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Developments in the practice of euthanasia or physician-assisted suicide and how these relate to normalization

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Submitted

ABSTRACT

Background

Although regulated in the law, euthanasia and physician-assisted suicide (EAS) in the Netherlands is legally still an exceptional medical act. One may wonder if the practice will gradually lose its exceptional character and will become (more) normal.

Aim

The question of our study was the following: is EAS becoming a normal act in the medical domain?

Methods

Via qualitative in-depth interviews, we asked 12 experts in the field of EAS with different professions (health law, ethics, health policy) about their views on recent developments, and a potential normalization, of EAS.

Results

The experts described both signs and causes of normalization as well as the opposite: EAS remaining an exceptional practice. They also described a tension between the wishes of the general public and the willingness of the physicians regarding EAS. Legally, EAS remains exceptional, while on a social-ethical level normalization is at hand. It was said that EAS has become a normal way to die.

Conclusion

Normalization in this form does not need to be problematic — there are no indications of abuse. Normalization of EAS has led to the moral obligation to motivate why a request is rejected and in this way contributes to the careful consideration of EAS.

INTRODUCTION

A growing number of states and nations have legal regulations that allow for the performance of assisted dying under certain conditions. In the United States assisted dying is regulated in several states, such as Oregon and Washington. In the rest of the world, it is regulated in Switzerland, Colombia, Canada, Belgium, Luxembourg and the Netherlands. Assisted dying can be subdivided into euthanasia (the active administration of lethal drugs at the person's request) and assisted suicide (provision of lethal medication to the person, again at his/her request). There are additional criteria in place that (try to) ensure a careful practice, these differ slightly between countries.(1-2)

In the Netherlands, physicians are the only ones who can be exempted from prosecution for the performance of euthanasia or physician-assisted suicide (EAS). The performance of EAS falls within the criminal law of the legal domain.(2-4) This makes EAS different from the rest of the medical acts a physician performs. Although there are more medical acts in which a physician can harm a patient — for instance an operation — these acts are 'normal medical practice' and fall within medical exception. Normal medical practice is overseen by the medical domain itself (medical ethics and medical disciplinary law) to ensure prudence. The medical profession ensures its standards.

In contrast with the medical framework, EAS falls within a legal framework. Its standards are therefore legal and not medical. These legal standards are called the due care criteria. Unlike normal medical practice, the performance of EAS is not 'legal until proven otherwise', it is a criminal offence until deemed otherwise.(3) There are special committees installed (the Regional Review Committees — consisting of a physician, ethicists and a jurist) that assess whether the physician who performed EAS has abided the due care criteria and will be exempted from prosecution. This makes EAS an exceptional medical practice.(4)

Aside from being legally exceptional, EAS is also in numerical exceptional — because the performance is quite rare for an individual physician — and emotional exceptional — because the performance of EAS is often emotionally burdensome for the physician.(5-7)

One of the fears expressed about legalizing EAS while keeping its exceptional status was that this would, over time, result in normalizing EAS.(8) In this paper, we'll explore what normalization in the context of EAS means and find an answer to the question if, after fifteen years of legal regulated EAS practice in the Netherlands, there are indications to think EAS is indeed subject to normalization. Could the practice have lost

some of its exceptional character and has it become (more) normal? What would this normality entail and how does it become visible?

In previous research, the first hand experiences of physicians have been studied.^(7, 9-11) Physicians however, do not have an overarching view of the practice of EAS. They are the ones who handle an EAS request, who decide if they are willing to grant a request or not, but a typical general practitioner — the physicians who receive the most requests for EAS — only receives an explicit request one or two times a year.⁽¹²⁾ Therefore, to learn more about potential normalization of EAS, we chose to ask experts in the field of EAS their opinion whether EAS in the Netherlands tends to become a normal act in the medical domain.

METHODS

Since we were interested in the opinions of experts on the subject of EAS, we chose a qualitative research design and used purposive sampling to select our respondents.

Someone was considered an expert if he/she is, or has been, extensively involved in either EAS research, EAS review committees or EAS policy making. The goal was to interview experts from different professions, in order to gather views from different perspectives. For this reason we selected 14 experts that were working the field in health law, ethics, medicine or health policy. The experts were invited to participate in this study via a personal invitation letter. One of our selected experts refused to be interviewed about the subject because of his/her own research, another because of time limitations. This resulted in the recruitment of 12 experts.

