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I think I'm old and I'm feeling pain, you said
And it's all running out like it's the end of the world, you said
And it's so cold, it's like the cold when you were dead
And you smiled for a second

Plainsong – The Cure

3

Developments in the practice of physician-assisted dying: perceptions of physicians who had experience with complex cases

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ABSTRACT

Background

Since the enactment of the euthanasia law in the Netherlands, there has been a lively public debate on assisted dying that may influence the way patients talk about euthanasia and physician-assisted suicide (EAS) with their physicians and the way physicians experience the practice of EAS.

Aim

To show what developments physicians see in practice and how they perceive the influence of the public debate on the practice of EAS.

Methods

We conducted a secondary analysis of in-depth interviews with 28 Dutch physicians who had experience with a complex case of EAS. Respondents were recruited both by the network of physicians working for SCEN (Support and Consultation for Euthanasia in the Netherlands) as well as via a national questionnaire wherein participating physicians could indicate their willingness to be interviewed.

Results

Three themes came up in analyzing the interviews. First, the interviewed physicians experienced a change in what (family of) patients would expect from them: from a role as an involved caregiver to being the mere performer of EAS. Second, interviewees said that requests for EAS based on non-medical reasons came up more frequently and wondered if EAS was the right solution for these requests. Last, respondents had the impression that the standards of EAS are shifting and that the boundaries of the EAS regulation were stretched.

Conclusions

The perceived developments could make physicians less willing to consider a request of EAS. Our results also raise questions about the role of physicians and of EAS in society.

INTRODUCTION

Euthanasia or physician assisted suicide (EAS) is regulated in Dutch law: physicians will not be prosecuted if they perform EAS while meeting the legal due care criteria.⁽¹⁾ The most important criteria are that the physician is convinced the request of the patient is voluntary and well-considered, and that the suffering of the patient is unbearable and without prospect of improvement. The Dutch legal system makes no distinction between euthanasia — administering of the lethal drugs by the physician — or physician-assisted suicide — providing lethal drugs to the patient by the physician. EAS is not considered a normal medical act, but physicians are the only people allowed to perform it. For physicians it is optional to perform EAS and not something they are obliged to do if a patient meets the due care criteria; there is no ‘indication’ for EAS. So, next to the legal criteria, a physician can use his/her own moral compass to reflect on whether or not he/she is willing to grant a request for EAS and under what conditions. This way, the law protects physicians (from prosecution), but does not necessarily empower patients who seek EAS. This also shows when looking at the normative background of the law. The law is mainly founded on the principle of compassion of the physician.⁽²⁻³⁾ Self-determination and autonomy of a patient also play a role — foremost because a request needs to be voluntary and well-considered — however they aren’t the main principles reflected in the law.

Although physicians are never obliged to perform EAS, voices of those who advocate the option of EAS, or even a right to die, have become stronger in Dutch society. The two initiatives that are probably best known are the ‘Of Free Will’ (Uit Vrije Wil) movement and the ‘End-of-Life Clinic’ (Levensindekliniek). The ‘Of Free Will’ movement filed a bill in 2010 in which persons older than seventy years without serious medical problems would get a right to assisted suicide.⁽⁴⁾ This proposal would have far-reaching consequences, since the Supreme Court in 2002 decided that for EAS the suffering from the patient has to stem from a medical condition.⁽⁵⁾ The ‘Of Free Will’ movement tried to set this requirement aside and leave the decision of assisted suicide to the people themselves, so that the role of the physician would be marginalized. The movement received extensive media attention and because it was widely supported by the public, the bill ended up being debated in parliament. While this bill was rejected in parliament, it sparked the societal debate on a ‘right to die.’⁽⁶⁾ Two years later, Right to Die-NL (NVVE) founded the End-of-Life Clinic, which was established to meet the needs of patients who meet the legal requirements for EAS, but have had their request rejected by their own physicians. The number of applicants has increased yearly since the start.⁽⁷⁻⁹⁾

These movements show that EAS is subject to a continuing debate in the Netherlands and they might reflect a shift in the way the public thinks about EAS. A previous study showed that the general public has a more permissive attitude towards EAS than physicians.⁽¹⁰⁾

These developments in society may well influence how people talk about EAS with their physician and how the physicians experience the practice of EAS. At this point, the perspective of physicians on this subject is underexplored. We chose to study the experiences of physicians who reported having experience with a complex case of EAS, since we expected these physicians had thought about and reflected on EAS and the role of the physician more extensively than average. The aim of our study is to see if and how physicians who had experience with complex cases of EAS perceive any important developments in the practice of EAS and to further explore these possible developments.

