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A Dialogue on Death

On Mental Illness and Physician-Assisted Dying

Rosalie Pronk

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A Dialogue on Death

On Mental Illness and Physician-Assisted Dying

ACADEMISCH PROEFSCHRIFT

ter verkrijging van de graad van doctor
aan de Universiteit van Amsterdam
op gezag van de Rector Magnificus
prof. dr. ir. K.I.J. Maex
ten overstaan van een door het College voor Promoties
ingestelde commissie,
in het openbaar te verdedigen in de Aula der Universiteit
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Chapter 1

General introduction

General introduction

'I did not tell you this in the email, but I am going to take all my medication and kill myself tonight'

This message was voiced by one of my respondents when I called her to discuss the date of our interview about her wish to receive physician-assisted death (PAD). We were supposed to have an appointment on Tuesday, but she emailed me on Sunday night to tell me that the interview could not take place because she was not feeling well mentally. After agreeing via email to move the appointment one week, she messaged me to state that she did want to do the interview on Tuesday, because she thought she was up for it. After that, she sent another email to cancel the interview again. And another email, asking if I could come over because she really did not feel well. I had never met this respondent. When I called her to tell her that I was not going to come over and do the interview, because I believed that it would not be a good idea to have an interview while not feeling well, she made the statement above. This put me in a difficult position; I couldn't do anything for her, as I was not a position to do so. After talking to her on the phone for some time, she calmed down a bit, and we agreed to meet each other for the interview a week after that, and I told her that I hoped that I would see her by then. A week later, after offering me something to drink, she went on to apologize for the week before. She felt fine again, and although she did still wanted to die from PAD, she did not want to commit suicide anymore. The interview went well, and as I drove home I was reminded again what makes the theme of my thesis so complicated.

This thesis revolves around a controversial issue, namely physician-assisted death for persons suffering from mental illness. The situation with the respondent makes somewhat clear why this is such a difficult topic. It shows various difficulties that physicians have to deal with, with regard to PAD in case of mental illness. A number of ethical and medical

concerns have been voiced in the literature: first of all, the ‘criteria of due care’ can be more difficult to interpret in the case of mental suffering compared as to somatic suffering. Although assisted dying is still a criminal offence, physicians are exempted from criminal liability if they meet the ‘criteria of due care’. These legal criteria are as follows:

- The physician is convinced that the patient’s request is voluntary and well-considered
- The physician is convinced that the patient’s suffering is unbearable and without prospect of improvement
- The physician has informed the patient about his situation and prognosis
- The physician has come to the conclusion, together with the patient, that there is no reasonable (treatment) alternative
- The physician has consulted at least one other, independent physician
- The physician has exercised euthanasia or assisted suicide with due medical care and attention

With regard to the criterion of ‘voluntary and well-considered request’, it can be complex to establish whether the patient’s death wish is in fact (temporary) suicidality, and part of the mental illness, or not.(1, 2) Furthermore, the capacity of the patient to understand their situation and make decisions regarding their end-of-life or treatment may be impaired.(3) Patients who are depressed, may for example hold the unjustified belief that chances of recovery are minimal, as that belief can be one of their symptoms.(4) The second criterion of the Dutch euthanasia act, stating that the ‘suffering must be unbearable and without prospect of improvement’, may also be difficult to interpret. The diagnostic and prognostic uncertainties that come with mental illness may make it difficult to establish whether a patient has a reasonable chance to recover.(2, 4) In addition to the concerns related to the ‘criteria of due care’, other issues have also been raised. Some authors argued that

persons suffering from mental illness are an exceptionally vulnerable group, and are in need of protection instead of the option of assisted dying.(2, 5, 6) Another concern regarding physician-assisted death in psychiatry relates to the concept of hope. It has been argued that by discussing the option of assisted suicide with a patient suffering from a mental illness may enforce feelings of desperation and demoralization (a loss of hope) in the patient, which could lead to unjustified beliefs about the impossibilities of recovery. (7, 8) Finally, transference and countertransference (the patient's unconscious feelings and attitudes toward the therapist and vice versa) are mentioned, as they may influence the decision-making process on both the part of the patient as well as the physician.(9)

Contrary to popular belief, PAD for mental illness has always been part of Dutch legislation. The Chabot case (1994) and the Brongersma case (2002) were influential in the development of the current euthanasia act.(10) Boudewijn Chabot (a psychiatrist) assisted in the death of his patient who suffered from a depression as the result of a complicated grief process. The patient refused all treatments options and was determined to die. After consulting (on paper) with seven psychiatrists and ethicists, who came to the conclusion that there were only theoretical treatments options left, Chabot assisted in her suicide. In its arrest on the case, the High Court ruled that it is the severity of the suffering that is of importance, and not the source of the suffering. (10) Thus the possibility for addressing requests that are based in mental suffering was established. In the later Brongersma case, the High Court ruled that the suffering must originate in a medical condition, either somatic or psychiatric. This prohibits assisted dying in case people suffer predominantly from psychological or existential problems, such as those who are 'tired of living'.(10) Guidance on how to interpret the criteria of due care in the case of mental suffering are provided by the Regionale Toetsingscommissies Euthanasie (RTE) and the Dutch Association for Psychiatry (NVvP). The RTE issued the EuthanasieCode in 2018 and

the NVvP provides a further interpretation of these criteria in their guideline ‘Levensbeëindiging op verzoek bij patiënten met een psychische stoornis’ (Termination of Life on Request in patients with a psychiatric disorder’).(11, 12)

Since 2002 the euthanasia act regulates the practice of PAD in the Netherlands. Physician-assisted death in the Netherlands is performed in two ways: by euthanasia and by physician-assisted suicide. In case of euthanasia, the physician terminates the life of the patient, at his or her explicit request, by administering the lethal drugs. In physician-assisted suicide, the patient terminates his or her own life by taking the lethal drugs that the physician provides.

