

# Hospice and euthanasia in the Netherlands: an ethical point of view

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## Abstract

*This contribution is a report of a two months' participant observation in a Dutch hospice. The goal of the observation was to gain an overview of moral decisions in a hospice in which euthanasia, a tolerated practice in the Netherlands, is not accepted as an option.*

*In an introduction, the development of palliative care in the Netherlands will be briefly presented. Subsequently, various moral decisions that were taken during the participant observation are presented and analysed by means of case reports. Attention is especially drawn to decisions that directly or indirectly relate to euthanasia. These moral decisions will be clarified in the light of the philosophy behind the concept of palliative care as it has evolved since the foundation of St Christopher's Hospice, London in 1967.*

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## 1. Introduction

As part of a research project on palliative care ethics, a two-months' participant observation has been made of terminal care practice in the Hospice Rozenheuvel in Rozendaal near the city of Arnhem in the Netherlands. In contrast to theoretical analysis, this study provided opportunities to experience the intrinsic connectedness of moral issues with everyday hospice practice. Medical ethics primarily requires identification, interpretation and explanation of moral issues through participation in medical practice. Only in connecting moral theory and medical practice can medical ethics acquire practical meaning.<sup>1 2</sup>

In this contribution, first the recent development of palliative care in the Netherlands will be briefly presented. This development cannot be understood without taking the practice of euthanasia into account. Subsequently, several complex moral problems directly and indirectly related to the problem of euthanasia which arose in hospice practice during the observation period will be discussed by means of case reports. In conclusion, these moral problems will be situated in the larger

perspective of the philosophy behind palliative care as it has evolved since Dame Cicely Saunders founded St Christopher's Hospice in 1967.

## 2. Palliative care in the Netherlands

Palliative care can be defined as "the study and management of patients with active, progressive, far-advanced disease for whom the prognosis is limited and the focus of care is quality of life".<sup>3</sup> However, the concept cannot be fully comprehended by a definition alone. Concepts are always situated in tradition within which they are shaped. In this respect, it is important to realise that the "palliative care" was introduced in 1975 as an alternative to the term "hospice". Palliative care comes forth out of the modern hospice movement which originated in 1967 with the foundation of St Christopher's Hospice.

In the Netherlands, this concept of palliative care is still in its infancy. Only since the beginning of the nineties have institutions been established which situate themselves in the above mentioned tradition. Currently, the Netherlands has six in-patient hospices and 29 palliative care units in nursing homes and hospitals.<sup>4</sup>

With regard to the supposed underdevelopment of palliative care it is argued that the Netherlands is in need of a small number of highly specialised professional hospices or palliative care units. These would primarily serve as education and consultation centres for nurses, general practitioners and medical specialists.<sup>5</sup> Thus, without becoming a medical specialty, specialists in palliative care would develop through education in these centres. Subsequently, these specialists would provide consultations to their colleagues in hospitals or primary care practice. Inpatient facilities would be of secondary importance as patient care would have to be situated in already existing institutions. Thus, it is not so much institutionalisation that is imperative. Far more important is the development of a caring attitude in which the authentic needs and wishes of the dying patient are met.

Outside the Netherlands it is often stated that the relative absence of Dutch palliative care can explain the Dutch practice of euthanasia.<sup>6,7</sup> Even though it cannot be denied that there is an element of truth in this statement, it is one-sided. A number of different factors play a role as well. Health policy (aimed at the reduction of the number of institutional beds and at decreasing the costs), the organisation of the health care system (with many nursing homes) and the good quality and accessibility of health care in general can provide just as good explanations for the relative invisibility of palliative care in the Netherlands.<sup>8</sup> Furthermore, Dutch society is increasingly secularised. Unlike most other European countries, the majority of the population no longer belongs to catholic or protestant churches. This, in its turn, can explain the liberal orientation of the Dutch government in moral matters. This attitude is also pervasive in medical practice. Thus, the virtual absence of palliative care is not the only factor which explains Dutch euthanasia policy and, vice versa, Dutch euthanasia policy is not the only factor that explains the virtual absence of palliative care.

