The role of nurses in euthanasia and physician-assisted suicide in The Netherlands

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ABSTRACT

Background: Issues concerning legislation and regulation with respect to the role of nurses in euthanasia and physician-assisted suicide gave the Minister for Health reason to commission a study of the role of nurses in medical end-of-life decisions in hospitals, home care and nursing homes.

Aim: This paper reports the findings of a study of the role of nurses in euthanasia and physician-assisted suicide, conducted as part of a study of the role of nurses in medical end-of-life decisions. The findings for hospitals, home care and nursing homes are described and compared.

Method: A questionnaire was sent to 1509 nurses, employed in 73 hospitals, 55 home care organisations and 63 nursing homes. 1179 responses (78.1%) were suitable for analysis. The questionnaire was pilot-tested among 106 nurses, with a response rate of 85%.

Results: In 37.0% of cases, the nurse was the first person with whom patients discussed their request for euthanasia or physician-assisted suicide. Consultation between physicians and nurses during the decision-making process took place quite often in hospitals (78.8%) and nursing homes (81.3%) and less frequently in home care situations (41.2%). In some cases (12.2%), nurses administered the euthanatics.

Conclusions: The results show substantial differences between the intramural sector (hospitals and nursing homes) and the extramural sector (home care), which are probably linked to the organisational structure of the institutions. Consultation between physicians and nurses during the decision-making process needs improvement, particularly in home care. Some nurses had administered euthanatics, although this task is by law exclusively reserved to physicians.

In The Netherlands, euthanasia and physician-assisted suicide have been investigated mainly within the medical profession.[1 2] Euthanasia and physician-assisted suicide are the responsibility of physicians, a role that is legally formalised in the Law on the Termination of Life on Request and Assisted Suicide of 2002.[3] Nurses are often involved in the euthanasia process, but their role is not enacted in that Law. Their role is clarified and demarcated in joint professional guidelines of physicians and nurses.[4] Concerned about the lack of legal status of nurses in euthanasia and physician-assisted suicide, nurses' professional organisations raised various issues to be included in the new law. One issue concerned the membership of nurses in the regional euthanasia review committees, whose task is to review reported cases of euthanasia and physician-assisted suicide on the basis of the due care requirements of the law. The associations argued that as nurses are often involved in the euthanasia process and they usually are very close to patients, they should be members of the review committees. Moreover, nurses are well-trained professionals and their expertise and experience should be used.[5]

However, the Health Minister decided that before any decision was taken about regulation of the role of nurses in euthanasia, their factual role in practice should be clarified. Consequently, the minister commissioned a study of the role of nurses in medical end-of-life decisions in hospitals, home care and nursing homes in order to advise the Dutch government on legislation and policy-making concerning the role of nurses.[6] This article reports the outcomes of this study in three settings: hospitals, home care and nursing homes. The role of nurses is presented with respect to the request by the patient for euthanasia or physician-assisted suicide, the decision-making process and the administration of euthanatics.

We used the definition of euthanasia and physician-assisted suicide as given in previous studies among Dutch physicians.[1] According to this definition, euthanasia means the administration of drugs with the explicit intention of ending the patient's life on his or her explicit request, and physician-assisted suicide is the prescribing or supplying of drugs with the explicit intention of enabling the patient to end his or her own life.

Attention to the role of nurses in euthanasia and physician-assisted suicide is increasing internationally. De Beer and colleagues[7] conducted an international literature review of 15 studies published between 1991 and 2002. In six of them the sample consisted of physicians and provided indirect information about the role of nurses.

In all the articles selected, data were gathered at a time when euthanasia was illegal, as was also the case in the Dutch studies. However, at the time of the Dutch studies, euthanasia was not a punishable offence in The Netherlands if the physician fulfilled the due care requirements. Euthanasia was also illegal when the Belgian studies were done.[8 9] This fact, together with differences in study designs, definitions used and the non-sector-specific description of results in studies, limits a reliable comparison with the results in our study (see Discussion).

METHOD

Participants

All general and academic hospitals, accredited home care organisations, somatic nursing homes

and nursing homes with both somatic and psychogeriatric patients in The Netherlands were invited by telephone to participate in the study. Of 488 locations, 191 (39.1%) agreed to participate: 73 hospitals, 55 home care organisations and 63 nursing homes.

