A dialogue on death

On mental illness and physician-assisted dying

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Chapter 2

Considerations by Dutch Psychiatrists Regarding Euthanasia and Physician-Assisted Suicide in Psychiatry: A Qualitative Study

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Abstract

Background: Euthanasia and physician-assisted suicide (EAS) in psychiatry are permitted in the Netherlands under certain legal conditions. Doctors may help patients who suffer unbearably and who have no prospect of improvement from psychiatric illnesses. Although this practice is permitted, it remains controversial, and the acceptability of EAS and the conditions under which it should be allowed are still debated. As the number of psychiatric patients requesting EAS is increasing, Dutch psychiatrists are becoming more reluctant to consider EAS.
Objective: This study aims for a better understanding of Dutch psychiatrists' considerations for supporting or rejecting EAS for psychiatric patients.
Methods: The data for this qualitative study were collected through 17 in-depth interviews with Dutch psychiatrists. These interviews were held from January until June 2016 as a part of the Third Evaluation of the Dutch Termination of Life on Request and Assisted Suicide Act.
Results: Irrespective of their own position in the debate, most Dutch psychiatrists consider reasons for and against EAS, including moral (justice and equality, professional responsibility, compassion), epistemological (how can one ever know the suffering is without prospect), practical, and contextual (mental health care provisions) reasons.
Conclusions: The variation in views on EAS in psychiatry seems to be related to a difference in views on the nature of psychiatric diseases. Some psychiatrists stress the similarity between psychiatric and somatic diseases, whereas others stress the fundamental difference. These opposing views could be bridged by a pragmatic view, such as a two-track approach to EAS.

Introduction

Although euthanasia and physician-assisted suicide (EAS) are still subject to criminal liability in the Netherlands, the Dutch Termination of Life on Request and Assisted Suicide Act (Wtl) allows physicians this option under certain conditions. A physician is exempted from criminal liability if and only if she acts in accordance with the legal criteria of due care as laid down in the Wtl and provides a statutory notification for the review procedure.(1) Especially relevant case law for EAS for patients with psychiatric disease is the Chabot case (in 1994), in which it was ruled that the severity of the suffering provides one of the moral grounds for EAS and that the cause of this suffering was irrelevant. In a later case, the Brongersma case (in 2002), the High Court added that the source of the suffering must lie in a medical condition.(2) Psychiatric diseases fall within the medical realm. Because the Dutch parliament has deliberately left the norms of the Wtl open to interpretation, the regional euthanasia review committees (RTE) developed a "Euthanasia Code" to provide guidance on how to interpret the criteria of due care.(3) In the Euthanasia Code, the RTE urge physicians to act with extra caution when assessing an EAS request from a psychiatric patient. Although the Dutch law does not require that an independent psychiatrist be consulted, the Euthanasia Code recommends it. The psychiatrist should give an opinion on the patient's competency, assess whether all treatment options are exhausted, and explore whether the suffering is without prospect of improvement. The number of requests for EAS by psychiatric patients increased in recent years and was estimated to have risen from 320 in 1995 to 1,100 in 2016.(4) The vast majority of these requests were denied.(5) The number of cases in the Netherlands in which EAS was performed on the grounds of a psychiatric disorder has grown from zero in 2002 to 83 in 2017.(6) The increase in demand did not lead to an increasing willingness on the part of the psychiatrists; to the contrary, the proportion of psychiatrists who could conceive of ever performing EAS decreased from 47% in 1995 to 37% in 2016.

(4) We also know that other physicians are less willing to perform EAS in the case of psychiatric suffering compared to their willingness in case of somatic suffering.(7) In 2012, the End-of-Life Clinic was established to provide EAS for patients who meet the legal criteria of due care but whose request was rejected by their own physician.(8) This clinic received a large number of requests by psychiatric patients and was responsible for carrying out 75% of the psychiatric EAS cases.(5) The occurrence of EAS for psychiatric patients led to a heated debate among professionals and the public, in the Netherlands and elsewhere, on the acceptability of and the right approach to this practice.(9-11) For this reason, special attention was given to EAS for psychiatric patients in the third and most recent evaluation of the Wtl. The aim of our study, which was a part of the Third Evaluation of the Wtl, was to provide insight into the various experiences, views, and considerations of Dutch psychiatrists regarding EAS for psychiatric patients. To improve our understanding, we held in-depth interviews with 17 Dutch psychiatrists. The study was set up to answer the following question: What are psychiatrists' considerations in supporting or rejecting the idea of EAS for psychiatric patients?