Assisted dying for patients suffering from mental illnesses though allowed in some countries, remains a very controversial practice. Only in Belgium, Luxembourg, the Netherlands and Canada, it is possible to receive assistance in dying when one suffers from a mental illness.(3, 13, 14) In 2020, the Dutch euthanasia committees (RTE) received 6938 reported cases of assisted dying: 6705 cases of euthanasia, 216 cases of assisted suicide and 17 cases of a combination of both. We know that there is an increase in requests for assisted death from patients suffering from mental illness, the estimation is that it rose from 320 in 1995 to 1100 in 2016.(15) Expertisecentrum Euthanasie (who perform most of the cases in which suffering from a mental illness is the reason for PAD) published a study on the background and course of PAD requests from patients suffering from mental illness. This study shows that the number of requests to them made by persons suffering from mental illness rose from 222 in 2012 to 696 in 2018. What they also found was that most requests come from female patients (60%) between the ages of 51-60, predominantly suffering from mood disorders. Although mood disorders were dominant, in 80% of the PAD requests the patient reports suffering from more than one disorder. This means that their problems are complex. Almost 60% of PAD requests made are denied by EE. In 20%

of the cases, the patient withdraws his or her request. Almost 10% of the requests are granted, and almost 4% of the patients commit suicide.(16) The waiting list for EE is currently up to two years for patients suffering from mental illness.(17) On the whole only a small minority of requests are granted. (18) Despite these low numbers we do see a rise in the number of cases reported to the RTE. Prior to 2008, reported cases of assisted dying for mental illness were not registered as a separate category, but from 2008 to 2020, the number of cases rose from 0 to 88.(18-21) At the same time there is another development; although the number of requests and the number of granted requests rose, psychiatrists in the Netherlands are becoming more reluctant to consider a request from a patient suffering from mental illness. In 1995, 47% of Dutch psychiatrists found it conceivable that they perform assisted dying solely on the basis of suffering from a mental illness, this number had decreased to 39% in 2016.(22)

It seemed worthwhile to investigate their concerns. How widespread are they? In case of somatic suffering, the general practitioner is often the physician that performs the assisted death (84.8%). In 65% of the psychiatry cases a physician working for EE was the most likely the one who performed the request.(18) The other 35% were performed by GPs and treating psychiatrists. What are the views of these professionals? Why are they an opponent or proponent of the practice, what reasons do they provide for their position?

Secondly we were interested in the patient's view. The patient is frequently spoken for by e.g. the psychiatrists. They voice for instance paternalistic concerns about the effect discussing death wishes have on their patients. Only one study included written statements from persons suffering from mental illness regarding their suffering, but no other study ever included the patients voice.(23) What are their experiences with and views on the matter?

Furthermore, patients often have relatives (friends, family) who are affected by this request, but we do not know what their experiences are. Do they support the wish to die of their relative, do they wish to be involved in the process of a request, do they wish for guidance or help in dealing with the request of their relative and why? This led to the following research questions:

- What are the views and considerations of the physicians involved in requests for assistance in dying from a person suffering from mental illness (psychiatrists and general practitioners)?
- What are the experiences, views and considerations of persons suffering from mental illness with regard to their own wish for assisted dying?
- What are the experiences, views and considerations of the relatives of persons suffering from a mental illness that have (or have had) a request for assistance in dying?

Methods

The data for answering the abovementioned research questions were collected through four studies: an interview-study amongst psychiatrists (as a part of the third evaluation of the euthanasia act), a mixed-methods study (questionnaire and interviews) amongst general practitioners, an interview study with patients suffering from mental illness who have a PAD request and an interview study with relatives of patients suffering from mental illness who have or have had a request for assistance in dying.

We sent out a questionnaire to 500 randomly selected Dutch general practitioners in order for us to gain insight in their experiences. Out of those 500 general practitioners, 110 responded (a response rate of 22%). We asked whether they have had experience with assisted-dying requests

in which mental suffering formed the grounds for that request, whether they ever performed or refused such a request and what their reasons were for refusing a request. We also asked them whether they find it conceivable to ever perform assisted dying in various cases (solely somatic suffering, somatic and mental suffering, solely mental suffering). We also held interviews with psychiatrists (17 interviews), general practitioners (20 interviews), patients with a PAD wish because of suffering from a mental illness (21 interviews) and their relatives (12 interviews). The interviews had an open character and were semi-structured through the use of a topic list. We asked the respondents about their views and considerations on various topics. The interviews were transcribed by a third party, and coded with the use of MAXQDA 2020. This led to code trees that were further analysed: different themes that emerged were subsequently identified.

Outline of this thesis

Chapter 2: ‘Considerations by Dutch Psychiatrists Regarding Euthanasia and Physician-Assisted Suicide in Psychiatry: A Qualitative Study’ explores the views and considerations that Dutch psychiatrists have regarding physician-assisted death in case a patient suffers from a psychiatric disorder. This study reports on the psychiatrists’ considerations for supporting or rejecting assisted dying for psychiatric patients.

Chapter 3: ‘Experiences and Views of Dutch General Practitioners Pertaining to Euthanasia and Assisted-Suicide in Psychiatry: a Mixed Methods Approach’. This mixed-methods study explores the experiences and views that Dutch general practitioners have pertaining to physician-assisted death in case of psychiatric suffering. This study includes a questionnaire study that reports on the number of requests that general practitioners received, whether they performed the request, what reasons were for denying a request and whether they find assisted death

conceivable in various cases. This chapter also includes an interview study that aims to explore the various considerations general practitioners have for supporting or rejecting assisted death in case of psychiatric suffering.

Chapter 4: ‘Do Doctors Differentiate Between Suicide and Physician-assisted Death? A Qualitative Study Into the Views of Psychiatrists and General Practitioners’. In this study we describe how psychiatrists and general practitioners view the relation between suicide and assisted death in case of psychiatric suffering. Do they distinguish between the two phenomena or not, what are the main differences (if any), and does physician-assisted death provide an alternative to suicide?

Chapter 5: ‘Feeling Seen, Being Heard: Perspectives of Patients Suffering From Mental Illness on the Possibility of Physician-Assisted Death in the Netherlands’. This is the first ever study that includes the voice of the patient with regard to this theme. We describe their experiences and views on the subject matter; why do they want PAD? Why do they consider their suffering to be unbearable and irremediable? What does the option of PAD offer them?

Chapter 6: ‘What About Us? Experiences of Relatives Regarding Physician-assisted Death for Patients Suffering From Mental Illness: A Qualitative Study’. With this study, we delved into the experiences of relatives of patients who have or have had a wish for PAD as a result of suffering from a mental illness. With this study, we report on their views on the PAD request of their loved one: do they support the wish? How do they experience the process, how do they view their involvement and their experiences with regard to support for them.

General discussion: This thesis concludes with a discussion of the main findings from the above mentioned chapters in relation to the literature, methodological considerations and some implications for practice and future research.

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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 incompatibility 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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Chapter 3

Experiences and Views of Dutch General Practitioners Regarding Physician-assisted Death for Patients Suffering from Severe Mental Illness: a Mixed Methods Approach

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Abstract

Background: In the Netherlands, physician-assisted death (PAD) is allowed under certain conditions. Patients who suffer from mental illnesses are not excluded from this practice. In 2018, general practitioners (GPs) performed 20 out of a total of 67 cases of EAS for psychiatric suffering

Objective: More insight into GPs' experiences and views with regard to PAD in psychiatry.