However, whereas in most other countries palliative care was developed, among other reasons, as a reaction against a burgeoning liberal attitude towards euthanasia,<sup>9</sup> palliative care in the Netherlands is developing in a context in which the medical practice of euthanasia has already been accepted by the majority of the population. The Dutch cabinet recently stated that euthanasia only makes sense within the context of palliative care.<sup>10</sup> The acceptance of euthanasia explains why palliative care in the Netherlands is developing in comparative isolation.<sup>11</sup> Few Dutch physicians attend international congresses on palliative care whereas, paradoxically, the practice of euthanasia in the Netherlands is one of the most salient subjects in these congresses.

In this contribution an account is given of a participant observation in the Hospice Rozenheuvel, in the village of Rozendaal close to the city of Arnhem. Of all Dutch hospices, Rozenheuvel comes closest to the model of the British hospices. It is an inpatient hospice with nine beds. The hospice physician also offers advice to general practitioners who take care of patients at home. When home care is no longer possible, patients can be admitted to the hospice and receive specialist palliative care. Apart from patient care, the hospice also coordinates educational and research activities. The hospice is affiliated to several foreign palliative care associations. Euthanasia is not considered as an option inside the hospice. The maxim that the patient's death should neither be

intentionally hastened nor uncritically postponed is pervasive for hospice practice.

### 3. Moral decisions relating to euthanasia in a Dutch hospice

In this section we will focus on various moral decisions concerning the above mentioned maxim (ie not intentionally to hasten, nor uncritically to postpone a patient's death) with the help of three case reports. The case reports are helpful because they indicate how the maxim is integrated in everyday hospice practice. Often, the application of this maxim is problematic and goes hand in hand with ambivalent emotions. Other options are often available. Sometimes, the needs and wishes of the patient are ambiguous. Sometimes, there are differences of opinion between the patient's loved ones. Ample discussion with the patients and their families cannot always neutralise these emotions for the clinical team.

#### Case 1: Sedation

A 50-year-old homeless man with a history of drug abuse and psychopathology had developed a malignant tumour from neurofibromatosis. He was diagnosed with a growing sarcoma in the left buttock. He was referred to the hospice at an early stage of the disease. The tumour was growing slowly, invading the sacral nerves but not metastasising. During a relatively long period morphine, carbamazepine, phentanyl, ketamine and bupivacaine were administered both subcutaneously (sc) and intrathecally and appeared successful for a while. However, his pain returned time after time. This made it almost impossible for the team to establish a consistent strategy of pain and symptom management. When in pain, the patient was screaming loudly, demanding euthanasia. However, on the days the pain was absent he explicitly rejected euthanasia. As this situation lasted for several months the team, together with the patient, began to burn out. During the last days of his life he suffered excruciating pain and sedation was considered. As levomepromazine 250 mg/24hours sc was unsuccessful, barbiturates were administered but the dose was insufficient to sedate him. He kept suffering from severe pain. The dose of barbiturates was increased, which made the last hours of the patient's life bearable. Fully conscious he said goodbye to the team and died peacefully.

The administration of a high sedative dose eventually alleviated distress but also hastened the death of this patient. There was no doubt that the hospice physician never intended this foreseeable and unavoidable outcome. The direct effect of the administration of the sedative medication is the

relief of the patient's suffering. The indirect effect is the hastening of the death of the patient. Furthermore, the good effect, the relief of suffering, was immediately caused by the sedation and did not result from the bad effect, the hastening of death. Finally, the administration of morphine can in itself, independent of its effects, not be considered as evil.<sup>12</sup> The morality of sedation illuminates the moral meaning of the principle of double effect.<sup>13</sup> Proponents of euthanasia often argue that in everyday practice, intentions are not so clearly distinguishable as the principle of double effect seems to imply. However, in hospice practice the distinction between euthanasia and unintentionally hastening a patient's death is crucial.

This does not mean that this particular case was unproblematic. It put a heavy strain on the caring team. All care-givers felt burnt out. Because of the emotional instability and manipulative attitude of the patient, it was extremely hard to develop a compassionate attitude towards him. In a review carried out afterwards a discrepancy was observed between the caring attitude of the team and the psychopathology of the patient. The latter required a specific tough approach with which the team members had not much experience. Therefore, a clear strategy of care, in order to deal adequately with the patient's needs and wishes, remained absent.