Reasons for non-participation varied: workload, other priorities, swamped with studies, reorganisation, sensitivity of the subject, no zest among nurses, no nurses employed in the organisation, participation in other studies, sickness of the manager, research tiredness, no or rare experience with requests for euthanasia/physician-assisted suicide.

Contact persons in the organisations recruited the respondents

When interest in participation was shown, the organisation was asked to designate a contact person to recruit the correspondents. This was usually someone working at management or policy level. The research group held the view that a random sample would give a limited response to the study. Therefore, it was decided that the research sample would consist of nurses who had experienced cases of euthanasia or physician-assisted suicide. Participation was further promoted by

- a guarantee of anonymity to both organisations and respondents;
- the provision to both contact persons and respondents of a copy of a letter from the Minister of Justice in which participation was recommended and respondents were explicitly promised protection against criminal prosecution if they disclosed illegal practices.

Because of an expected low recruitment of nurses in nursing homes, caregivers working as team leaders or coordinators in the field of nursing in such homes were also recruited.

The contact persons recruited 1509 nurses or caregivers, who all received a questionnaire. The number of responses suitable for analysis—that is, of which one or more parts could be used for analysis—was 1179 (78.1%).

Data collection

Data were collected using a questionnaire. The results of a qualitative preliminary study, together with data from previous studies and insights from ethics and law, were the basis for the construction of this questionnaire. It was checked by experts on content and on questionnaire construction and statistics. It was then pilot-tested with 106 nurses (85% response rate). The research team discussed the outcomes, adapted the questionnaire where necessary and again tested it with three other nurses.

The respondents were asked to place their responses within the context of their most recent case of a request for and/or administration of euthanasia or assistance in a suicide within the previous 2 years. These cases took place in 2001, 2002 and 2003.

The respondents were guided through the questionnaire, avoiding sections that had become irrelevant due to their previous responses. This explains the variability in the number of nurses responding to items in the results section. The next paragraph, for example, begins with 799 cases and ends with 129 cases. Variability is further accounted for in the paragraphs below.

The data were analysed using SPSS version 11.5 for Windows.

RESULTS

Requests for euthanasia or physician-assisted suicide

In 101 of 900 cases (11.2%), patients had made the request known before admission to the ward (hospitals and nursing homes) or at their first contact with nurses (home care). These cases were not analysed for this part of the study, because the nurse had no opportunity to be the first person with whom patients discussed their request for euthanasia or physician-assisted suicide.

In 37.0% of the other 799 cases, the nurse was the first person with whom patients discussed their explicit request for euthanasia or physician-assisted suicide. In 36.8% of the cases, the patient spoke with the physician first, and in 17.3% the patient first raised the request when both the physician and the nurse were present—for example during the physician's rounds (table 1).

The data show considerable differences between hospitals/nursing homes and home care.

When the patient spoke with the nurse first and this concerned the respondents themselves (not a colleague), the five most mentioned, and sometimes overlapping, reasons why patients first raised their request with a nurse (n = 129) were that

- the nurse had a confidential relationship with the patient (42.6%);
- the nurse had more contact with the patient than the physician (20.1%) and
- the relationship between physician and patient was not confidential enough to allow discussion of the subject (11.6%);
- the nurse was easily accessible (10.9%);
- the patients first wanted clarity for themselves (8.5%).

The decision-making process

During the decision-making process, consultations between physicians and nurses were more frequent in hospitals and nursing homes than in home care (table 2).

The purpose of the consultation between physician and nurse is that the nurse can give and possibly explain her opinion about the specific case.

In this analysis, 146 of 900 cases were ignored because the decision-making and the administering of euthanatics did not take place within the same ward or organisation, or the patient died during the decision-making process or the decision had been taken before the patient was admitted to the ward (hospitals and nursing homes) or before the first contact between patient and nurse (home care) and therefore nurses could not have played a role in the decision-making process.

Contrary to what happened in hospitals and nursing homes, in home care only individual consultation generally took place (table 3).