Eight of the respondents have current or former experience in Review Committees, six work as an ethicist, six in research concerning EAS, four in health policy (including or specifically directed to end-of-life issues), three as a (SCEN)physician, two are specialists in health law, and one is active in interest groups concerning EAS. There was some overlap among the categories. When quoting a respondent in the result section the main expertise of a respondent is mentioned.

To explore their views, semi-structured face-to-face interviews were performed. M.C.S. and P.B.V. conducted these interviews: four interviews were carried out together, six by M.C.S. and two by P.B.V. alone. The interviews lasted 46 to 108 minutes. The aim was to explore the experts' views on developments in the field of EAS, focusing on the question whether EAS is normalizing. For this purpose, during the interview the following themes were addressed: 1) the most important developments in the field of

EAS in the last years; 2) normalization of EAS in society and in medical profession; 3) the consequences of a (possible) normalization; 4) the differences between EAS and normal medical treatment; 5) possible future developments in the field of EAS. The term normalization was not defined by the interviewers, and experts were asked to define it themselves.

Analysis

All interviews were audio recorded and transcribed. M.C.S. and P.B.V. independently analyzed the data with use of ATLAS.ti 7 software. First, they read and analyzed the transcribed interviews using open coding. After four interviews, they compared the open codes and identified recurrent themes and patterns. This resulted in a code scheme which was used to analyze all interviews. The code scheme was adapted or supplemented if new important themes were found. Using inductive analysis, we identified different themes that we categorized in signs and causes of normalization, signs and causes of an exceptional practice, and tensions around normalization.

RESULTS

What is normalization? Our respondents mentioned different aspects of this concept. For most respondents, it was a term that described an increasingly accepted practice, a practice that was truly part of the profession of a physician. Most experts were of opinion this was happening or had already happened with EAS. Other respondents interpreted the term normalization in a legal sense, as 'EAS being normal medical practice'. These respondents said normalization had not happened yet, but some of them could see it happening in the future. Others said that for patients in the late stages of their disease — for instance terminal cancer — who asked EAS, this form of normalization was already in place albeit not (yet) laid down in the law.

We will start the result section with signs and causes of normalization, followed by signs and causes of remaining an exceptional practice, and finish with the tension that emerged between the public and physicians. Many experts mentioned both sides: a movement towards normalization and at the same time remaining exceptional.

Signs of normalization

One of the first things experts said about important developments in the field of EAS, was the increase of reported EAS cases. They mentioned this was a sign that EAS has

become “one of the possible ways in which a person can die in the Netherlands” (R8, ethicist).

Related to this, they mentioned that EAS has become part of the profession of a physician, especially for general practitioners. This does not imply that dealing with EAS is not difficult or stressful, but it is something a physician sometimes has to do: “it seems as if physicians think of it as part of their job” (R5, health policy).

The next theme that came up in the interviews, were the sources of suffering in which the performance of EAS was acceptable. The respondents said that there has been a shift from interpreting unbearable suffering as ‘suffering caused by a terminal illness’ towards a broader perspective on suffering: less focus on terminal disease, more openness to other situations where suffering can occur. Some of the interviewed experts said “this shift was in accordance with the initial intent of the law” (R11, interest groups).

Our respondents also mentioned that many people in society take the view that a physician should not be resistant when a patient is asking for EAS. Some interviewees mentioned that because the option of EAS has been laid down in law, people thought they could demand EAS. Another interviewee said that “people like those who work at Right-to-Die societies inform their members that euthanasia is not a right. But still, in times of need, people don’t think that rational. If you really want to have it [EAS] done, you will not think ‘oh, it is only a request and they are allowed to say “no”’. Then you look for arguments to get what you want.” (R10, health law).

When asked if something has changed in the liberty of a physician to reject a request, most experts said that a physician was always free to reject a request for EAS and that nothing has changed in that respect. However, it is somewhat expected that the physician should have solid reasons not to be willing and should be open about these reasons towards the patient. Declining an euthanasia request is no longer the default option; being morally obliged to justify your decision to reject a request, just as much as to grant a request, is a clear sign of normalization.

“I’m of opinion that, with the law as is, it’s part of the physician’s professionalism not to simply reject a request. He should give a reason. For instance ‘I’ve moral objections’, that’s valid. Or: ‘I’ve already done euthanasia four times in the past year and I’m emotionally not able to do it again right now’. So, he has the right to reject a request, but should handle that professionally. Asking for euthanasia is de facto asking for help. A physician ought to react to a request for help. This does

not imply he's obliged to grant the request. (...) For me, the obligation to refer — if the physician is not willing — is embedded in the fact that it is a request for help to a professional. This professional does not have to do it himself, but if he's not able to, he ought to say 'I am not able to help you with this, but I'll refer you to another physician.'

