

# Impact of euthanasia on primary care physicians in the Netherlands

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**Background:** There is only limited knowledge about the emotional impact that performing euthanasia has on primary care physicians (PCPs) in the Netherlands. **Objective:** To obtain more insight into the emotional impact on PCPs of performing euthanasia or assisted suicide, and to tailor the educational needs of vocational PCP trainees accordingly. **Methods:** Qualitative research, consisting of four focus group studies. The *setting* was primary care in the Netherlands; 22 PCPs participated, in four groups (older males, older females, younger males and a group with interest with regard to euthanasia). **Results:** Various phases with different emotions were distinguished: before (tension), during (loss) and after (relief) the event. Although it is a very rare occurrence, euthanasia has a major impact on PCPs. Their relationship with the patient, their loneliness, the role of the family, and pressure from society are the main issues that emerged. Making sufficient emotional space and time available to take leave adequately from a patient is important for PCPs. **Conclusions:** Many PCPs stressed that young physicians should form their own opinions about euthanasia and other end-of-life decisions early on in their career. We recommend that these issues are officially included in the vocational training programme for general practice. *Palliative Medicine* 2007; **21**: 609–614

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## Introduction

The process of a prolonged illness, when the patient knows that it is fatal, can cause pain and humiliation, but that is not the only perspective: the patient has the opportunity to think about his or her life and consider 'unfinished business' and in this respect the physician may be a key figure in helping the patient to come to terms with life. Many patients who are dying become spiritual, and start to think about the meaning of life. They benefit from a good relationship with their primary care physician (PCP), the last port of call for many. However, there are many difficult medical issues that require attention, such as the communication problems that arise in patients with dementia and the avoidance behaviour of physicians when they fail to name the terminal illness, as happens in some cases of lung cancer.<sup>1,2</sup>

For the PCPs themselves, helping patients who are dying can be one of the most rewarding elements of their daily

work. Furthermore, adequate terminal care is an essential element in establishing good working relationships with the relatives of patients and the community in general. Terminal care is one of the few remaining ritual context-laden periods in the history of a family, and is therefore, important in primary care. Now that the beginning of life (obstetrics) is no longer a part of their job, to be of help at the end of life can still be a key element in work satisfaction for PCPs.

However, decision-making at the end of life can be also be particularly difficult and involvement in euthanasia, in particular, although highly infrequent, may have a major impact on PCPs.<sup>3</sup> Physicians have been reported to have emotional (28%) or burdensome (25%) feelings and to experience general discomfort in 42% of all cases of life-termination, and especially in the case of euthanasia (75%).<sup>3,4</sup> Four types of decision areas have been discerned: alleviation of symptoms, life-termination without an explicit request, assisted suicide and euthanasia. Each subsequent category caused significantly more discomfort to the physicians.

Because of what may be described as religious tolerance or indifference, PCPs in the Netherlands have traditionally been in a position in which they had a considerable amount of freedom to make decisions about life and death. The stable

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primary care situation in which most patients stay with one practice and one PCP for most of their life, supports this context. The performance of euthanasia rarely occurs during the working life of a Dutch PCP: on average only a few times in thirty to forty years.

On 1 April 2002, euthanasia and physician-assisted finaly became legal in the Netherlands; in Belgium a euthanasia law came into force in September of the same year. Under the Dutch penal code, physicians are no longer penalized if they adhere to an extensive notification procedure and meet the statutory requirements for prudent practice (<http://nl.site-stat.com/minbuza/minbuza/s?en-pdf.pdf.euth-amendedbill->). These requirements are: unbearable and hopeless suffering, no reasonable alternative in the light of the patient's situation, a voluntary explicit and repeated request, the provision of adequate information to the patient, consultation with a colleague, medically correct performance and a written report. As most other countries have no such legislation, lessons from the Dutch experience may have relevance in other countries.

As there is only limited, and not very detailed knowledge about the *emotional impact* that end-of-life decisions concerning patients have on PCPs in the Netherlands,<sup>5–9</sup> our objective was to obtain qualitative insight.

## Methods

As we aimed to make an extensive investigation of a relatively new subject, we chose qualitative research. The fact that the subject is sensitive might make it difficult to get physicians to talk about these issues,<sup>10</sup> so qualitative research was considered to be a suitable method with which to investigate a range of reactions and mechanisms: what and how do physicians feel and think about these issues, and what are their attitudes and experiences?

### Focus groups

To help the physicians to share their experiences and to promote a safe environment for discussion, a focus group study design was chosen.<sup>11,12</sup> This method generates richness in the detail of complex experiences, and elucidates reasoning behind actions, convictions and attitudes.<sup>13,14</sup> In a focus group, experts with experience meet and this promotes openness.