Design: The data for this study were obtained through a survey amongst 500 randomly selected Dutch GPs and by in-depth interviews with 20 Dutch GPs.

Setting: A survey study and in-depth interviews

Subjects: Dutch GPs

Results: 86 out of 101 GPs found it conceivable to perform EAS in case of somatic disease, and 51 out of 104 GPs found it conceivable in the case a patient suffered from a mental illness only. The main reason given for refusing an PAD request was that the criteria of due care were not met. Reasons for supporting psychiatric PAD related to responsibility, self-determination, compassion, fairness and preventing suicide.

Reasons for not supporting psychiatric PAD were related to the scope of medicine, a perceived lack of experience, uncertainties regarding the criteria of due care and life-expectancy.

Conclusion: GPs are less likely to perform PAD for suffering from a mental illness, compared to somatic suffering. Some GPs apply an extra criterion of 'life-expectancy' in case of PAD for suffering from a mental illness. Refusing PAD based on a long life expectancy keeps open the possibility of recovery, but may also just prolong the suffering and add to the unbearableness of it.

Keywords: physician-assisted death, psychiatry, General Practitioners, psychiatric patients

Introduction

Physician-assisted death (PAD) is a regulated practices in the Netherlands. The Dutch Termination of Life on Request and Assisted Suicide Act (WtI) is in force since 2002, and allows physicians to perform PAD if (and only if) certain conditions, the criteria of due care, are met. PAD is neither a right of the patient nor a duty of the physician, as it is not considered a 'normal medical act'. Physicians are free to refuse a request for PAD, and indeed do so for a variety of ethical, psychological and personal reasons.(1, 2)

In 1994, the Dutch Supreme Court ruled that there are no grounds to exclude patients who suffer from a mental illness from the option of PAD (3). The number of requests for PAD by patients suffering from a mental illness has risen since, and is estimated to have increased from 320 in 1995 to 1100 in 2016.(4) The number of performed cases also increased, from zero in 2002 to 67 in 2018.(5) This shows that although the numbers are rising, the vast majority of requests are denied. A recent study of patients at Expertisecentrum Euthanasie showed that patients who requested PAD on grounds of suffering from a mental illness were predominantly female, and suffered from depression.(6) The majority of these patients had more than one psychiatric diagnosis, and were between the ages of 41-60.(6) An analysis of granted PAD requests for psychiatric suffering between 2015 and 2017, showed that 77% on grounds of suffering from a mental illness regarded women, and 51% were between the ages of 50-70.(7)

The support for psychiatric PAD is higher in the general public than among physicians. (8, 9) Physicians in general are less likely to perform PAD for a patient exclusively suffering from a psychiatric disorder.(2, 4) The percentage of psychiatrists who can conceive of ever performing PAD on a patient suffering from mental illnesses decreased over the years. (4) A previous study showed GPs find it less conceivable to perform PAD when a patient suffers from a mental illness, compared to for example suffering from cancer.(2)

Various issues arise regarding PAD for psychiatric suffering: the ‘criteria of due care’ can be more difficult to interpret in case of psychiatric illness compared to somatic suffering. It can be harder to establish whether the patient’s death wish is part of the mental illness, or not. (10, 11) The capacity of the patient to understand her situation and make decisions regarding her treatment may be impaired. (12) Patients who are depressed may for example hold the unjustified belief that chances of recovery are minimal. (13) The second criterion of the Dutch euthanasia act, stating ‘suffering must be unbearable and without prospect of improvement’, may also be difficult to apply. The diagnostic and prognostic uncertainties that come with mental illnesses could make it difficult to establish whether a patient has a reasonable chance to recover. (11, 13) Another issue that is mentioned in the literature is the vulnerability of patients suffering from mental illnesses, and their need for protection. (11, 14, 15) A final concern regarding physician-assisted death in psychiatry relates to the concept of hope. It has been argued that discussing the option of assisted suicide with a patient suffering from a mental illness might provoke feelings of desperation and demoralization (a loss of hope) in the patient, which could lead to unjustified beliefs about the impossibility of recovery. (16, 17)

Dutch GPs also receive and perform requests for EAS from patients suffering from mental illnesses. In twenty of the 67 cases in which a patient suffering from a mental illness received PAD in 2018, the GP was the notifying physician. (18) This study was set up because there is an increase in EAS requests of patients suffering from mental illnesses (4), and we do not know GP’s experiences and views on the subject matter. What, for instance, are their reasons for supporting or rejecting the possibility of PAD in case of psychiatric suffering? Therefore, we aimed to answer the question: what are Dutch GPs’ experiences with and views on PAD in case a patient suffers from a mental illness?

Methods

Design and data collection

We sent out questionnaires to 500 randomly selected Dutch GPs. We obtained the addresses from a national databank of registered physicians (IMS Health), that works in accordance with the national privacy act (AVG act) The inclusion criterion was that the GP had been working in patient care for the past year.

In October 2018, GPs received a four page questionnaire with questions on their experiences with EAS in psychiatry (see supplementary survey 2). The questionnaire was similar to the one that was sent out to 500 psychiatrists as part of the Third Evaluation of the Dutch Euthanasia Act. (4) GPs were asked for their experiences with and their opinion on PAD: would they find it conceivable to ever perform PAD for a patient suffering from a mental illness, and, did they, in the year prior to receiving the questionnaire, have experience with a request for PAD by a patient suffering from a mental illness? The data were obtained from October 2018 until February 2019. One reminder was sent during that period of time.

We also interviewed 20 GPs (9 women and 11 men) from September 2018 until February 2019, in order to obtain more in-depth information about the views of the GPs. The interviews were explorative in nature, and guided by a topic list that included more topics than reported in this paper. The questions were formulated in an open way, in order to provide enough opportunity for the physicians to talk about their experiences and views. From the richness of data we had to choose, and chose what we believed to be the most relevant data. The interviews were conducted by two researchers: RP (PhD student) and NS (Master student). Interviews lasted approximately 1.5 hours, and were held at the GPs location of choice. An informed consent-form that emphasized the voluntary and confidential character of participation was signed before each interview. All participants agreed on the use of an audio-device, which was kept

at the Amsterdam UMC at a place only accessible to RP. All interviews were transcribed verbatim by a third party, who signed a confidentiality agreement. Data saturation was reached, as no new information came up during the last interviews. No repeat interviews were carried out.