(R11, interest groups)

According to several experts, it can be expected of a physician that he/she makes a distinction between personal and legal reasons for not granting a request. It was also expected of physicians that they were well-informed about the possibilities the law offers and that it was morally unjust to reject a request which would probably meet the due care criteria without referring to another physician.

“Whatever the reason, a doctor is never obliged to carry out euthanasia. A doctor can always say ‘no’, but if so, you [the doctor] have to give the reason why. In my opinion, you have a duty to actively reflect on the reasons why you are not willing in this particular situation. Maybe you are reluctant, but you have to gain a clear insight. Are the legal requirements fulfilled? If not, it [EAS] is impossible. But maybe there are personal reasons at stake — maybe you carried out euthanasia last week, something like that, I don't know. But you should explore these considerations. This has nothing to do with normalization, this also applies to other medical acts. Here the doctor is at charge.”

(R10, health law)

Referring to normalization, the experts also mentioned the role of the Regional Review Committees. They questioned what the Review Committees contribute to the practice if nearly all cases are considered prudent: have they become superfluous? The interviewees also mentioned a recent development within the Regional Review Committees: a distinction is made between reports which do not raise any questions ('normal' euthanasia) and ones in which the due care criteria are not unambiguously met. The first category will not be discussed in a meeting if all members digitally agree that they raise no questions.

Causes of normalization

Some of the causes for normalization mentioned by the experts were related to general changes on a societal level — not specifically related to EAS but nonetheless influenc-

ing the practice of EAS — while others were more closely related to the practice of EAS itself.

To start off, the experts we interviewed described an increased importance of self-determination and more focus on the autonomy of the patient. When talking about unbearable suffering and self-determination, some of the respondents also said that nowadays people have a reduced acceptance and endurance of severe suffering.

“I think people are less willing to accept to suffer until the end. They say something like ‘I don’t want to experience that’. That’s the whole new aging generation; people who are used to take matters into their own hands and are less willing to put their fate in someone else’s hands. The baby boomers are used to take control, and they want to with respect to their life.”

(R6, ethicist and health policy)

In the previous section, we described the expansion of the sources of suffering that were considered acceptable for the performance of EAS as a sign of normalization. An important cause for this, according to the experts, is that the due care criterion of ‘unbearable suffering’ has received more substance by the decisions of the Regional Review Committees.

Several respondents mentioned the difference between generations of physicians. Older doctors became physicians in a time where you would be prosecuted if you performed EAS and were open about it. Also, it was not yet clear what was the right method or drug to use. An atmosphere of secrecy surrounded EAS. Young doctors all grew up with the notion that EAS was a possibility, with guidelines on how to discuss and perform it. *“For young doctors, in practice for around five years or so, it seems as if euthanasia is something that is part of the job.”* (R5, health policy)

A last cause for a potential normalization of EAS mentioned by the experts, was the increasingly open communication in society about EAS. Patients were not afraid to ask for EAS and to talk about it in the open. Because of this open communication, people hear more about experiences of EAS (most often very positive) from the bereaved, and this makes them familiar with the option of EAS.

Sign of EAS remaining an exceptional practice

Next to signs and causes of normalization, the experts also mentioned a sign and causes that were indications of an opposite movement: where EAS remains an exceptional practice. This sign was specifically seen in the medical profession.

In the previous section we have written about a reluctant attitude of physicians in general. Apart from this, the experts also noticed a reluctant attitude for performing EAS in patients suffering from dementia, a psychiatric illness or an accumulation of illnesses associated with old age. This reluctance was founded on reasons of principle.

“Twenty five years ago, we already had requests from patients with a psychiatric condition. So I don’t understand why physicians would say ‘this is a new group of patients requesting EAS, we don’t know how to handle these requests’. However, they are very reluctant, maybe even more reluctant to help these patients than before.”
(R3, health law).

Causes of EAS remaining an exceptional practice

Overall, like said before, every process towards EAS is emotionally intense and time consuming for a physician: EAS can feel like a burden. According to our respondents, this can be seen as a general indication that EAS will stay an exceptional practice.

However, there are also more specific reasons. Some EAS requests are more burdensome than others. Take for instance requests based on psychiatric suffering. It can be harder for physicians to assess whether the patient’s suffering is truly without prospect of improvement. A possible explanation why physicians are reluctant to perform EAS with psychiatric patients is obvious: these are often complex cases, that take more time and consideration than usual.