METHODS

Study design and recruitment

Because of the exploratory and open nature of our question, qualitative interviews best suited our research question. In-depth interviews with physicians, conducted for a study into characteristics of EAS requests that make some EAS requests particularly complex were used in a secondary analysis. This means the primary end of the interviews was not to find out important developments in the practice of EAS, but to get a detailed description of the experience of a complex case of EAS. However, although not the main topic, during the interviews the respondents spoke a lot about what changes they had experienced in the practice of EAS and how they interpreted this changing environment.

Recruitment was carried out in two ways. We asked SCEN (Support and Consultation for Euthanasia in the Netherlands) physicians if they had experienced an unusually complex case. SCEN physicians are specially trained in offering an independent second opinion in EAS requests. From the 103 responses we received, we selected nine respondents for an interview. Second, we recruited physicians who had participated in a national questionnaire and had indicated they were willing to be interviewed about their experience about EAS in an in-depth interview and had experience with a complex case. A total of 186 physicians were willing to be interviewed; by purposive sampling we selected 18 physicians for an interview based on their experience with a

complex EAS-request. We furthermore selected our respondents to include a variety in age, work-experience and specialty. In addition, there was one physician who had heard about our study and asked to be included.

A total of 28 interviews was conducted, none of the approached physicians refused to participate. There was no previous relationship between the participants and the interviewer. Interviews lasted 37-97 minutes and were conducted at their workplace or home. Nine of the respondents were female. The respondent's age ranged from 36 to 68 years and they all had experience with EAS requests and the performance of EAS. 22 respondents worked as family physicians, six worked as medical specialists (three elderly care physicians, a psychiatrist, an internist and a lung specialist). Next to this, six of the respondents also worked as a SCEN-physician. Interviews were conducted by researchers D.G.v.T. and M.C.S., both trained in qualitative research methods. All the interviews conducted for the primary analysis were also used in the secondary analysis.

In accordance with the Dutch legislation, the study did not need review by a medical ethical committee, as Dutch law specifies that ethics approval is only needed when 'participants are subject to procedures or are required to follow rules of behavior'.⁽¹¹⁾

Analysis

All interviews were recorded and transcribed verbatim. One respondent wanted to receive the transcript of the interview. This respondent had no further comments upon reading the transcript. Atlas.ti 7 was used as support in analyzing the data. First, all interviews were read again for this secondary analysis by M.C.S. and the first five interviews were open coded. MS discussed these codes with D.L.W. and B.D.O.-P. and they developed a code scheme together. With this code scheme the rest of the interviews were coded, and the scheme was adapted when an important theme came up during the coding process. Codes that were used: current legislation, societal debate, position of the physician, position of the patient, position of the family, (lack of) feeling understood, EAS as a patient's right, type of condition and the subjectivity of assessing the due care criteria. After coding all interviews, inductive analysis was used to find the central issues the interviewees mentioned.

RESULTS

We identified three broader developments, mentioned by the physicians: the impression of a change in the position of the physician in EAS, EAS requests not primarily motivated by a medical condition, and the feeling of shifting standards.

Physician's position: involved caregiver or distant performer?

The interviewed physicians spoke about the ongoing public debate about EAS and the ease with which the position of the physician is overlooked. Because of this, they felt like a mere performer of EAS, whose own position or opinion should not matter. See box 1, quotes of R11 and R20.

Interviewees not only described this tendency when talking about the public debate, but said they had experienced it in conversations with some of their patients as well. Some patients — or their direct family members — seemed to think EAS is easy, while the physicians themselves perceive EAS as something difficult and exceptional. Physicians got the impression that some of their patients think EAS is an option that should be available to them if they so desire. See box 1, quotes R3 and R7. Physicians tried to avoid the position where they felt pressured to perform EAS, but sometimes could not escape this feeling.

Box 1 Physician's position

R11, GP: *“That is basically the public opinion. That’s also what the judiciary say too, like ‘doctors shouldn’t make such a fuss. It’s allowed, isn’t it? So then you should just get on with it’”*

R20, GP: *“I get very annoyed at how easily politicians make statements. They know nothing about it. Like recently, with the End-of-Life Clinic and how easily they then say ‘Well, the doctors aren’t cooperating’. People have no idea what it entails for a GP.”*

R3, GP: *“Then they [family members] asked again, saying ‘Yes, he wants euthanasia’. I said ‘Sure, but I want to hear it from him’. At that moment he didn’t say clearly that he wanted euthanasia, and he was lying comfortably in bed without pain. I felt then that the family was putting an incredible amount of pressure on me. [...] Of course that was a bit reminiscent of the slogan that ‘the option for is the right to’. Obviously we do interpret it like that sometimes, but of course that’s not how it works.”*

R7, GP: “Well, she reckoned that I should just do that, given my role as a physician, because of the unbearable suffering for the patient without prospect of improvement that she thought was definitely the case here. She wanted to die in a humane manner and thought that I should assist her in that.”