We developed a question route beforehand, and tested it in a brief pilot discussion in a Department of General Practice. An experienced moderator (a qualified psychologist with ample experience in moderating groups, Lenie Overmars) led all the focus groups, and one researcher (IH) was present as an observer. For the pilot discussion, one focus group session was held with four PCPs and one of the PCPs was interviewed. On the basis of this discussion and

the interview, slight adaptations were made in the routing of the questions, resulting in three main themes: (1) emotional experience; (2) coping (dealing with and managing the event) and (3) role of the physician.

### Sampling

A list of PCPs from the West of the Netherlands was compiled by means of the snowballing method.<sup>15</sup> We invited more than 50 PCPs by phone to participate in this project. The inclusion criteria were: at least one personal experience in the performance of euthanasia or assisted suicide.

In order to include a broad range of experiences, 22 of the PCPs who had been invited to participate were purposefully sampled in four explorative, descriptive focus groups discussions, held in the period August – November 2003. The groups were homogenized according to age and gender. There were six male PCPs in the first group and six female PCPs in the second. Most of the PCPs in these two groups had been in practice for at least 20 years. The third group consisted of five male PCPs under 46 years of age (36–45; 2–13 years in practice), and the fourth group consisted of five PCPs (three women and two men) who had participated in a Dutch organization called ‘Support and Consultation Regarding Euthanasia (SCRN)’.

### Data-analysis

All discussions were videotaped or audiotaped. When available, the exact text of the video or audio recording was transcribed (one tape was unavailable because the video was stolen). The data were reported anonymously. Two experienced qualitative researchers (IH and AMT) analysed the transcripts, using content analysis within a coding frame of the three themes (1) emotional experience; (2) coping (dealing with and managing the event) and (3) role of the physician.<sup>16–18</sup>

## Results

### Emotional experience

*Impact of the first occasion.* Many older PCPs described problematic, and sometimes even traumatic experiences, such as loneliness, mixed feelings, and contradictory emotions:

“I felt very lonely. I couldn’t share that with anyone. Wild stories about the police went round. Nobody could tell you how it [euthanasia, HvM] was done. I had no idea how it would be or how long it [the dying process following euthanasia, HvM] would take. I felt powerless and alone.” (L, female)

“I found it [performing euthanasia, HvM] very hard and lonely the first time, but I felt I’d done a good thing.” (B, female)

One PCP mentioned the lack of formal procedures at that time:

“Not having to justify [legally, HvM] oneself was hard.” (P, female)

At that time there was less medical expertise available with regard to palliative care, and that roused emotions among the PCPs. However, it also helped them to share experiences about medical-technical affairs that had not gone well, such as a prolonged duration of the dying process or a patient who became conscious again after a while. Several physicians had regrets, and felt guilty about not managing matters more quickly and more efficiently:

“What I lacked during the first years was support and knowledge.” (L, female)

Some of the older PCPs, more males than females, (1) had ‘heroic feelings’ because they were able to help someone:

“I was flattered with the trust.” (S, male)

Some PCPs regretted their first performance of euthanasia for reasons such as ‘insufficient awareness [of the other palliative possibilities, HvM]’, ‘having been manipulated [by the family or the patient, HvM], not having everything under control’ and described their experiences as ‘pioneer work’, ‘we learned by experience back then’.

There was a difference between the impact of the first experience and the overall impact. They felt different emotions before, during and after the performance of euthanasia:

“I was tense. The patient had HIV, I was very much aware of that. It was very scary. I was extremely preoccupied with the technique.” (J, female)

a) Tension *before* the performance. In various different wordings, many shared this emotion:

“It was terribly creepy, I never went anywhere with as much lead in my shoes as that morning when I took my bag with the medication in it.” (T, male)

b) Loss *during* the performance. When the patient said goodbye, a number of physicians described feelings of loss and abandonment. One physician told us how he experienced this as an emotional moment, and how touched he was to see the love and commitment of the family. This physician was not sure where he should set his boundaries. Many physicians experienced the medical aspect as scary; in the home situation, with a terminally ill patient who has very poor circulation it may be difficult to find access for the

drugs or to establish whether the patient has actually died, with the result that they felt pressured to succeed:

“What I found most difficult [about the act of performing euthanasia, HvM] was to find a good vessel [to inject the drugs in, HvM].” (H, female)

c) Relief *after* the event. Many physicians felt relieved that they had been able to do something for the patient. When it went well they felt great satisfaction, although a number of physicians remarked that the relief was greatest if the request for euthanasia or assisted suicide was withdrawn:

“If the patient [who requests euthanasia, HvM] dies of natural causes I feel very relieved.” (G, male)

“Nevertheless, I still always have a sense of guilt. I feel as if I’m an executioner. Who am I to have the right to do this? (G, Male)”