Respondents

We selected the respondents in various ways: on the basis of their replies to the questionnaire, through the network of the Amsterdam UMC, by addressing physicians following a mental healthcare training (kaderopleiding GGZ) and through snowball-sampling. We aimed for a variety in gender, working area and views on psychiatric PAD. We interviewed 11 men and 9 women, coming from rural areas, smaller and bigger cities in the Netherlands. On the basis of the questionnaire, we selected GPs who were opposed to psychiatric EAS and those who were open to the option or performed PAD in case of psychiatric suffering.

Data analysis

The questionnaire was analysed using IBM SPSS Statistics 25. We used descriptive data analysis in order to obtain the results.

Out of the 20 interviews, 19 were analyzed as one interview was lost because of technical difficulties. After coding and discussing the first two interviews together, RP and NS both analyzed all the interviews separately with the use of MaxQDA 2018 and discussed them afterwards. We coded inductively, by developing codes, code trees and identified overarching themes. After the analysis, the results were discussed by both researchers and with the supervising researchers (DW and SV).

Results

Response rate

Out of the 110 GPs who responded to the survey, 108 met the eligibility criteria. The response rate was 22%. Two GPs had not been working in patient care during the past year. We structured the quantitative data according to the results from the qualitative study.

What are the GPs experiences with and views on PAD for patients suffering from mental illnesses?

Table I. shows the experiences that the GPs had with PAD requests for patients suffering from a mental disorder. (see table I.) The table shows that a significant number of GPs had ever been asked to assist in a patient's death, and that most requests are denied because the criteria of due care were considered not to be met.

Table II. shows their answers on the conceivability of performing PAD in case of somatic suffering only, in case of somatic and mental suffering, and in case of only mental suffering. (See table II.) The table shows that most GPs would consider performing PAD in case the patient suffers from a somatic illness and when a patient suffers from a somatic and mental illness. Approximately half of the GPs would consider performing PAD when a patient suffers solely from a mental illness.

Reasons for being in favour of the possibility of psychiatric PAD

The interviews showed that the GPs had multiple reasons for supporting the possibility of PAD in psychiatry. These arguments related to responsibility, self-determination, compassion, fairness and preventing suicide.

Some GPs indicated that they felt responsible for their patients, and wanted to look after their interests. For some this was a personally felt responsibility, whereas for others this meant a responsibility connected to their profession:

R: Yes, I actually think that if I stand beside my patient as a doctor, then I have to protect their interests. Of course, how far do you go with that? But in my case, it goes as far as helping someone to die in case life is unbearable.

I: Whether that is on somatic grounds or psychiatric grounds?

R: Yes, if I can empathize with it (R16)

In the survey, the GPs were asked whether they believed everyone has the right to self-determination in respect to his or her own life. 56 out of 105 agreed with this statement, 19 disagreed and 30 GPs gave a neutral answer.

In the interviews, respondents indicated that patient self-determination was an important reason for them to be in favor of psychiatric PAD:

I: Could you tell me something about how you view euthanasia or physician-assisted suicide in case of a psychiatric patient?

R: Well, I believe that I am very liberal in general, not in the political sense of the word, but that I find it very important that a human being, if he is capable, should be able to make his or her own choices. In that sense, euthanasia in psychiatry is just as normal as euthanasia for other reasons, and a euthanasia request of a patient is justified if a patient asks for that well-considered, for whatever reason. (R4)

Respondents mentioned in the interviews that they could empathize with the suffering and that it was meaningful for them to be able to offer a relieve to that suffering:

I: Could you tell me a little bit more about when you would find it conceivable that you would cooperate with a psychiatric patients' euthanasia request?

R: You can imagine that if you see somebody that often, see how difficult his life is, how much they are suffering, that you at some point just grant somebody that it can stop. That you saw them for so long, that you just grant it to them...that it is better for them yes. (R17)

Many GPs compared patients with psychiatric diseases to patients with somatic diseases. Some highlighted the differences, but there were also GPs who emphasized the similarities between the two groups:

I think my general attitude is fairly liberal, so I can understand that, yes. I see it as sort of a chronic illness, and just as with many chronic illnesses, you can have a wish for euthanasia as a patient. And psychiatry in itself does not mean that you cannot oversee the consequences. I believe that enough psychiatric patients can oversee them, and hence can have a realistic wish for that. (R12)

In the questionnaire survey, the GPs were asked to give their opinion regarding the statement that PAD is an acceptable option to prevent suicide. The GPs proved to be divided over this matter: 38 out of 103 agreed with the statement, 31 disagreed and 34 gave a neutral answer.

In the interviews, some respondents wished they could have prevented the suicide of patients by providing PAD:

I: What is your opinion about physician-assisted suicide in psychiatry? Do you believe that it [i.e. psychiatric disorders] can provide a justified reason...?

R: Yes, I do think so. I have experienced some cases, from very nearby, of patients who suffered from a psychiatric condition who ended their lives. Also in the river across from here, a hundred meters from my house. And then I thought to myself, what a misery, how could it have ever come this far. Why

couldn't I have helped this woman?(...) So I think in some cases, those lives [i.e. of psychiatric patients] are without prospect of improvement and the patient suffers unbearably (R16)

Reasons for not being in favor of the possibility of psychiatric PAD

In the interviews, some GPs indicated that they were of the opinion that ending a patient's life does not fall within the scope of medical practice, as the medical profession is concerned with keeping patients healthy and alive:

On the other hand, killing someone is not a medical act. So the whole euthanasia-issue, should that be in the hands of doctors? Why? We are more involved in life, and keeping life as optimal as possible. (R14)

Respondents also mentioned that they viewed mental suffering as existential suffering. They indicated that relieving existential suffering does not fall within the scope of medical practice and that doctors do not have the expertise to evaluate existential suffering:

And I believe we as doctors should stay away from existential suffering, because existential suffering is of all times. We have to relate to that. There is nothing medical about it, so we should not make it medical. (R 11)

Some respondents believe that ending the life of a patient suffering from a mental illness could fall within the medical realm, but indicated that it is the task of a psychiatrist, and not of a GP.

I don't think this should be the task of the GP, because it is about complex psychiatric problems. It is not about a seasonal depression or a relationship crisis. This is about a serious deep wish that people have. That belongs to psychiatry. (R6)

Respondents mentioned that they felt not at ease with handling a request from a patient suffering from a mental illness, because they lacked the experience:

It is so far from the diagnoses that normally lead to a euthanasia request, that it is a shady area for me. I don't feel at home with it. I think that has to do with the lack of experience I have in treating severe psychiatric patients. I refer them all. (R16)

You know, a GP knows a little about a lot. And the psychiatrist knows a lot about a little, just as any specialist. And I know for sure that I have big gaps in knowledge when it comes to assessing psychiatric patients. (R3)

Respondents indicated that psychiatrists have more knowledge on the interpretation of the criteria of due care in case of suffering from a mental illness, on mental competence, on how to differentiate between a pathological and non-pathological wish to die, and on possibilities for improvement:

I would not be able to assess whether there is no prospect of improvement. For that, in case I would consider performing euthanasia, I would consult a psychiatrist to assess the mental competence and on whether there is no prospect of improvement. (R6)

However, certain advantages of GPs compared to psychiatrists were also mentioned.