When respondents themselves were involved in the decision-making process, they indicated which other persons, apart from physician and nurse, participated in the team consultation. In hospitals (87 cases), the four most mentioned persons were

Table 1 Care providers with whom patients first discussed their request for euthanasia or physician-assisted suicide (%)

Care provider	Hospitals (n = 381)	Home care (n = 278)	Nursing homes (n = 140)	Total (n = 799)
Physician	23.4	62.2	22.9	36.8
Physician + nurse	22.3	8.3	21.4	17.3
Nurse	45.1	22.3	44.3	37.0
Other	3.7	–	2.8	2.3
Unknown	5.5	7.2	8.6	6.6

Table 2 Role of nurses in the decision-making process (%)

Consultation	Hospitals (n = 359)	Home care (n = 267)	Nursing homes (n = 128)	Total (n = 754)
Between physician and nurse	78.8	41.2	81.3	65.9
None between physician and nurse	14.2	49.8	10.9	26.2
Unknown	7.0	9.0	7.8	7.8

Table 3 Forms of consultation between physician and nurse (%)

Consultation	Hospitals (n = 224)	Home care (n = 90)	Nursing homes (n = 92)	Total (n = 406)
Individual only	41.5 (93)	88.9 (80)	33.7 (31)	50.2 (204)
Team only	12.5 (28)	1.1 (1)	4.3 (4)	8.1 (33)
Both individual and team	33.5 (75)	3.3 (3)	57.6 (53)	32.3 (131)
Other or unknown	12.5 (28)	6.7 (6)	4.4 (4)	9.3 (38)

pastor/mental attendant (33), social worker (20), psychologist (8) and physiotherapist (5). In nursing homes (53 cases), the four most mentioned persons were pastor/mental attendant (31), psychologist (24), physiotherapist (12) and social worker (11).

In 845 of 900 cases, the physician took the decision to grant or not to grant the patient's request.

It should be noted that 55 cases were ignored because the decision-making and the administering of euthanatics did not take place within the same ward or organisation, the patient died during the decision-making process, or nurses discovered afterwards that euthanasia had been performed.

In 657 cases, physicians had decided to grant a request for euthanasia or physician-assisted suicide. In 88.6% of these cases, the nurses had agreed with the physician's decision, and in 10.8% nurses disagreed or had doubts about the decision. The three most frequently mentioned reasons for either disagreement or doubts were (n = 69): conscientious objection by the nurse (41); the patient's condition not being serious enough (26); no evidence of unbearable suffering (19).

In 188 cases, physicians decided not to grant a request for euthanasia or physician-assisted suicide. According to the nurses, physicians had various motives for these decisions. The five most frequently mentioned reasons were: wanted to give palliative care (46.3%); no evidence of unbearable suffering (26.6%); the institution did not allow euthanasia and physician-assisted suicide (18.6%); conscientious objection (15.9%); no hopeless suffering existed (14.4%).

When a request was not granted, 60.1% of nurses supported the decision and 37.2% either disagreed or had doubts about it. The three most mentioned reasons for disagreement or doubts were (n = 70): the request was realistic (49); hopeless suffering did exist (39); unbearable suffering existed (31).

Administering the euthanatics

In 610 of 900 cases, euthanasia or physician-assisted suicide was performed. However, the analysis in this paragraph is based on the 205 cases in which respondents themselves were present when euthanatics were administered and therefore could have played a role in administering them.

When nurses were present (n = 205), they mainly had tasks of supporting patients (85.6%) or relatives (92.1%).

In 53.7% of the cases, nurses had one or more tasks related to administering the euthanatics. The four most mentioned activities are presented in table 4.

In 5 cases (2.4%), nurses administered the euthanatics, in one case (0.5%) the nurse anaesthetist administered the euthanatics, and in 19 cases (9.3%), nurses administered the euthanatics together with the physician (table 5). In these latter cases (n = 19), nurses opened the infusion with euthanatics or started up the infusion pump with euthanatics (16), or they injected the euthanatics via a gastrostomy drip-feed (1). In two cases, more than one nurse was present and a colleague-nurse performed the activities.

The reasons why nurses administered the euthanatics were not investigated, but five nurses indicated that the physician was inexperienced in operating the infusion system.

DISCUSSION

Study limitations and strengths

Medical end-of-life decisions such as euthanasia and physician-assisted suicide are sensitive, complex issues that can be difficult to study through quantitative methods. It is difficult to get insight in the reasons or motives for nurses' actions by such an approach. Another limitation of the study is the "fragmented" involvement of nurses, which often had to do with the nurses' changing duties and/or task-orientation. In a number of cases, the nurse was not involved in all stages of the process, with the result that some data are missing.