Non-medical reasons for EAS

Physicians were asked about their opinion on requests of EAS in cases where there was no medical condition underlying the request. Most physicians were under the impression these type of requests came up more frequent in the last years and had difficulties with the idea of EAS in these cases. They wondered if this was something that they should be responsible for and mentioned the growing public debate about these cases. Most physicians expressed the view that these requests based on non-medical reasons stemmed from loneliness and that this was not a medical problem but a societal one, not something for which EAS was the right solution. Most physicians also mentioned not feeling competent to make a decision about EAS in these cases where suffering was mostly existential, not motivated by a medical condition; they felt it did not belong to the domain of medical professionals. These respondents said for instance, that in such cases people should take their own responsibility and not rely on their physician for assistance in dying. See box 2 for accompanying quotes of R4, R24 and R27.

On the other hand, one of the physicians (Box 2, R25) had a different perspective. He thought it was wrong to reject patients with an EAS-request and to advise them to terminate their lives themselves. Physicians can perform EAS in a technically good and correct manner and should do so if requested.

Another physician (see box 2, R28) did not understand why other doctors have trouble helping people if they consider their lives completed.

Box 2 Non-medical reasons for euthanasia or physician-assisted suicide

R4, geriatric specialist: “I find the societal aspect of the ‘tired of living’-issue very difficult. I can certainly understand that becoming lonely can make you feel you are done with life, but isn’t that partly because of how our society functions? And how we behave towards one another, and individualism, and not knowing your neighbours anymore and that kind of thing. That’s what I find difficult about this issue. [...] As a doctor, I find that the difficult side to the ‘tired of living’-issue. Because I’m the one who has to perform the euthanasia. I also think it should stay that way, that the doctors should keep that role. But I think society should not become so impoverished that the doctor has to deal with its deficiencies, with the effects of the lack of warmth in society. Because that’s what I see as the problem.”

R24, GP: “I often see people who say their life is completed, very lonely people too. And then I think gosh, we are getting into a situation where people are choosing to die because of loneliness. [...] There really are people who weigh up the options and think ‘Yes, my life is completed, I don’t want to keep going’. Well if there’s something that lets people end their own lives, I say that’s fine, but I don’t see any role at all in these cases for me as a doctor.”

R25, geriatric specialist: “I find it incredibly confrontational if I’d have to negotiate with a patient and say, ‘You want to die? Right, well do it yourself then. And I can tell you how, too’. [...] In such a situation, I also think, ‘Yes, these people are basically going to rely on something that we are so exceptionally good at as doctors: performing euthanasia. We are very competent at it technically and we also do it by the book. And people want that, quite rightly.”

R28, pulmonary specialist: “Well, I don’t have too much difficulty with the legislation. As far as I’m concerned it could even be a bit more flexible, but that’s not my decision. Elderly people who are tired of living? I wouldn’t find that a problem.”

Shifting standards

Interviewees also spoke about the impression they got, that the boundaries of EAS had shifted over time. Their impression was that nowadays a more diverse range of reasons for EAS is permitted than before. One of the respondents mentioned a patient whose request he had rejected before and who left his practice. The physician said he was relieved that she left, because if she still had been his patient, he would find it much harder to reject her request, because nowadays it is publicly known that EAS is allowed in cases with similar type of suffering. Terms that the interviewees used in the context of shifting standards were: ‘stretching the boundaries of the law’, ‘broader understanding of the concepts’, ‘shifting borders’ and the ‘slippery slope’. Interviewees expressed their concern about this, and wondered aloud how to interpret this shift, what it could mean for society and for the future practice of EAS. See box 3 for supporting quotes.

Box 3 Shifting standards

R7, GP: “I know that the euthanasia legislation has become a bit more flexible now, right? People can also have a combination of many different ailments due to old age.”

R9, GP: “I have the feeling that the Regional Review Committees are also being a bit more flexible in interpreting the concepts — what is and isn’t acceptable.”