GPs argued that they have more room to be empathetic to the situation of the patient, and because they often know the patient for a very long time, including their social context and background.

In general, the GPs favored working together with psychiatrists during the assessment of the request:

I do feel competent, but I believe you should do it together, because a psychiatrist has to tell you what has happened and how it helped.

You have to know whether you've missed something. So, I don't think you should do it by yourself, it is a collaboration. (R17)

Table III shows how GPs reacted to various statements about the evaluation of the criteria of due care.

In the interviews, some respondents expressed concerns related to uncertainty about the criteria of due care, as they told us that one can never know for certain whether a patient can get better:

And sometimes those people recover. And if you open up the possibility for euthanasia, they never have that option again. We cannot judge that, we are not God. (R11)

Also, interviewees found it difficult to determine whether a patient's suffering from a mental illness is unbearable or not, in comparison with somatic suffering. Reasons provided were that the suffering is not visible (as it often is in case of somatic suffering), it is less objectively measurable than somatic suffering, and the suffering is harder to empathize with because of a lack of psychiatric susceptibility of the doctor:

I: What about the unbearableness, do you consider it enough if the patient says 'this is unbearable for me' and you see that it is, is that enough? Or do you really need to be able to empathize with it?

R: Well, when he says it and you see it, I think that is already a lot, that heads towards empathizing. I myself do not have any psychiatric susceptibility, or sombreness, so I will never be able to empathize with that, I will never feel that. (R12)

Some interviewees indicated that the life-expectancy of a patient is a relevant factor in being opposed to the idea of psychiatric PAD.

Respondents mentioned that the relatively long life expectancy of patients suffering from mental illnesses, compared to somatic patients, made them more hopeful regarding possibilities for recovery.

The longer the life expectancy, the greater the chances are, that is my hope, that things will work out. Either intrinsic or extrinsic, that something can be done so that it can work out with that person. (R13)

Also, the fact that a person's life is significantly cut short, and that a person has a whole life ahead of them was considered to be relevant:

Well, because I have the idea that in general with psychiatric complaints, psychiatric problems, it is very hard to determine whether someone will get better or not. And besides that, her age played an important part, because she has –in my eyes- a whole life ahead of her. That is a different situation than someone with metastasised cancer who doesn't get better anymore. (R9)

This GP mentioned that ending the life of a young person feels unnatural to him:

And I can imagine that in case of a very young patient, I would find that very difficult. It feels unnatural to kill a young person. So, I would be troubled by that, yes, that plays a role in case of psychiatric patients. (R15)

Discussion

Summary

This study was set up to gain insight into the experiences and views of Dutch GPs regarding PAD in psychiatry. We combined two studies in order to obtain these results: a survey-study and an interview-study. The results from our survey-study show that Dutch GPs find it less conceivable to perform PAD in case of only suffering from a mental illness, compared to cases of PAD with regard to only somatic or combined somatic and mental suffering. The most important reason given for not granting a request from a patient suffering from a mental illness is that the doctors felt that they did not meet the legal criteria of due care.

Strengths and limitations

A strength of this study is that it provides insight into a very controversial practice. To our knowledge, no previous qualitative studies have been performed amongst GPs specifically regarding PAD in case of patients suffering from mental illnesses. Another strength is that we have combined two types of studies in order to obtain our results, a quantitative and a qualitative study. In that way we were able to show a broad view of the experiences and considerations of the GPs.

A limitation of the questionnaire is the low response rate (22%), which may have led to selection bias. It might be possible that those with a negative attitude towards PAD were more inclined to respond to our questionnaire, in order to show their dissatisfaction. Our results are, however, fairly consistent with other studies on the subject, so we have little reason to believe that selection bias may have taken place.(2, 9)

Comparison with existing literature

Studies regarding the acceptability of PAD among psychiatrists in the Netherlands show that they also find it significantly less conceivable to perform PAD in case of mental suffering only, and that this has even decreased over the past few years.(2, 9) In contrast to this, the overall acceptance of psychiatric PAD among the general public increased, and remained the same or also increased among other physicians.(12) Although the Dutch euthanasia law does not differentiate between somatic and mental illnesses, the GPs do seem to make a distinction. It seems that the physicians are reluctant to perform PAD, while the number of psychiatric patients who request PAD has only gone up.(4) Whether PAD is seen as morally acceptable or not in these cases depends on how one balances different values. On the one hand there is the value of equality, as an aspect of justice, and this was mentioned explicitly by our respondents(19). They state that patients suffering from mental illnesses may suffer just like patients with somatic diseases, and hence should also be eligible for PAD. On the other hand, it may be more difficult for physicians to fulfil the legal criteria of due care in case of a request from a patient suffering from a mental illness, as is evidenced by the fact that most requests were rejected for that reason. We do not know whether the physician actually did not meet the criteria in those cases, or whether they had difficulties determining whether the criteria were met. In the interview study the respondents indicated that they did experience difficulties evaluating the criteria. GPs felt insecure with regard to their own expertise on psychiatry.

Just like the GPs, psychiatrists indicated that they were uncertain about certain aspects of the process, however their uncertainty regarded the evaluation of the criteria, not their own expertise.(4) Some GPs expressed lack of knowledge about the treatment of mental illnesses and found this to be problematic when it comes to PAD. This is interesting, as we would expect them to also experience a lack of knowledge in case

of many somatic diseases, and hence to be equally hesitant to perform PAD in case of somatic suffering. However, this was not indicated by the GPs. It may be the case that the relatively long life expectancy of the patients and the fact that a mental illness is rarely terminal plays a role here. The majority of common PAD cases involve patients with cancer(18), and in these cases the patient is very likely to die from the disease within a short period of time. The certainty that these patients will pass away in the foreseeable future seems to diminish the physicians' fear of misinterpreting the criteria of due care. Some GPs seem to apply an extra criterion of due care, namely that of life-expectancy. On the one hand they feel that helping a younger patient to die is unnatural, and on the other hand they related the life-expectancy to the criterion of 'no prospect of improvement'.