For some physicians, this is also a matter of expertise, according to our respondents. In some cases, physicians just don’t know if EAS is legally possible or have misconceptions about the legal criteria. This can cause an overly reluctant attitude ‘just to be on the safe side’.

Another reason the experts mentioned, was a claiming attitude of the patient and/or family members. They felt the patient was entitled to EAS. This could cause physicians to become more aware that EAS is not normal, not something anyone can claim. If they feel the patient thinks of EAS as a right, they can become reluctant.

“So, you see patients getting more demanding and start claiming things. Euthanasia as well, although you should not claim euthanasia. Physicians will become resistant.”

(R6, ethicist and health policy)

The last reason for physicians to be hesitant some of the experts mentioned, is the option for patients to take matters into their own hands. ‘Why should I be the one to perform EAS, if you are autonomous, you can also take care of your death yourself’.

Tension between the public and physicians

Looking at the different signs of normalization and remaining exceptional practice, it becomes clear that our experts attribute the signs of remaining an exceptional practice to physicians, while signs of normalization are attributed to a broader public of both physicians and people in general. They claimed that the extent of normalization in society is not in sync with that of the physicians. Physicians are more reserved about performing EAS than the public thinks is justifiable. The experts recognize that this creates a tension between the wishes of patients and the willingness of physicians. They all thought this tension was felt by the physicians, but differed in opinion whether this was something new or that this feeling had always been inherent to handling EAS requests.

Many experts we interviewed mentioned the End-of-Life Clinic (an initiative that started their practice in 2012) as an important player within this tension by either increasing or decreasing it. Patients whose request is rejected by their own treating physician, but who meet the due care criteria, can register at the End-of-Life Clinic. Mobile teams, consisting of a nurse and a physician, will then assess the request of a patient and, if the criteria are indeed met and the treating physician is still not willing to perform EAS, the physician of the mobile team will grant the request of the patient. Most of the experts saw the clinic as a sign of normalization, but others thought that it had nothing to do with normalization and in fact showed exactly the opposite: the fact that the End-of-Life Clinic still receives many requests from patients, shows that in general, physicians still have great difficulties with EAS.

The experts did not all agree on how the End-of-Life Clinic influenced the practice or the debate. Some thought the clinic makes a sort of specialization of EAS, which is a form of normalization in itself. Others said that, since the End-of-Life Clinic had to

follow the same rules and regulations, it did not generate normalization. One of the interviewees phrased his/her viewpoint on the clinic as follows:

[on the topic of the End-of-Life Clinic] “Well, I think there are a several important aspects to the End-of-life Clinic. On one hand, it’s an alternative for patients if their physician rejects their request [for EAS]. I think that’s the biggest impact. I noticed two ways of reacting to this. Doctors who think ‘great, let them take care of it’ and others who say ‘well, if they say this fits the legal criteria, I will perform it myself’. I did not see that coming, that doctors would use the ELC as a sort of center of expertise. I think it’s an interesting development: the ELC supporting physicians who had difficulties or doubt performing it themselves. That’s something unexpected. [The ELC] heated the discussion, it increased the right of the patient, because it presented an alternative to the patient. Needless to say, it is not a right of the patient. [EAS] is a favor you need to be granted. However, I think, the End-of-Life Clinic influenced... Well, in the eyes of the public, you should be allowed EAS if you meet the due care criteria. So the impact is huge. I think it also questioned the foundations of EAS: what is extraordinary about EAS and should you be willing to perform EAS outside a treatment relationship? These type of questions. I don’t think these are all direct effects. But it gave the discussion of EAS new input, new impulses, by raising new questions.”

(R4, ethicist)

DISCUSSION

Normalization?

We started with the question whether or not EAS is starting to become normal medical practice. The Royal Dutch Medical Association mentioned in a position paper on EAS that “euthanasia is an exceptional medical procedure [...] and will never become ‘standard.’”⁽¹³⁾ According to Koopman and Boer legalization of EAS has contributed to normalization, however they do not provide a further understanding or definition of normalization.⁽¹⁴⁾ The respondents in our study mentioned both signs and causes that confirm the idea of EAS as a normal medical practice, but also the opposite. In the introduction, we already stated that the exceptional character of EAS can be understood at different levels, and it is likewise for normalization.