*Patient-doctor relationship.* A number of physicians, especially in the older age-group, indicated that they could only perform euthanasia if they had at least a minimal relationship with the patient:

“I want to build up a relationship beforehand [before euthanasia, HvM], remain in contact with myself.” (C, female)

One physician even had suicidal ideations as a result of the process of preparing to perform euthanasia:

“I need to care deeply for someone to be able to perform euthanasia. I have only performed euthanasia for people for whom I cared and whom I knew well. . . You suffer a loss yourself when someone like that dies. I sat in my car beforehand, and felt so miserable. I thought, if I drink this potion myself, now, it’s all over. I even took some drops. . .” (L, female)

*Loneliness.* Many physicians in all groups talked about feelings of loneliness, and not being able to share their emotions. However, the word lonely was seldom mentioned by PCPs in the younger age-group (2), they talked about being ‘alone’. A physician from the SCRN group:

“There is a feeling of loneliness [about these medical actions around the deathbed, HvM] that people can’t empathize with. I don’t feel the need to share this with people, except with colleagues perhaps.” (A, female)

*Family.* The PCPs mentioned various feelings concerning the role of the family, varying from gratitude and satisfaction to pressure, manipulation and tension and sometimes even

conflict. They also described their emotions concerning the family:

“What has struck me most is the commitment of the family [to the patient’s circumstances, HvM], they all sympathized. I found that unique, and stood there with tears in my eyes.” (E, male)

However, the relationship with the family can also induce anxiety:

“I didn’t know how the children would react after the euthanasia [they reacted positively, HvM].” (D, male)

One PCP described a difference of opinion about reporting the event to the authorities (W, male). He wanted to report the event, but the family did not. Afterwards, he regretted not having stuck to his own decision. Some physicians described a feeling of being manipulated. For instance, a patient’s son asked a PCP (M, male): how long will it take with mother? A question that often comes up is: who should be with the patient during the performance of euthanasia?

“Half the family was in the room and they said: ‘we’re going upstairs for five minutes [so the PCP could perform the euthanasia, HvM], then when we come back it will be over.’ I felt terribly manipulated.” (H, female)

## Coping

“My first and only euthanasia case was in 1998. She had several metastases from a primary tumour, and asked for euthanasia in the first consultation. Afterwards, I felt I was not ready with my conviction. In the Netherlands, the idea is you don’t have to suffer and you can ask for euthanasia. I felt slightly put upon, angry. My partner is also a PCP. She dropped out for over a year after some difficult terminal patients.” (K, male)

Euthanasia is a drastic, and sometimes even traumatic event for the PCPs involved. They cannot simply resume their daily routine afterwards:

*Taking time.* Many physicians find it important to take time after they have performed euthanasia or assisted suicide, to reflect on the event, to bid someone farewell, to take a day off or to do something relaxing. They blame their overall lack of time as a bottleneck for coping. How to cope is a personal issue for every physician.

*Sharing.* The importance of talking about the experience is stressed: to ‘let off steam’ directly afterwards, to share the experience with colleagues, a partner or a good friend, to come to terms with the loss:

“We have a ritual that my partner also has to know about it. She’s also a PCP and knows how hard it can be. She waits. It often bothers me the next day. Then I think: I want space. A year ago, when I had sabbatical leave, I noticed that several dead patients were still in my head (not only those who died from euthanasia). It got me down. A ritual would be good for me, but time is just lacking. I don’t experience posttraumatic stress disorder, it’s the inevitability of the assignment [and the social responsibility that the PCP has, HvM]: ‘That person should die.’” (G, male)

Most male physicians in the younger age-group stressed the importance of support from colleagues, listening and giving advice, being coached by an experienced physician and having colleagues who support the performance itself:

“I can’t talk about it [the emotional impact of euthanasia, HvM] at home, but I have a discussion group with fellow PCPs, and a bit of a chat with our practice assistant is also quite good”. (S, male)

“I usually share my experiences with my assistant, she knows the people involved. I had extensive psychological counselling after one case of euthanasia”. (U, male)

## Role of the physician

*Dilemmas and pressures.* Although some PCPs indicated that they had no problems with a request for euthanasia or considered it their duty, many of them are wrestling or have wrestled with the dilemma of why they, as doctors, have to end life or to perform euthanasia. Many experience it as untoward pressure from society.

“In the USA, there are people who execute the death penalty on authority of the judge. In Holland, we [as PCPs, HvM] are appointed as such, to take someone’s life (A, female).”