Although these reasons are understandable and physicians always have the right to refuse a request, we think that one aspect remains underexposed. Patients with mental illness whose suffering is without prospect of improvement do not have a shortened life-expectancy as a result of their condition, which means that in the worst case, their suffering could go on for decades. Although the physicians retrieve hope for recovery from the fact that the patient has a relatively long life-expectancy, this is different for the patient. We know that the thought that the suffering will continue for a long time adds to the unbearableness of the suffering. This is illustrated by the fact that some patients suffering from mental illnesses postpone their actual PAD after they received approval for PAD. It is thought this happens because knowing that there is a way out relieves some of the suffering.(20, 21) Refusing PAD on the basis of a long life expectancy keeps open the possibility of recovery, but may also just prolong the suffering and add to the unbearableness of it.

Implications for research and/or practice

As this study shows that GPs are concerned about their perceived lack of knowledge regarding mental illnesses and their treatment, one implication could be that we would need to create more opportunities for the GPs to receive guidance when evaluating requests for PAD from patients suffering from mental illnesses.

Declaration

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Table I. EAS requests from patients with a psychiatric disorder, questionnaire data

	Yes N=	No N=	N=
Has a patient ever asked you to assist with his or her suicide in the foreseeable future? (n=106)	43	63	
Have you ever provided assistance in suicide to a psychiatric patient? (n=43)	3	40	
Have you ever refused a request for assistance in suicide from a psychiatric patient? (n=43)	37	6	
What was the reason for the refusal of this request? (n=37) * multiple answers possible			
I never perform assisted suicide			6
I never perform assisted suicide in case of a psychiatric patient			7
Did not meet the legal criteria of due care			19
Personal objection specifically related to this case			8
Other			7

Table II. **Conceivability of performing a request for assisted suicide**

	Yes N=	No N=
Do you find it conceivable that you will perform assisted suicide in case of a patient with a somatic illness? (n=101)	86	15
If not, would you refer the patient to another physician (who may possibly grant the request)? (n=15)	15	
Do you find it conceivable that you will perform assisted suicide in case of a patient with a somatic and psychiatric illness? (n=102)	81	21
If not, would you refer the patient to another physician (who may possibly grant the request)? (n=19)	19	
Do you find it conceivable that you will perform assisted suicide in case of a patient with a psychiatric illness? (n=104)	51	53
If not, would you refer the patient to another physician (who may possibly grant the request)? (n=52)	51	1

Table III. **Statements**

	Agree N=	Neutral N=	Disagree N=
it is impossible to assess whether a psychiatric patient's suffering is unbearable and without prospect of improvement' (n=104)	15	35	54
it is never possible to establish whether a wish to die is ever well-considered (n=104)	12	34	58
it is possible to establish whether the wish to die is the part of the underlying pathology (n=105)	21	36	48

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Chapter 4

Do Doctors Differentiate Between Suicide and Physician-Assisted Death? A Qualitative Study into the Views of Psychiatrists and General Practitioners

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Abstract

Physician-assisted death for patients suffering from psychiatric disorders is allowed in the Netherlands under certain circumstances. One of the central problems that arise with regard to this practice is the question of whether it is possible to distinguish between suicidality and a request for physician-assisted death. We set up this study to gain insight into how psychiatrists and general practitioners distinguish between suicidality and physician-assisted death. The data for this study were collected through qualitative interviews with 20 general practitioners and 17 psychiatrists in the Netherlands. From the interviews, we conclude that physicians distinguish three types of death wishes among patients suffering from psychiatric disorders: ‘impulsive suicidality,’ ‘chronic suicidality,’ and ‘rational death wishes.’ To discern between them they evaluate whether the death wish is seen as part of the psychopathology, whether it is consistent over time, and whether they consider it treatable. Some considered physician-assisted death an alternative to a ‘rational suicide,’ as this was perceived to be a more humane manner of death for the patient and their relatives. We argue that physician-assisted death can be justified also in some cases in which the death wish is part of the psychopathology, as the patient’s suffering can be unbearable and irremediable. Physician-assisted death in these cases may remain the only option left to relieve the suffering.

Keywords: Suicide, Physician-assisted death, Psychiatry, Psychiatric patients, Euthanasia, Netherlands

Introduction

In the Netherlands, patients who suffer from psychiatric illnesses are not excluded from the practice of euthanasia and physician-assisted suicide (EAS) (the term ‘Medical Aid in Dying’ (MAID) is also used, in both Canada and the US. However, we will make use of the term ‘EAS,’ as this is how it is used in the Netherlands). The Dutch Supreme Court ruled in the Chabot case (in 1994) that the unbearable nature of the suffering should be leading, regardless of the source of this suffering.(1) Physician-assisted death for patients suffering from psychiatric illnesses solely is also permitted under strict criteria in Belgium, Luxembourg, and Canada.(2, 3) In the Netherlands, a physician is allowed to provide assistance in dying if he or she meets the legal criteria of due care. These criteria hold that there should be a voluntary and well-considered request, the patient’s suffering should be unbearable and without the prospect of improvement, the patient should be informed about his or her situation, there are no reasonable alternatives to relieve suffering, an independent physician should be consulted, and the method used should be medically and technically appropriate.(4)). The third evaluation of the Dutch euthanasia act, from 2016, shows that 88% of the general public supports the euthanasia law.(5) However, EAS in case of psychiatric suffering is less accepted. Evenblij et al. showed that of the general public 53% thought that people with psychiatric disorders should be eligible for EAS, 15% was opposed to this, and 32% remained neutral.(6) Dutch psychiatrists are generally very reluctant to perform EAS for psychiatric suffering. An important reason for their reluctance lies in the difficulty they have in determining the difference between a request for EAS and suicidality.(5) Whether it is possible to distinguish irrational suicidality from rational death wishes matters because there is a societal commitment to suicide prevention.(7) The general thought is that irrationally suicidal patients should not be eligible for EAS, as they require treatment for their psychopathology.

Psychiatrists view suicide as an act that is often the result of mental illness: those who want to commit suicide are not capable of making that decision due to their mental illness.(8) Some, however, argued that patients who suffer from a mental disorder can have a rational wish to die, for example, even in the case of schizophrenia.(9, 10) The Dutch Association of Psychiatry (NVvP) takes a similar stance in their guideline on physician-assisted dying in the case of psychiatric suffering. On the one hand, they state that suicidality is often the result of underlying psychopathology. In those cases, the patient suffers from a psychiatric disorder that obstructs a clear judgment and therefore conflicts with decisional competence.(11) On the other hand, the NVvP does not entirely reject the option of EAS, which implies that the NVvP also believes there is such a thing as a rational death wish. EAS could, however, only be acceptable if it could be established that the patient is suffering from a psychiatric illness, suffers unbearably without the prospect of improvement, and made a considered (rational) request.