Methods

Design

As a part of the Third Evaluation of the Dutch Termination of Life on Request and Assisted Suicide Act, 17 interviews were held with Dutch psychiatrists from January till June 2016. The interviews were explorative in nature and semistructured with the use of an interview guide that consisted of topics and open questions. All interviews were conducted by the same researcher (R.P.), who is a PhD student at the Amsterdam UMC (Universitair Medische Centra). She held the interviews at the psychiatrist's location of choice; interviews lasted between 1 and 1.5 hours. Only the participant and researcher were present at the interview. The confidential and voluntary character of the interview was emphasized. An informed consent form was signed before the interview started. All respondents agreed to the use of an audio recording device, provided by and kept in a closed place at the Academic Medical Center (AMC) Amsterdam; only the researchers had access to the recordings and transcripts. The interviews were transcribed verbatim by a third party, who signed a confidentiality form regarding the content of the interviews. Interviews were held until no new considerations came up in the interviews, so data saturation was reached. Transcripts were returned to participants for comments or corrections. One psychiatrist sent the transcript back with corrections to statements. No repeat interviews were carried out.

This study did not require review by an ethics committee under the Dutch Medical Research Involving Human Subjects Act, since it did not involve imposing any interventions or actions and no patients were involved. Informed consent was obtained before every interview.

Respondents

The respondents were selected through purposive sampling, aimed at achieving a variety in experiences, views, sex, subspecialty, and type of work environment. Views varied from being strongly opposed to EAS in psychiatry to being reluctant toward EAS in psychiatry to having an open attitude. We included psychiatrists who did and who did not have actual experience with performing EAS in cases of psychiatric suffering. No relationship was established prior to the study commencement.

Respondents were recruited (via e-mail) at the End- of-Life Clinic, through the professional network of the researchers, through snowball sampling, and through random sampling at the website of the Dutch Patient Federation. Of the 22 respondents who were approached, 17 responded and were willing to cooperate by giving an interview. Reasons for not wanting to participate in the study were not investigated. Respondent characteristics can be found in Table 1.

Data Analysis

Sixteen interviews were included in the data analysis, as 1 interview was lost due to technical problems. All interviews were analyzed by 1 of the authors (R.P.) with the help of MaxQDA 12, a software program used by Amsterdam UMC for the analysis of qualitative data. All relevant fragments were given codes, which led to code trees. After comparing and discussing the codes and code trees of 5 interviews with a second coder (J.G.), the first coder (R.P.) further analyzed the coded fragments and identified overarching themes. We worked according to the principles of grounded theory. The process of data analysis and the results were discussed with the supervising researchers (DW and SvdV) and with the research group conducting the Third Evaluation of the Dutch Termination of Life on Request and Assisted Suicide Act.

Results

Our respondents (noted individually as R1, R2, and so on) mentioned a wide range of considerations regarding EAS in psychiatry. We discuss these under two headings: (1) considerations for supporting the idea of EAS in psychiatry and (2) concerns related to EAS in psychiatry.

Considerations for Supporting the Idea of EAS in Psychiatry.

Even though our respondents expressed ambivalent feelings regarding EAS in psychiatry, they offered a variety of considerations. These frequently related to moral concepts such as fairness and autonomy, professional responsibility, and compassion. However, the obligation to prevent suicide was also mentioned.