R12, GP: *“Of course that shifts over time, as you see now with the shifting boundaries for dementia and mental competence and that kind of thing. [...] That is inherent in humans, I reckon, and it’s also inherent in the procedure: you start testing the limits. And that’s also the difficult thing about it.”*

R17, GP: *“Isn’t this a sliding scale that we’ve ended up with? That we shift the boundaries every time? Or can society still stipulate the boundary — ‘This far and no further?’”*

I: *“How do you see this?”*

R: *“I don’t really know. I think we’re on a sliding scale. That we really are increasingly progressing towards a situation where you manipulate society, manipulate life.”*

DISCUSSION

The themes the interviewees spoke about were a change in the position of the physician where they felt like a mere performer of EAS, EAS in non-medical cases, and their impression that the standards of EAS are shifting. For most of them, these developments were reasons for concern.

Personal boundaries vs legal boundaries

Our study showed, that physicians sometimes felt pressure, either from society or from (family members of) patients, to perform EAS. A national study has also asked if physicians felt pressured by either the patient and/or his family, and found around 12%-17% of physicians reported this feeling.⁽¹⁰⁾ In the accompanied interview study most physicians did not recognize this in conversations with their patients, but confirmed that family members sometimes can be claiming.⁽¹⁰⁾ A study conducted by the Royal Dutch Medical association (KNMG) found that 75% of the physicians felt pressured by the (relatives of the) patient.⁽¹²⁾ The tension between the wishes of the patient and the willingness of the physician is probably inevitable because of the open norms in the due care criteria, such as the unbearableness of the suffering of the patient. Because the public knowledge about EAS is increasing, people are more aware of the possibilities the law offers.

The experience of shifting standards can be explained by the idea that for a long time, physicians could have been under the impression that their own boundaries were correspondent with the legal boundaries. EAS was, and still is, mostly performed in

patients suffering from cancer or other clearly physical ailments (79% in 2010).(13) Most Dutch physicians are willing to perform EAS in these cases.(14) The last few years, EAS in patients suffering from dementia, psychiatric diseases or an accumulation of diseases of old age has gained a lot of media attention, and there has been an increase in performance of EAS in these cases, although it is still rare: the most recent report of the Review Committees mentions 41 cases of psychiatric diseases, 81 cases of dementia and 257 cases of an accumulation of diseases of old age, on a total of 5305 cases of EAS in 2014.(15-16) In assessing these cases, the Regional Review Committees gave more substance to the open criteria of ‘unbearable suffering without prospect of improvement.’ The Royal Dutch Medical Association also explicitly state in their position paper of 2011 that EAS is possible in these uncommon cases, although they consider a restrictive approach to be appropriate. This way they take position between the Review Committees and the physicians. Now that it has become more commonly known that EAS in these cases is legally possible, physicians may feel this as a shift in legal boundaries, while it only shows that their own (personal/moral) boundaries are sometimes more strict than the requirements of the law. From a legal perspective, this does not have to be problematic for physicians, since they are free to follow their own moral considerations when it comes to EAS — although patients may find it hard to understand when they do so. However, it can become problematic when this experienced shift is accompanied by a feeling of being put under pressure (as shown in the section ‘Physician’s position: involved caregiver or distant performer?’), because then the physician can feel restricted in this freedom. This could have two possible consequences: either the physician feels compelled to perform EAS against his/her personal standards, or the physician may become resistant to perform EAS altogether. Patients may experience some arbitrariness in the final decision of a physician whether or not to grant a EAS request, because physicians follow their own moral consideration.

Exceptional or normal?

The developments the respondents mentioned can be interpreted as the overall tendency of EAS becoming increasingly ‘normal’ in the eyes of the public instead of being truly extraordinary or exceptional. It might lose its particular legal status and become incorporated in the medical domain. Is this true, and if so, is it something that should worry us?

EAS as ‘becoming more normal’, can be understood as increased acceptance of EAS (‘accepted practice’), or this could be seen as a shift to EAS being a treatment on indication (‘normal medical practice’). It is important to distinguish these two types of

normalization, because they have different implications. A treatment on indication implies that a patient is entitled to EAS if (s)he meets the due care criteria; an accepted practice does not necessarily imply this.