In the Netherlands, both psychiatrists and general practitioners (GPs) respond to requests for EAS from patients who suffer from psychiatric illnesses.(12)). It is highly relevant how they view the relation between suicide and EAS, as they are the ones that assess the requests for EAS from these patients. We therefore conducted a qualitative study with 17 Dutch psychiatrists (as a part of the Third Evaluation of the Dutch Euthanasia Act) and 20 Dutch GPs on their views and considerations concerning EAS in psychiatry. We addressed the issue of EAS for persons suffering solely from psychiatric illnesses, and not from a combination of somatic and psychiatric illnesses. The relation between suicidality and EAS was one of the topics covered in the interviews. We chose to address this question by using a qualitative method, as this allowed physicians to elaborate on their views and considerations.

Methods

Design

The interviews with 17 Dutch psychiatrists were held as a part of the Third Evaluation of the Dutch Termination of Life on Request and Assisted Suicide Act. These interviews were held from January until June 2016. The interviews with the 20 Dutch GPs were held from September 2018 until February 2019. All interviews were held with the use of a topic list. Two pilot interviews were held to check whether the topic list was complete. The results presented in this paper are a part of a broader study on EAS among psychiatrists and general practitioners.

Two researchers conducted the interviews, RP and NS. RP performed all interviews with the psychiatrists, and 8 out of 20 interviews with GPs. NS conducted 12 of the interviews with Dutch GPs. To prevent bias, NS was trained by RP to do the interviews with the GPs, and she observed one of RP's interviews. RP also observed one of NS's interviews. They discussed these afterward to come to a mutual understanding about how to conduct the interviews. The interviews were held at the physician's location of choice and lasted between one and 2 h. All physicians signed an informed consent form, which included statements on confidentiality and the voluntary character of participation.

Respondents

The respondents were selected through purposive sampling. We aimed for a variety in experience with psychiatric EAS requests, views on psychiatric EAS, sex, subspecialty within psychiatry, and work environment. We included respondents who were in favor and against psychiatric EAS, who did and did not have experience with assessing and performing psychiatric EAS requests.

We recruited the psychiatrists at Expertisecentrum Euthanasie (previously: End- of-Life Clinic), through the professional network

of the researchers, through snowball sampling and through the website of the Dutch patient federation. We recruited the GP's through a questionnaire that was held under Dutch GPs, by addressing physicians following mental healthcare training, through the network of the Amsterdam UMC and snowball sampling.

Data Analysis

We lost one interview with a psychiatrist and one interview with a GP due to technical problems, so a total of 16 interviews with psychiatrists and 19 interviews with GPs were included. All interviews were transcribed verbatim and inductively coded by RP. NS conducted 12 interviews with GPs. Three interviews with GPs were separately coded, compared, and discussed with NS. Five interviews with psychiatrists were also independently coded by a second coder (JG). We coded and created code trees to identify overarching themes. Data analysis and the results were discussed with the supervisors of the study (DW and SV). The results of the interviews with psychiatrists were also discussed within the research group that conducted the Third Evaluation of the Dutch Termination of Life on Request and Assisted Suicide Act.

Results

Three Categories of Death Wishes

Concerning patients who suffer from psychiatric disorders, most physicians distinguished between different types of death wishes, namely (a) impulsive suicidality, (b) chronic suicidality, and (c) a well-considered and persistent wish to die.

What you always do, in case of a psychiatric patient is evaluate how suicidal they are. And if you suspect they really are suicidal, you have to do something. Usually, you consult the experts, have them evaluated.

But the fact that someone is suicidal, is something completely different than a euthanasia request (GP - R8)

That was one of the clients who was treated here, who had a persistent death wish that differed from the chronic suicidality that we often see with personality disorders. And the client indicated that she wanted to actively do something about that. (...) (psychiatrist - R13)

Impulsive suicidality (a) was characterized as a temporary wish to die, often related to emotional events, and a symptom of the psychopathology of the patient. Chronic suicidality (b) was characterized as being more persistent and frequently occurring, but still a symptom of the psychopathology of the patient. A rational death wish (c) was characterized as a well-considered persistent wish to die, unrelated to emotional events, and not an expression of the psychopathology. These patients carefully consider their situation and prospects and make an informed decision about whether they want to live or not.

However, there was also one respondent who did not believe there exists such a thing as a 'rational death wish,' as they indicated that all death wishes are the result of emotional distress:

(...) this is also one of my opinions: that rational suicide does not exist. That is the humanistic liberal thought that humans are rational beings, but I have never seen a rational suicide. All of this so-called weighing... (...) I have got a lot of experience, I have worked for 40 years in large hospitals, with large ERs and saw 3 cases of (i.e. 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), weighing 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 (psychiatrist - R8).

Multiple respondents mentioned that a death wish can be seen as a continuum, and suicidality is at a different position within that continuum than EAS is. Consistency over time was seen as a relevant factor in relation to that continuum:

I: I want to pick up on the death wish that is the result of a disease, let's call that 'suicidality', and a long-lasting wish to die because someone thinks he/she suffers unbearably. What, to you, constitutes the difference, how do you separate those two?

R: Notably because of the phase that someone is at. So that depends on the clinical situation. (...) 'time' is an important factor, and where someone is. If someone, if you assess someone and there is no depression (...) and there still is a death wish, if that repeats itself during time, then you could say that it is not the result of a disease.. (GP - R13)

*A man of 25 years old. What did he do? He went to the *name of the bridge*, and knotted a rope around it, around his neck, jumped (...) and the rope snapped and he went into the water, he wanted to commit suicide, he really tried (...). He swam to the side, got into the car and drove here [i.e. to the physician] (...). I think it is nice that he comes here for help, and then you start to do all kinds of things. But it shows how it goes with suicides. (...) 'This example shows impulsivity. A genuine euthanasia request is discussed during multiple conversations, that is consistent in general, that is completely different. (GP - R8)*

However, some respondents did not believe such a continuum exists:

I always call that the 'blackmail argument'. First of all, it is incorrect. Violent suicides are not an extension within a continuum of a well-considered gentle death, of a gentle suicide... towards a gruesome suicide. (...) There is no such thing as a continuum (...) But the thought that there is a continuum, there is no such thing. If you check the literature,

it is a binomial distribution. So a small group of violent suicides, and a larger group of the repeated lighter [i.e. attempted] suicides. And they don't mix. (psychiatrist - R8)