Fairness and autonomy. The first consideration related to the concept of fairness. One respondent stated that it would be unfair to exclude psychiatric patients from the possibility of EAS, as they can fulfill the legal criteria and suffer from a medical condition:

> *We have a law which states that EAS is permitted if the suffering is a result of a medical condition, and if certain criteria are met. Medical conditions also cover the area of psychiatry, psychiatry is a medical discipline, a medical specialization. In case of psychiatric disorders, it is also possible to suffer unbearably without any prospect of improvement. This means that the law is also applicable to this group. (R9)*

Another argument supporting EAS in psychiatry is the view that patients have the right to autonomously choose death instead of life. Psychiatrists indicated that EAS provides an opportunity for self-determination for the patient, but emphasized that this idea applied only to patients who have decisional competence regarding the request for EAS:

It is an opportunity for self-determination, it is a dignified ending. (…) it (i.e. psychiatric suffering) may even be more severe than suffering from a somatic disease, especially a somatic disease that leads to death, of course that is horrible, but at least that suffering is final. Suffering from a chronic psychiatric disorder is endless. (R11)

Responsibility. Psychiatrists expressed how they felt responsible for their patients. We found 3 ways in which the respondents described their responsibility. The first way related to a personally felt responsibility for ensuring that the patient's situation is well taken care of:

I feel a certain degree of responsibility for individual clients. If I have a client who deals with this (i.e., request for EAS), I would like the proper arrangements to be made. If that means I have to take responsibility myself, then I would be willing to do so.(R13)

Second, they described a responsibility that is part of the doctor's responsibility as a member of a professional group that accepted EAS as a possibility:

If we decide that this is something we want to offer to psychiatric patients, we should all do it. Yes, all psychiatrists. I would say 'no, unless', and if that 'unless' is the case, you should be able to do it. Just like any doctor would, we (i.e., psychiatrists) are also doctors. (R3)

The final way of describing related to a responsibility to contribute to the "good life" of the patient and therefore also to a "good end-of-life":

As a doctor, I am committed to the well-being of people, which includes a good end-of-life. I work according to the principle that we need to help patients achieve self-realization, make their own choices and extract from life what they want. When faced with people who then say 'I don't want this life, please help me to end it', I feel conflicted, because I never

once thought I would become a psychiatrist to end someone's life. To the contrary, I became a psychiatrist to keep them alive. But I can imagine that helping people to die is an act which would be consistent with my striving for a good life and good end-of-life for the patient. (R4)

Compassion. The last reason for supporting the idea of EAS was related to compassion. All psychiatrists agreed that psychiatric illness can be very severe and tragic. Some even went as far as to state that they believed it might even be worse than terminal somatic illness, as there is no prospect of a (relatively) foreseeable end to the suffering. In such cases, they felt that the extent of the suffering could evoke feelings of compassion, which provided a reason to support the idea of EAS:

Sometimes when you come across situations where you feel very compassionate, you can get the idea that it would be more compassionate to just make it stop. (R6).

Preventing suicide. The special obligation psychiatrists have to prevent suicide was mentioned more than once. The respondents differentiated between "irrational suicide," "chronic suicidality," and "rational suicide." Irrational suicide and chronic suicidality were characterized as the result of emotional events and part of the psychiatric disorder, whereas a rational suicide was described as being more well considered. EAS was presented as an option for patients with a rational death wish but not for patients with irrational and chronic death wishes:

I would like to prevent a situation in which someone who, because his relationship just ended, impulsively drinks too much, drives too fast and drives his car into a tree. However, if someone who has had treatment for ten years because of a psychotic disorder and has the prospect of never leading a normal life feels he has no alternative but to jump of a high-rise building, I sincerely hope he would consider a request for EAS so I could offer a dignified and less lonely end. (R11)

It was also stated that a dignified end would be of importance not only to the patient but also for her social environment:

> *That you offer an alternative. Suicide is a miserable intervention for the patient; it is a very lonely road to take. It is also horrible for the bereaved; they are left with a lot of questions and guilt. It is also hard for caretakers. So, the social environment is heavily affected. I believe EAS is a better alternative to that. (R5).*

Concerns Related to EAS in Psychiatry

For some interviewees the concerns led to outright rejection of EAS in psychiatry, but more often they led to reluctance and carefulness. Respondents mentioned 4 types of practical, epistemological, and contextual concerns: (1) the incompatibleness of treatment goals and EAS, (2) the danger of transference, (3) the interpretation of the criteria of due care, and (4) mental health care provisions in the Netherlands.

