permissible because his patient asked for it, and needed it. It was like shooting a wounded and dying soldier who could not be helped otherwise.

Research

An oncologist made a plea for evidence based care and for an improved research methodology for palliative care. It was his opinion that there was so much we did not know in palliative care. For instance, in the palliation of the symptom of fatigue, when was the right moment to give steroids? When should steroids be stopped? Which steroid preparation was best? In randomised controlled trials (RCT) the goals were set by the professionals: e.g. tumour response or survival. This was probably not the best way for palliative care. Perhaps there should be patient centred trials where the goals of treatment were set by the patient rather than the professional.

Education

There is no specific education in palliative care for undergraduates. In the Netherlands a GP told of a meeting she attended with a specialist and medical students. They were discussing the care of a patient with widespread metastatic disease and an unknown primary. The discussion focused on diagnosis and histology. The practitioner claimed that she really had to fight to say that there was more to do even when one said there was nothing that can be done.

The CCC in Nijmegen has been involved with the production of an interactive palliative care teaching package suitable for students from different levels from volunteers to professionals working in palliative care. An exciting initiative such as this would be a real stimulus to the dissemination and implementation of the principles of good palliative care. The demonstration video is now available but sadly the project cannot proceed until funding is made available.

Why not hospice Holland?

Two hospices have been created in the Netherlands as a result of the enthusiastic commitment of charismatic individuals. Such a pattern of development is reminiscent of the early days of the hospice movement in the UK. However there are cultural differences which will mould a different model of palliative care in the Netherlands compared to the UK.

The Dutch people live with a historic uncertainty; the sea. They have been successful in living in an environment which they need to control in order to survive. If the extensive network of dykes and canals fail to control the sea, the country would sink beneath the waves. This need for control is also manifested by giving personal autonomy a high ethical priority. For autonomy to be respected the individual needs honest information. The Dutch value and expect honesty from their doctors and nurses. They wish to have control at the beginning and ending of life. Hence the high rate of home childbirths and the wish for the option for euthanasia to be available. Dutch people want to be independent, autonomous. 'We don't want to make bows to the Queen.' They

want the issues surrounding the care of dying patients to be debated in the public arena. Perhaps this openness and willingness to debate the issues surrounding euthanasia will prove to be a window of opportunity to explore the alternatives offered by palliative care.

Some doctors felt that there could be dangers in building a fence around a part of care which is part of all specialties; there is a risk in leaving everything to palliative care specialists. The same doctors suggested that the need was not for another specialty but for more integration.

The hospices which do exist tend to be religiously based, which may tend to threaten those people with no religious conviction.

Hospices in the UK depend heavily upon their trained volunteers. There is no such organisation of volunteers in the Netherlands.

CONCLUSION

There are highly skilled doctors, nurses and other health care professionals in the Netherlands who are striving to develop good palliative care in the patient's home. It is felt that there is a need for education in the principles of palliative care at all stages of professional development and for the public. Patients and their health advisers should be aware that pain clinics are available. GPs do not generally have appointments in hospitals but work entirely in the community. Perhaps hospital practitioner posts in pain clinics could be created to improve the continuity of patient care and also to enable GPs to gain further experience in palliative care.

The Netherlands is developing its own pattern of palliative care. There is a hope that every hospital caring for patients with cancer will have a multidisciplinary pain control clinic. Efforts are being made to improve the environment of the oncology ward to make it more appropriate for patients admitted for palliative care and to extend hospital based out-patient care to help to enhance the quality of life of patients with advanced cancer.

Some Dutch doctors expressed apprehension about creating a specialty of palliative care.

Patient care in the UK has benefited from the teaching and clinical expertise of specialists palliative care doctors and nurses. It is important that specialists in palliative care continue to empower their colleagues working in other disciplines to develop their own palliative care skills.

This study did not include the views of a hospice director from the Netherlands. Such an opinion would contribute to the debate and should be included in a follow up visit. However, the interviews with the selected doctors, nurses and psychologists revealed that euthanasia is a difficult issue for professionals in the Netherlands. Euthanasia is not undertaken lightly and causes a great deal of stress to health care professionals. Although many doctors feel that excellent symptom control would reduce the number of requests there remain a tiny group of patients who wish to exert a final autonomy. The publicity surrounding the euthanasia debate may be an opportunity to educate people of the potentials of palliative care. The moral distress of doctors and relatives caused by euthanasia decisions should act as a warning to those doctors in the UK who are tempted to support legalising euthanasia in this country. Those doctors, in the Netherlands, who are practising the highest standards of palliative care deserve encouragement and support in their efforts from their colleagues. The govern-

ment and media also have a responsibility to increase public awareness of the possibilities of palliative care. Possibilities which extend beyond symptom control to include the psycho-social and spiritual concerns of the patient and his family. Only when this type of holistic palliative care is an integral part of the undergraduate and continuing medical education of every Dutch doctor who is caring for dying patients, can there be any possible justification for euthanasia on the grounds of 'there is nothing more I can do'.

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