The experts we interviewed thought that from a legal point of view EAS has not become normal medical practice, because for that to happen it would have to be taken out of the criminal code. This has not happened and there are no recent initiatives for doing so. Strictly speaking, EAS has not really been legalized, it has only been legally regulated, which means that it still has an exceptional status compared to other medical acts. So, legally speaking it has not been normalized.

On a social-ethical level however, our respondents were of opinion that the general public perceives of EAS as a normal act, something that is and should be a fully accepted practice. Physicians take on a somewhat more nuanced view, but according to our respondents, the young generation of physicians also thinks of EAS as part of their profession, as something they have to relate to. They can't just ignore EAS, if only because it has also become part of their medical training. Our finding that rejecting a request should be sufficiently motivated best supports this idea.

In the next section we will address the question if this aspect of normalization is problematic.

Is normalization problematic?

In what way can an accepted practice be problematic? From a practical perspective, it would be problematic if requesting EAS turned into claiming EAS which could paradoxically cause physicians to become more hesitant to consider or perform EAS. Some would consider normalization bad in itself, regardless of its consequences, because they feel it should only be allowed if it remains exceptional. Then, normalization would be 'sliding down' the slippery slope.

The (logical) slippery slope argument tells us that accepting *A* will inevitably lead to accepting *B*, wherein *B* is a morally objectionable practice. An increase of performance of EAS could be interpreted as (a movement towards) *B*⁽¹⁵⁻¹⁶⁾ if the practice of EAS is acceptable only because it is a rare practice. However, even if the numbers of EAS would double, the percentage of death caused by EAS is still small compared to the total amount of death.⁽¹⁷⁾ An unintended consequence of EAS as an accepted practice, is the fear that EAS would become 'too easy'. In that case, EAS would be acceptable as long as it is a hard, difficult practice, and the morally objectionable practice would be a lighthearted and carefree attitude towards EAS. We have just mentioned quite the opposite movement above. The only way in which EAS has become easier is the fact that it is better known what falls within the criteria of due care. The consideration and performance of EAS is still a burden for physicians, as

previous research also illustrated(6-7), and when considering EAS for a patient that's suffering from dementia or a psychiatric illness a physician is often extra cautious.(18)

Next, can the shift towards motivating why a request is rejected be seen as part of the slippery slope? The underlying fear would be that physicians are pushed towards performing EAS instead of rejecting it and would cause a less careful practice to rise. We think this is not the case; instead, motivating why a request is rejected is part of increased prudence. Rejecting a request without any justification, or based on incorrect assumptions — for instance a physician who thinks that it is a legal requirement that the patient has to be in the terminal stage of the disease(19) — is not taking good care of a patient, it's not taking their request for help serious. A possible fear that granting a request is subject to less and less careful consideration is not grounded, since the due care criteria ensure a solid argumentation for granting a request. One could say that the legal regulation of EAS will prevent us from moving from *A* to *B*, since everything that falls outside of the boundaries of the law is a criminal act.

None of the interviewed experts mentioned the fear that patients might feel pressured to ask for EAS — either because of financial reasons and/or pressure by relatives — an argument that is often used in the slippery slope debate in the popular media or by pro-life organizations as an example of a morally undesired practice.(20-21). The fact that our experts did not mention it might be explained by the Dutch health care system where everyone has assurance for care that is needed, so it is not very likely for financial incentives to play a big role in a wish to die. If a person asks for EAS because he/she is pressured into this by someone else, the request is no longer voluntary and therefore it does no longer fall within the boundaries of the law.

Strengths and limitations

One of the main limitations is the fact we asked experts to describe developments in a practice most of them don't have experience in doing. We had good reasons for doing so (as described in the methods), but it remains a limitation of our research that we asked for opinions instead of experiences. Interviewing experts also has its benefits. By doing so, we managed to get an overview of the Dutch landscape of euthanasia.

We did not provide a definition of normalization beforehand to our respondents. Not defining the concept beforehand made it possible to include a wider range of views on normalization, and to give a more nuanced answer to the question how normalization applies to EAS.

Our classification into signs and causes of normalization and remaining exceptional practice should be seen as a conceptual framework to understand certain changes and developments in the practice. This classification came up during the analysis of the interviews and was not used by the respondents themselves.

Conclusion

On the legal level EAS has not normalized, while on a social-ethical level normalization is at hand. Normalization in this form does not imply a problematic situation — there are no indications that this has led to any undesired consequences. Normalization of EAS has led to the moral obligation to motivate why a request is rejected and in this way contributes to the careful consideration of EAS.

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