Incompatibility of treatment goals and EAS. For some respondents a death wish could be discussed within treatment, but only as a symptom of a psychiatric illness and not as a real option. For them, offering EAS was seen as incompatible with treatment. It was suggested that the End-of-Life Clinic fulfilled an important need, as it offered a place for the patient to freely talk about their wish to die without psychiatrists' being burdened by also having to treat the patient:

> *Without the burden of also having to treat the patient (the End-of-Life Clinic) offers a place where the patient can freely talk about it (i.e., the death wish). She can of course discuss her wish with us, but we always also have to deal with the treatment task we gave ourselves. So, that is not 100% free. (R13)*

Countertransference. Countertransference was characterized as "identifying with the patient" (R9) or "to become part of a particular dynamic" (R1). Some warned that this could interfere with the psychiatrist's ability to objectively consider a request for EAS:

> *But that was a difficult process, because I had my doubts about how psychodynamics played a part. I often was allocated to a role on both sides of the ambivalence… 'do I want to die' or 'do I want to live'. I almost became part of her own psychodynamics. I didn't get sucked into that, but the whole dynamic did take place, so I had to pay a lot of attention and stay alert as to how much distance I could still keep. (R1)*

Independent consultation, peer supervision, and seeking second opinions from colleagues were considered possible ways to examine if and how countertransference affects the request for EAS.

Interpretation of the criteria of due care. Two criteria of due care frequently posed problems: (1) a voluntary and well-considered request and (2) unbearable suffering without prospect of improvement. The respondents remarked that a wish to die could be part of a psychiatric disorder:

> *And second, it is the case in psychiatry that a desire to die and a wish to die are, as a rule, an expression of the disorder itself. (R8).*
> *We come across a lot of chronic suicidality, or someone crying out 'I am going to end this'. If we would understand all that as requests for EAS, we would be wrong. The vast majority, maybe 95% of these statements, are not requests for EAS. (R13).*

The respondents addressed the complexity of distinguishing irrational death wishes and chronic suicidality from a well- considered request for EAS. They emphasized the need for careful evaluation and thorough examination of the expressed wish to die. Some even stated EAS should

not be offered to psychiatric patients because in their opinion all death wishes are always an expression of emotions, hence irrational:

> *(…) this is also one of my opinions: that the balanced suicide does not exist. That is the humanistic liberal thought that the human is a rational being, but I have never seen a balanced suicide. All of this so-called balance…(…) I have got a lot of experience, I have worked for 40 years in large hospitals, with large ERs and saw 3 cases of (attempted) suicide a week, for 40 years, so I have talked to a lot of them. A lot of the people who considered it carefully (i.e., suicide attempt), balancing the pros and cons…if you take the time to go through them, these are all hollow phrases. It is all emotions, it is all pain, anger, indignation, despair. (R8).*

These respondents expressed the belief that it is the duty of the psychiatrist to always stand by and treat their patients and never to offer EAS.

With regard to the second criterion, "unbearable suffering without prospect of improvement," several respondents indicated that they experienced difficulties in determining whether the patient's suffering was unbearable. It was stated that mental suffering is difficult to objectify. Some respondents indicated that the unbearableness of suffering is something only the patient can determine:

> *So if a client keeps repeating that it is unbearable and he acts in accordance with this, I tend to accept this, even though I cannot completely understand or feel it myself. (R13).*

On the other hand, respondents expressed the belief that the patients' experience is relied upon too much:

> *What I object to is that unbearable suffering becomes something stated by the patient. I find this a narrowing of the concept. I still find myself*

drawn to the idea that unbearable suffering is something intersubjective, an intersubjective suffering that is not just stated by the patient. It should not only be felt, but it should be critically looked at. (…) So, unbearable suffering is not only what the patient expresses, as is assumed these days, but the unbearableness should be critically looked at regarding its intersubjectivity by both the doctor and consultant.(R10).

Psychiatrists also indicated that it is difficult to establish whether there are treatment options, especially when there is more than one diagnosis or when diagnoses change over time:

The difficulty with psychiatric illness is that most symptoms are trans-diagnostic. So, you will encounter psychosis, depression and cognitive problems throughout all diagnoses. Most things are trans-diagnostic. We do have the 'flagship diagnoses', but they don't apply to most people; most people have two or three diagnoses. So what do you do when they have two or three diagnoses, what are the guidelines? (R2).