Another problem concerned the intractability of the patient's pain. This intractability did not only come from his clinical picture and his history of drug abuse. Also his attitude towards his pain, and by that the character of his pain itself, differed radically from one moment to another. Sometimes he appeared to be able to tolerate the pain. Other times, especially during the nights, he was screaming for a doctor to come and relieve his suffering, thereby awakening other patients.

The team's inability to deal with this patient's needs together with the intractability of his pain led to the eventual decision to sedate the patient, who was a highly problematic character. Even though the principle of double effect can justify the decisions taken, it cannot be denied that there is an appearance of pragmatism in the attempts to sedate this patient. The suspicion arose that the caring team would be quite pleased if the sedation hastened the patient's death. As euthanasia is often criticised as a poor solution when there is a shortage of palliative care,<sup>9</sup> in the experience of the caring team this case could be criticised for the same reason. One of the main aims of hospice-based palliative care in the Netherlands is to reduce the high number of euthanasia cases, through compassionate care. In this case this aim was frustrated. This frustration can hardly be

explained by moral theory. Only by taking into account the practice of palliative care, with its range of emotions, attitudes and habits, can the problems of this case be understood.

### **Case 2: Withdrawing life-sustaining treatment**

A 58-year-old divorced female lawyer suffered from a non-small-cell bronchus-carcinoma metastasised to the spinal column and the brain. During the first conversation with the hospice physician she stated that she wanted euthanasia if her suffering became unbearable. The hospice physician informed the patient gently that although the option was not available in the hospice he would never abandon her. If she would persist in her request, she could be transferred to the hospital.

After her admission her pain decreased. For a period of two months she enjoyed life in the hospice, saying that for the first time in her life she finally was able to get rest. Everyone who spoke to her regularly noticed how well she developed emotionally and how she became more and more able to give voice to her many "soul wounds" of the past. Her relationship with her two daughters grew more intense than ever.

However, the time came when her energy started slipping away. She wanted to die. Because of an increasing headache and nausea a corticosteroid called dexamethasone was proposed. She refused it as she was afraid of its life-prolonging effects. Only later, when the symptoms became aggravated, did she agree to have corticosteroids. This relieved her suffering. However, she became more and more tired. Again, she explicitly requested euthanasia. She wanted to be transferred to the hospital. In an emotional discussion with her daughters the hospice physician proposed discontinuation of dexamethasone and the control of her pain and nausea by alternative measures. She was relieved by this proposal as her two daughters both disliked the idea of euthanasia. She died peacefully four days later under heavy sedation.

Twenty-five per cent of all patients admitted to Hospice Rozenheuvel state they want euthanasia when suffering becomes unbearable.<sup>14</sup> However, in the last four years, only two hospice patients out of 571 have persisted in their wish; they were eventually transferred to the hospital to undergo euthanasia.

In palliative care the assessment of the patient's reasons to request euthanasia is paramount.<sup>14</sup> In this respect the public nature of the Dutch euthanasia debate enhances the openness of the communication between the physician and the patient with regard to euthanasia. Placing the

needs and wishes of the patient in the centre requires an absence of taboos. In palliative care, the patient should feel free to discuss all relevant concerns with the carers.

This patient uttered two euthanasia requests during her stay in the hospice. The first one was made at her admission. It appeared to stem from an urge to remain in control and to be independent. This attitude had characterised her entire life. This urge for control and independence clearly remained present during the first week of her stay in the hospice. Only when she came to feel at home in the hospice did she learn to accept her dependence on the caring people surrounding her. She became able to deal with her soul wounds of the past. In these two months she never repeated her request for euthanasia. When she felt that everything was said and done, she started to deteriorate and began to feel burnt out. A second euthanasia request came up but this time for different reasons.

Because one of the effects of the corticosteroids was life prolongation it seems questionable to regard the administration of corticosteroids as futile from a medical point of view. However, futility of medical treatment in palliative care does not only relate to the medical realm but is situated in the larger context of the needs and wishes of the unique individual. Medication with the primary function to postpone death can be considered futile in palliative care if the patient no longer experiences any benefit. The assessment of futility requires extensive discussion with the patient and her/his family to find out whether the treatment is beneficial. As this patient was burnt out and ready to die it was decided, after ample discussion, to discontinue dexamethasone. In her immediate reaction to this decision the patient said to the hospice physician: "So I don't have to undergo euthanasia?" It thus appeared that she never really wanted to be killed.