Though only the most recent cases were included, bias could occur because of the retrospective character of the data. Furthermore, nurses could have interpreted a case differently than the physician did, especially when insufficient consultation took place between physician and nurse.

To improve the validity of the results, much attention was paid to the interpretation of the different types of medical end-of-life decisions by the respondents.

The study got high participation rates, many organisations nationwide were involved and many cases of high quality (most recent cases) were included. Therefore, though non-response could have affected the results a little, we feel justified in concluding that the study was representative of Dutch nurses who have had experience with euthanasia and physician-assisted suicide.

Requests for euthanasia and physician-assisted suicide

In 37% of the cases analysed, the patient spoke first with a nurse about the option of euthanasia or physician-assisted suicide. This result partly contrasts with the results of the literature review by De Beer and colleagues,[7] which indicated that nurses often are the first caregivers to receive a request.

Unlike the case in hospitals and nursing homes, in home care the physician was more often the first person with whom patients discussed their request for euthanasia or physician-assisted suicide. An explanation might be that in home care the patient–physician relationship is, generally speaking, more longstanding and confidential than in the other sectors.

Given the intimacy and sensitivity of the subject, it is remarkable that in a significant number of cases (17.3%), patients discussed their request simultaneously with the physician and the nurse. As this mainly occurred in hospitals and nursing homes, this phenomenon may be due to working methods, that is, regular rounds. Patients may raise the issue during these visits.

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Table 4 Activities of nurses in administering the euthanatics (%)

Nurse's task	Hospitals (n = 87)	Home care (n = 6)	Nursing homes (n = 17)	Total (n = 110)
Passing euthanatics to physician	40.2 (35)	33.3 (2)	70.6 (12)	44.5 (49)
Checking physician's actions	40.2 (35)	16.7 (1)	29.4 (5)	37.3 (41)
Inserting infusion bag with euthanatics	28.7 (25)	16.7 (1)	5.9 (1)	24.5 (27)
Showing physician how to insert infusion bag with euthanatics	26.4 (23)	–	5.9 (1)	21.8 (24)

Table 5 Persons who administered the euthanatics (%)

Person administering	Hospitals (n = 143)	Home care (n = 24)	Nursing homes (n = 38)	Total (n = 205)
Physician	83.2 (119)	87.5 (21)	89.5 (34)	84.9 (174)
Physician and patient	–	–	5.3 (2)	1.0 (2)
Patient	1.4 (2)	4.2 (1)	2.6 (1)	2.0 (4)
Physician and nurse	11.9 (17)	8.3 (2)	–	9.3 (19)
Nurse	3.5 (5)	–	–	2.4 (5)
Nurse anaesthetist	–	–	2.6 (1)	0.5 (1)

When patients spoke with a nurse first, respondents suggested that patients might simply be seeking orientation and for that reason did not (yet) like to speak with their physicians. An additional reason might be that the patient knows the physician has to agree with the request before euthanasia can be performed at all; fearing a negative or evasive response by the physician, he or she first approaches the nurse. However, it is desirable that nurses advise patients to discuss their request with the physician as soon as possible in order to clarify each other's expectations and views.

The decision-making process

In home care, which has by far the largest reported number of cases of euthanasia in The Netherlands, the nurse is considerably less involved in the decision-making process than in the other settings. These differences may be related to the different organisational structure in home care, where physicians and nurses usually do not work in the same organisation. Moreover, they do not generally encounter each other, whether in the presence of the patient or elsewhere.