They wonder whether they have an obligation to perform euthanasia, and how they can defend their own point of view. Keeping up with the spirit of the times (‘being a modern doctor’) plays a role in this respect. Some chose not to perform euthanasia:

“When euthanasia was not performed I found the deathbed a special aspect of the profession. It was an honour to be allowed to guide someone to his or her final moment. With euthanasia, I always feel: ‘was that necessary’? I hate it. The patient is no longer granted the time for a natural dying process. He’s saddled with the question ‘when do I want euthanasia?’. To have to decide about the moment of death has created enormous unrest around the deathbed.” (V, male)

A number of male PCPs in the younger age-group indicated that they did not take it for granted that they should comply with requests and perform euthanasia. One PCP said that he had not yet made up his mind. He was not sure whether he had considered the issue carefully enough. He felt that it was his task to make euthanasia a subject of discussion with patients.

An (ex) SCRNP PCP:

“We were crazy to do it, looking back. Who am I to do this? Euthanasia was put on my plate. It’s a rotten job. I apparently felt, thought, that it was normal that PCPs did this. How did we let ourselves into it in this way? I wanted to be important as well. I wish they would no longer ask me, but I’m scared to say so. Perhaps I will have the courage to say so in a few years time. I feel very close to people, but I also feel angry: ‘what do you think you can ask of me?’” (G, male)

*Development and ageing.* Experience has helped PCPs to deal with the various issues concerning euthanasia. They have progressed, and most of them have become more reluctant to perform euthanasia. They protect themselves more, indicate that they have learnt their lessons and adhere more closely to their own views. They are more able to withstand manipulation:

“I felt I had done something [euthanasia, HvM] terrific back then. Now, I no longer know whether it is good for me.” (N, female)

*No more euthanasia.* A number of PCPs have decided not to perform euthanasia any more:

“It took me a long time to say so, but I think that this [euthanasia, HvM] is not good for me. I would be doing something that I cannot support. I feel much calmer now.” (V, male)

“I now say clearly to everyone: I don’t perform euthanasia any more. To my surprise a number of people say: ‘Doctor, you are so right, I understand completely.’ Then I thought to myself: how deep do these requests really go? I found that disconcerting to notice.” (A, female)

*Rules.* Physicians considered the support of regulations such as the extensive notification procedure and the publication of requirements for prudent practice to be a positive development, and they also appreciated the improvements in the medical technical expertise and palliative knowledge:

“I find it all much easier now. You discuss (the request for) euthanasia with different people. There are rules. You let someone watch over your shoulder. I find that better.” (L, female)

*Euthanasia and palliative care.* A trend towards increased use of sedation and more palliative care was described by several PCPs, especially in the SCRNP group who had received additional palliative training. The same trend can be seen in various research projects in the Netherlands.<sup>19</sup> The fourth special-interest SCRNP group provided few additional insights. In general, they had more or more intense experiences with end-of-life decisions. For instance, one PCP had many terminally ill AIDS patients at that time:

“I can say no now, with my acquired palliative knowledge, without leaving patients in the cold. I want to be skilled in palliative care and also able to perform euthanasia well. I want to feel good about this (L, female, SCRNP group)”.

## Discussion

This qualitative study provides a description of the wide variation of personal experiences PCPs in the Netherlands have with regard to the performance of euthanasia. Although it allows no quantitative generalizations,<sup>20,21</sup> given the limited prescriptive authority to conduct assisted suicide or euthanasia globally, the information may be relevant for physicians in other countries.<sup>22</sup> For example: although physicians should, of course, acknowledge the needs of the patient and the family, fundamentally, they should also acknowledge their own needs, such as the need: (1) to make up their own mind; (2) to discuss decision-making beforehand with a colleague; (3) to invite a colleague to be present; (4) to ‘let off steam’ afterwards and (5) to take time off for themselves.

More openness, as in the Dutch situation, appears to have been beneficial, judging from the experiences of the younger physicians. Building and maintaining a good relationship and good communication with the patient and the family is essential, especially around the deathbed.<sup>23</sup> The physician should be able to deal with diverse and complex external forces, withstand pressure and sometimes even withstand ‘manipulation’. Previous research has shown that GPs who are willing to perform euthanasia sometimes feel forced by patients to offer them euthanasia as one of the options, owing to the hopeless circumstances in which patients can find themselves.<sup>4</sup>

Many PCPs stress that physicians should start early to develop their own views with regard to euthanasia and other end-of-life issues. In our new student-centred vocational training curriculum for general practice, we try specifically to help the trainees to develop their own perspective on issues concerning death and dying ([www.hovumc.nl](http://www.hovumc.nl), in Dutch). Especially the older physicians indicated that for them it has been a long road to becoming (more) aware of their own views. The trend among physicians to ‘stay closer to their own beliefs’ is also a lesson for the younger generation. The statements made by the younger physicians

indicate that they more often adopt this attitude, and frequently receive support from older, more experienced colleagues. Moral deliberation could contribute to improving the way in which PCPs deal with moral problems, such as euthanasia.<sup>4</sup>

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