### Case 3: Euthanasia

A 55-year-old man was suffering from a bladder carcinoma. He had excruciating colic pain and constipation. Together with his general practitioner he was seen at home by the hospice physician. The hospice physician advised phentanyl 10 mg/24 hours, which is already an enormously high dose. At the same time efforts were made to activate colon movements and treat constipation. When the patient's pain did not diminish the general practitioner, without further consultation, increased the dose of phentanyl, which however also increased the colic pain. He did not pay attention to the constipation. After several pain attacks the patient requested euthanasia because of his excruciating

pain. When the hospice physician was informed about the decision of the patient he rushed to the patient's home. He prescribed other medication which decreased the cramps. When euthanasia was performed by the general practitioner, the patient was almost free from pain.

His wife and his daughters were opposed to their loved one's decision. His son, however, supported his father's decision. After the husband's death, his wife became severely depressed. She was cared for by the hospice bereavement team.

This case illustrates the findings of a recent report that evaluated the notification procedure with regard to euthanasia.<sup>15-17</sup> According to this study in 88% of all 3,200 annual euthanasia cases the treatment at that time was palliative in character. In 83% of all cases the euthanising physician stated that treatment alternatives were no longer available. According to the physicians these patients were suffering unbearably and irreversibly. The inability to palliate the suffering of these patients was the main reason behind the decision in favour of euthanasia or physician-assisted suicide.

As mentioned above, there is a broadly shared acknowledgement that much can be improved with regard to palliative care in the Netherlands and this case highlights the necessity for this improvement.<sup>18, 19</sup> Increasing the doses of phentanyl by the general practitioner to diminish the colic pain of this patient led to a reverse effect. Presumably, if the general practitioner had had better knowledge of pain and symptom control (or if he had consulted the hospice physician more often) this case of euthanasia could and would have been prevented.

Furthermore, the role of third parties in this case, notably the son of the patient, may well have infringed the autonomy of the patient's request. It remains questionable whether, on the day of the patient's death, just when his pain became bearable for the first time in weeks, his euthanasia request was really autonomous.

The assumed preventability of this euthanasia case shows in retrospect that a liberal attitude towards euthanasia may lead to excesses. Uncritically legalising euthanasia may well paralyse the development of creative palliative care. After all, if only little attention is paid to the preventability of euthanasia by adequate treatment and care, there would not seem to be a need for the development of palliative care.

Finally, one other consideration deserves attention. Euthanasia may have profound and still unpredictable effects on the bereaved. Following a loved one's death by euthanasia, psychopathological symptoms may well occur in the bereaved.<sup>15</sup>



The maltreatment of this patient's pain, which eventually was the reason for undergoing euthanasia, was for the patient's wife a terrible experience. It illustrates the importance of the provision of bereavement services by the people who cared for the deceased.<sup>20 21</sup>

#### 4. Conclusion

Palliative care practice is pervaded by complex moral problems. In this article some of these problems, directly and indirectly relating to euthanasia, have been discussed. However, it is important to note that palliative care as a concept of care is itself morally motivated. The foundation of St Christopher's Hospice in 1967 by Dame Cicely Saunders arose from two moral discomforts. First, there was a moral discomfort with mainstream medicine. Many people became aware that care for the terminally ill was seriously underestimated in mainstream health care.<sup>22 23</sup> Medicine focused primarily on technological interventions and repair of bodily disorders. Its main goal was cure. If cure was not possible, prolongation of life became imperative. Second, there was a moral discomfort with the growing influence of the British Voluntary Euthanasia Society, which pleaded for the legalisation of euthanasia.

In palliative care nothing is undertaken to postpone unnecessarily or intentionally to hasten death. Life-prolonging treatment, which is potentially harmful for the wellbeing of terminal patients and which can make the acceptance of their situation more difficult, is deemed futile. Intentionally hastening death is regarded as dangerous and unnecessary since patients' requests for euthanasia are often ambivalent and preventable in the context of good palliative care.

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