Other studies have also indicated large differences in the participation of nurses in the decision-making process between hospitals and home care: 83.3% and 20% of cases, respectively, in one study[8] and 78% and 16% of cases in another.[10] However, several reasons hamper the comparison of results with those of other studies: (partial) absence of a sector-specific description;[9 11] analysis of cases regardless of whether nurses provided care during the decision-making process;[8 10 11] (partial) small study populations;[8 10 11] analysis only of cases in which euthanasia was performed;[8 10 11] and carrying out of the study when euthanasia was still fully illegal.[8 11]

Although physicians are encouraged to involve nurses in decisions about euthanasia in The Netherlands, they are not legally required to do so. The joint guidelines of physicians and nurses[4] state that if a nurse is involved in the daily care of a patient who has requested euthanasia, it is highly desirable that the physician includes the nurse in the decision-making process. A reference to this role is also made in the physician's report to the regional euthanasia review committee; the physician has to indicate whether a nurse was consulted and what the nurse's view was. This is in contrast to Belgium, where the legal regulation of euthanasia stipulates that the physician must discuss the patient's request for euthanasia with members of the nursing team who are directly involved in caring for the patient.[12]

Another issue is the lack of agreement between nurse and physician in the decision-making process. Nurses reported that they felt more satisfied when a request was granted than when it was denied. When nurses disagreed with the physician's decision to refuse a request (37.2%), this was often caused by a certain empathy with the patient. However, this type of solidarity with the patient may be misleading if the request is not sufficiently assessed from different perspectives—for example as a hidden appeal for help. Furthermore, nurses may interpret the due care criteria differently from physicians. However, it may also be true that physicians ground their decision on conscientious objections while the nurses' arguments are based on the due care criteria only. Physicians and nurses may also interpret requests or the circumstances of requests differently because patients may have expressed themselves differently to the various care providers. Patients may, for example, be positive about the request with the nurse but express doubts to the physician.

Administering the euthanatics

When nurses checked physician's actions or showed them how to handle an infusion system, this can be considered a way of ensuring a good course. Moreover, nurses are generally more experienced with infusions, which may be a reason for double-checking the physician's actions or providing instructions. Sometimes nurses inserted the infusion bag, while the physician opened the infusion. These are not "administering" actions by nurses. In our study, the demarcation between administering and non-administering actions was set by the moment in which the euthanatics flow into the patient.

While the administration of euthanatics is by law exclusively reserved to the physician, in some cases the nurse performed this act. Sometimes this occurred because the physician was insufficiently experienced in adequately managing the infusion. As the moment of infusion is important to the patient and/or relatives, nurses may feel compelled at that very moment to take over the procedure. Despite the intentions of nurses to supply "good care", such activities are illegal under Dutch law and do not qualify as emergencies.

Other studies[8 13] confirm nurses' administration of euthanatics with or without the physician, in home care in 17.2% and 4.0% of cases, respectively, and in hospitals in 58.8% and 21% of cases. However, comparison is problematic, because in the other studies all cases were analysed regardless of whether a nurse was present as the euthanatics were administered,[8 13], or because the demarcation line between administering and non-administering activities has not been defined,[8 13] or because a sector-specific description is (partially) missing.[8]

As the last lawsuit in this area in The Netherlands dates from 1995, physicians probably have since then not officially reported the administering of euthanatics by nurses. However, nurses who administer euthanatics or assist in a suicide risk both criminal prosecution and disciplinary measures. Moreover, physicians should be aware of their responsibilities and not leave such activities to nurses. It is important that physicians and nurses discuss and review each other's responsibilities and tasks before taking action.

CONCLUSIONS

This is the first Dutch survey exploring the role of nurses in euthanasia and physician-assisted suicide from the nurses' perspective. The study also indirectly offers insight in the approach by physicians, to which the role of nurses is closely related.

The study clearly shows that the role of nurses needs further specification. First, a sector-specific description of it is necessary, given the large differences between the intramural (hospitals and nursing homes) and extramural (home care) sectors. Second, a stage-specific description of the role of nurses is necessary, as their role varies in the various stages of the euthanasia process. For instance, in the decision-making process the consultation between physicians and nurses needs improvement, while in administering euthanatics nurses performed illegal actions by administering euthanatics.

In the policy advice to government, it has been emphasised that multidisciplinary institutional guidelines could play an important role in improving collaboration between physicians and nurses and in preventing procedural misunderstandings that could lead to ethical problems and legal offences. However, in home care it may be difficult to develop joint guidelines for physicians and nurses, because in general they work from different organisations. Nevertheless, especially in this sector nurses could benefit from guidelines in which their role and responsibilities are clearly described.

With regard to the demarcation of responsibilities and tasks between physicians and nurses concerning euthanasia and physician-assisted suicide in other countries than The Netherlands, the Dutch data may provide relevant information.

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