Sometimes a patient is diagnosed with schizophrenia, but it turns out to be a personality disorder, or vice versa. It is striking that these major changes can occur, but that is something that is considered a given in psychiatry. (R1)

The respondents indicated that the relatively long life expectancy psychiatric patients have, certainly compared to most somatic patients asking for EAS, complicated the evaluation of possible treatment options and future recovery. They indicated that therapeutic options may become available in the future, which leads them to conclude that those deaths could have been prevented:

You don't know which developments awaits us, therapeutically or by understanding these expressions (i.e., a request for EAS). Maybe in eight years' time, we will find ourselves saying that we did not treat a group of people correctly and that their deaths were unwarranted. (R1)

Mental health care. A very contextual concern we identified related to the mental health care system in the Netherlands. Although mental health care was considered to be of a high level in the Netherlands, respondents commented on what they saw as the suboptimal functioning of mental health care. This was ascribed to budget cuts, which they believed caused a reduction in the quality of treatments, long waiting lists, demotivation of treatment providers and a focus on short-term treatments, leaving long-term psychiatric patients without appropriate treatment options:

> *I believe that the mental healthcare is of a very high level in the Netherlands, generally speaking. We are of course used to this high level, but if you look at it from a global perspective, I think we are at the top. The treatment options are not what they used to be, but globally speaking still on a high level. The relentless budget cuts and the right-wing policies have left clear traces. Mainly the regulation-mania of wanting to control everything and the suspicion with which the black box of mental healthcare is being looked at. We have to communicate every move we make, which not only has led to demotivation but also to erosion. A lot of time for substantial treatment is lost due to administration and organizing things. So, that is definitely a big problem. (R13)*

> *This has been a gradual change, taking years. When I started (i.e., working as a psychiatrist), you could take someone into 'open therapy', which could take up to two, three, or four years. But care assessments became harder and harder, and funding is reduced. Institutions and funders don't want treatments to be provided by psychiatrists, because they are the most expensive. It (i.e., treatment) has to be provided by less expensive staff. Some of them have enough skill, but I believe it's wrong if psychiatrists let them take that away. It's part of the job of a psychiatrist, and you cannot practice that part anymore. Only for people who can afford it, that's not okay, it is not right. (R7)*

Psychiatrists indicated that it is difficult to weigh the fact that previous treatments might not have been optimal in relation to the current situation and to the possibility of future improvement:

> *And then there are the reasonable alternatives. What are reasonable alternatives in case the budget-cuts have cut back on all the qualified caretakers? (R10)*

A final consideration pertained to the question of how the psychiatric discipline understands psychiatric disorders. Some respondents expressed concern that the "biological view"—which the psychiatrists viewed as currently dominant in psychiatry—has a defeatist nature and influences the patients' thinking about treatment options or other possibilities for improvement and makes them more inclined to request EAS:

> *We tend to attribute this (i.e., psychiatric disorders) to handicaps, permanent defects, often brain defects. This is the language we think and act in. I believe this is also involved in thinking about EAS, because people (i.e., patients) pick up on that, internalize the negative expectations, and start to have their own negative expectations about their lives, goals they could achieve, and whether they will ever wake up one day and think 'my life is meaningful'. This is very problematic, because practice teaches us that people can most definitely be tempted. (R2)*

Discussion

Although EAS has been open to psychiatrists for over a decade in the Netherlands, debates on the permissibility and conditions for this practice are ongoing, while at the same time, the number of psychiatric patients requesting EAS has significantly grown. However, the vast majority of these requests are denied. Dutch psychiatrists are very reluctant to provide EAS, and their reluctance has only grown over the years. Our study explored the considerations that Dutch psychiatrists have, discussed their concerns, and showed the complexity of the issue.

It is remarkable that most of the arguments put forward in favor of EAS in psychiatry are of a moral nature. Respondents speak of fairness, respect for patient autonomy, their professional responsibility, and their compassion. Clearly these psychiatrists are very aware that their patients are indeed that, patients, with the same rights to treatments and respect as somatic patients. This equality between patients naturally, in the view of its proponents, demands equality also in the access to EAS.