We've seen that patients sometimes claim EAS, which could be interpreted as a manifestation of patients considering EAS as a right, as a treatment on indication. A national study that looked into the public opinion regarding EAS found that a small majority (57%) of the public would want EAS to be a patient's right.⁽¹⁰⁾ Patients can also be inclined to think they are the only ones who can assess the due care criteria of unbearable suffering, while the due care criteria explicitly state that the physician must be convinced the patient's suffering is unbearable. Physicians, however, still experience EAS as something exceptional and are not always willing to perform EAS even if the due care criteria have been met. Since EAS is still in the hands of the physicians, it is unlikely that EAS will become 'normal medical practice' any time soon.

Can we find more support for the idea of EAS as an accepted practice? None of the physicians we interviewed were negative about the existence of the law on physician-assisted dying. They did not question EAS as such, they only questioned the specific developments they noticed. Acceptance of EAS is also high in physicians in general; 93% of Dutch physicians either considers him/herself as liberal towards EAS or is willing to consider EAS under certain circumstances.⁽¹⁰⁾ The same study found that only 5% of the general public opposes the option of EAS under all circumstances. This attitude of acceptance in the Netherlands is steady over the years.⁽¹⁷⁾

A consequence of an accepted practice, could be the emergence of a distinction between normal and the abnormal cases of EAS. Is this distinction applicable to EAS? Since 2012, the Regional Review Committees started making a distinction between reports of EAS that raise no questions ('niet vragen oproepend': NVO) and reports that do ('vragen oproepend').⁽¹⁸⁾ The NVO-cases are assessed digitally by all members of the committee. If everyone agrees the due care criteria have been met, the case will be accepted without the committee discussing it in person. All other cases are discussed in the monthly meeting of the committee. NVO-cases are often cases where the patient is terminally ill with a short period of time left to life, for instance, cancer patients with a short life-expectancy, who are suffering from severe pain and other physical symptoms such as nausea, extreme fatigue and functional loss. One could argue making a distinction like this, is a form of saying 'these are normal cases of EAS, and these are not' and this way it functions as a way to frame the debate: the subject is no longer about the acceptance of EAS in general, but about the acceptance of more unusual and rare EAS cases.

Solving a societal problem?

Another theme that emerged from our results, is the relation between the medical profession and society. Respondents were worried that a societal problem (eg, loneliness in old age) gets translated into a medical problem, because the solution for this problem might be sought in EAS and the doctor is the only one allowed to perform EAS. In such cases, the wish to die is not clearly based on a medical condition, but the solution is found in medical practice. Clearly, many older patients also have medical issues, but research has shown that for some of them the predominant reason for a wish to die is founded in a feeling of being disconnected to life, and with that, loneliness.(19) This raises the issue of medicalization. Patients are dependent of their physician; so it is in the hands of the physician whether or not the patient will die in this fashion. Physicians, even if they don't want to, are entrusted with this.(20)

Strengths and limitations

For this study, we used interviews that were held in the context of 'complex cases' of EAS. Selection bias may have influenced the content of the interviews: physicians who report complex cases may be more likely to express concerns about developments in EAS, and therefore, our results may reflect developments that are not generally felt by all physicians in daily practice.

A limitation is that we have not been able to adjust the topic list along the way to include important topics that came up during the interviews, we could not sample and include physicians with distinct different views on the developments in the practice of EAS, and we cannot make claims about data saturation. However, the presence of contradictory opinions shows we included physicians with a range of ideas.

The physicians we interviewed are the ones who thought about (their part in) developments in the practice of EAS more than we expected an average physician would have. It is in reflection on the more difficult cases when physicians mention the developments described in the results and start to reflect on the role of society. In qualitative research, our type secondary analysis is a common way of analysis; to look at the data and see what themes emerge from it, to leave room for the unexpected.

Conclusion

Although, in the Netherlands, physicians are the only professionals who may perform EAS, their perspective on developments in the debate on EAS has not been explored in depth. The developments the physicians mentioned in the interviews where, for most of them, cause for concern. As long as physicians are the only professionals to perform EAS, their perspective and concerns need to be heard. One of the concerns

is that physicians can feel pressured by the developments they mentioned, and in reaction to these issues, physicians could feel forced to cross their own moral boundaries, or in reverse, they could become less willing to consider a request of EAS.

Our results also raise concerns about the role of the physician and of EAS in society. It is becoming increasingly clear that the personal boundaries of physicians do not always coincide with the legal boundaries. This makes it apparent that physicians are entrusted with a decision that makes them and the public occasionally feel uneasy. Although it is likely that a discrepancy will remain in individual cases between the wishes of the patient and the willingness of the physician, more understanding could be achieved by communicating more clearly about the legal boundaries and by explaining that physicians are allowed to have personal reasons to reject an EAS request.

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