Other psychiatrists, however, stress the difference between somatic and psychiatric patients. For them, the very nature of a psychiatric illness makes it impossible to evaluate a request for EAS. Suicidality is a symptom of the disease for them, never a well-considered death wish. On top of that, the nature of the therapeutic relationship in psychiatry may lead to countertransference, further complicating the evaluation of a death wish. The due care criteria in the law are also more difficult, if not impossible, to interpret in the case of psychiatric patients: when is the suffering of a psychiatric patient well and truly without any prospect of improvement, and how can we know that no other treatment will ever work? Psychiatry is wrought with far more diagnostic and prognostic uncertainty, with more difference of learned opinions, than most cancers.

Clearly, these two views on the nature of psychiatric illness -the one that sees it as fundamentally different from somatic disease and the one that sees no fundamental, but a gradual difference- also reflect different views as to whether access to EAS is a good thing. The Dutch law, the Euthanasia Code, and the professional guideline issued by the Netherlands Psychiatric Association (NVvP) hold the view that there is a gradual difference between EAS requests by psychiatric and somatic patients.(3, 12) The Euthanasia Code and the guideline both emphasize the need for more caution and extra care in the evaluation of a request for EAS by a psychiatric patient. The view that the difference is of a more fundamental nature is not recognized by these guidelines, but was clearly voiced by some respondents.

The way to cope with these opposing views in the Netherlands, where the practice has been legal for some years, may lie in a more pragmatic view, the idea that we need a two-track approach, as suggested by Vandenberghe.(13) 15 In this approach, the request for EAS is evaluated, while at the same time "recovery oriented care" is continued in parallel. Thienpont and Verhofstadt gave empirical evidence for the thesis that patients' seriously discussing their death wish and the option of EAS may help them to continue living.(14, 15) In their research, patients' having the option to proceed with EAS and being taken seriously by their physician gave them enough peace of mind to refrain from EAS. This research provides us with a strong argument for the evaluation of a death wish within a therapeutic relation, and not outside it, as is the case at the End-of-Life Clinic.

Finally, although the respondents differed in their assessment of a special nature of psychiatric illness, there is one worry many of them share, namely the state of the Dutch mental health care system. The flaws they observed in the mental health care system complicated the respondents' evaluation of the due care criteria. They had difficulties gauging the prospect of improvement, suspecting previous treatments had not been

optimal. Many respondents stated that Dutch mental health care is deteriorating, especially the care for chronic patients. This shared belief that no appropriate care is given to chronic psychiatric patients most surely explains a part of the reluctance psychiatrists have to perform EAS.

Strengths and Limitations

One of the strengths of this study is that it provides new insight into a subject that is highly controversial. Up-to- date information is essential for a useful debate on EAS in psychiatry. Literature on EAS in psychiatry is predominantly medical-ethical and quantitative in nature. A strength of our study is that it provides in-depth empirical information on the subject. This is the first qualitative study among psychiatrists that provides information on their views and considerations. As mentioned, one audio file was lost due to technical problems, resulting in the loss of 1 transcript and corresponding data.

Also, the authors are not mental health care professionals, which could potentially lead to bias in their coding. Results might not have been sufficiently interpreted as a result of this gap in knowledge.
When reading this article, one must bear in mind that this study was also performed in a specific area, the Netherlands. The Netherlands have a long history of debating EAS and a relatively liberal attitude compared to other countries. The social support and quality of medical care in the Netherlands allowed and justified such a practice. The results of this study must be viewed with this particular context in mind.

Table 1. **Respondent characteristics**

Sex	Women (n=4) Men (n=13)
Subspecialty within psychiatry	Mood disorders Substance-related and addictive disorders Schizophrenia spectrum and other psychotic disorders Personality disorders Obsessive-compulsive and related disorders Forensic psychiatry Trauma- and stressor-related disorders
Geographical area of work	Smaller or bigger cities (n=12) Rural area (n=1) All over the Netherlands (mobile teams of the End-of-life clinic)(n=4)
Type of work institution*	Academic medical centres (n=4) Private practice (n=3) Forensic mental healthcare facility (n=1) Dutch mental healthcare institution (n=7) End-of-life Clinic (n=4)

*some psychiatrists worked at multiple work institutions, so overlap can occur

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