Treatment for Suicidality

Respondents expressed that they believe it is their responsibility to treat patients and prevent deaths that are the result of impulsive suicidality and chronic suicidality (a, b), but not necessarily those that are the result of a rational death wish (c)

That does not mean that we have to accept all those impulse suicides, no, that would not be good. If somebody is suicidal, it is often a temporary state of mind. And after a few months, that person might look back onto that very differently, so you have to pull them away from that edge. (GP - R14)

[when the patient says]" I want this to happen when I'm really in touch with a medical professional, that would be the best. That is my deep inner wish. I am completely convinced about this, help me please, because if this does not happen, if I do not get what I want most, I will stagnate" Well, then it is difficult for me not to. (...) if this really is something authentic, why wouldn't I help you? What stops me is that I would have to kill you, something that I really, deeply, do not want to. But if you would want to commit suicide... If you go with a blissful smile, dangling on the staircase of your choice, it is all as you wished, who am I to sort of comment on that? If it is in line with who you are. But the moment that I have the feeling that your reasoning is flawed, you tell me this in pain, this is not in line with other sides that I know of you, then I think it is my job as a therapist to confront you with that and not to say 'you know what, okay'. (psychiatrist - R4)

GPs indicated that they find it complicated to assess the due care criteria for patients suffering from psychiatric illnesses: whether a patient has decisional competence, whether the death wish is well considered and without the prospect of improvement. Many GPs indicated that they prefer to work together with a psychiatrist:

I think that I would refer them to a psychiatrist with a clear question: are there any reasonable treatment options? That is a question that I would like to see answered. And also whether somebody is mentally competent.
(GP - R15)

Suicide or Physician-Assisted Death?

For some respondents, EAS could provide an alternative for a rational suicide. This respondent told us that he discusses the option of EAS with a patient if he has a long-lasting wish to die:

I mean, someone who thinks he can fly and jumps out of a window, I find that horrible, I want to prevent that. Someone who impulsively, because his relationship broke up, drinks too much, drives too fast and hits his car against a tree, I really would like to prevent that. But 10 years of treatment because of a psychotic disorder, having the prospect of never leading a normal life, and then having to jump off a high-rise building. I would sincerely hope he would request euthanasia, so I could offer a dignified and less lonely ending. And that rational suicide, I would like to translate that to euthanasia. (psychiatrist - R11)

Whereas some respondents thought EAS could serve as an alternative for suicide, various respondents expressed that they did not believe that EAS is a good alternative, for which they provided multiple reasons. The first reason related to the belief that the category of patients who commit suicide differs from the category of patients who request EAS:

No, I think that those who commit suicide, they might be more vigorous or don't want any help with that, but they do not experience the threshold that people who request euthanasia do. It is a different, it is often a different population. (GP - R4)

Those numbers don't go down because of self-euthanasia or euthanasia, because if that would have been the case, we should have seen that happening, with the doubling of the euthanasia cases in the past five years, the gruesome suicides have not reduced. That is because it is an entirely different population, you should not confuse those two.. (psychiatrist - R10)

Another reason provided was that it is not necessarily the case that people who do not have their EAS request granted, commit suicide:

No, I don't think that at all. No, this is a misunderstanding. I think that it is definitely not the case that people who received euthanasia would otherwise have committed suicide, that is not the case. It might be the case sometimes, but not all times. The reasons for euthanasia and the reason for suicide might differ. It can be the case that you are very mad because of the rejection of your euthanasia request, and that you are taking revenge, (...) So, dying may have an interactional meaning, a communicative meaning instead of it being an answer to the big problem of 'I cannot live with the pain I have'. So, those are two different lines of argument, that does not have to be about the same thing.. (psychiatrist - R4)

A third and final reason was that threatening to commit suicide to receive EAS can be a form of manipulation. This respondent indicated that he did not want to be at the receiving end of this manipulation and that he will turn to emergency care instead of providing EAS:

I would not let myself be forced. It cannot be the case that the patient is blackmailing me and says 'if you don't do it, I will do it myself'. I would

never agree in such a situation. If I really believe that there is a big suicide risk, if the odds are really big, then that is a reason for me to get the emergency care involved. I would not think 'oh, I will just agree with him because he is really serious'. I would not accept that. (GP - R15)

What Do Physicians Perceive to be the Difference Between EAS and Suicide?

The respondents suggested multiple differences between suicide and EAS. We describe these differences under the following headings: (a) the causes and meaning of death wishes differ, (b) physician-assisted death as less traumatic, (c) treatability of the condition, and (d) consistency of the death wish and suffering.

The Causes and Meaning of the Death Wish Differ

Respondents mentioned that they viewed suicidality as part of the psychiatric disorder, either an expression of it or directly caused by it, whereas an EAS request was considered an authentic expression of the person.

That seems wrong, because when somebody is suicidal. I was just saying (...) then that is the result of their psychiatric disorder, or a bad mood, or voices that someone hears, or irrational thoughts. While if someone has a persistent death wish, and I don't think about a 20- or 30 year old, but when they have lived a long life, when it has been a long and hard road that they don't want to take anymore, then it is not the result of a disorder, but it comes from a whole person who does not want to live anymore. (...). (GP - R17)

He also had a psychiatrist with whom he spoke, and I thought it was quite hard, so I asked that psychiatrist whether it was the result of depression or another psychiatric disorder. And he really analyzed it, and was able to say that this was a man who was always able to do things his way, it was

really authentic for him, it fits, and that it was not a treatable psychiatric disorder. (GP - R7)

A second discerning factor was that suicidality was seen as an emotional reaction to a certain situation, in contrast to a well-considered wish to die:

R: That was with one of the clients that we have in treatment here, and at a certain moment there was a persistent death wish that was different from the chronic suicidality that we often see with personality disorders. This client indicated that she wanted to actively do something with that [i.e. her wish to die]. Then we decided to have a two-track approach, on the one hand, the application for Expertisecentrum Euthanasie, and on the other hand the treatment trajectory.

I: And if you say that the death wish was something different than chronic suicidality, what is the difference between those two. What constituted the difference?

R: I think that a difference is, chronic suicidality is something we see a lot, especially with borderline patients, but also with other personality disorders. It is often connected to emotion regulation problems, or emotional wounds. So, suicidal thoughts occur frequently, arise often, and can often be traced back to emotional wounds, in which someone justifiably or unjustifiably feels hurt by a circumstance, because of a reaction of someone. But there are also moments in which that does not occur. So you see that it occurs over the years, increases in some periods, so that they arise every week or even multiple times a week. But that there are also periods when they don't occur, or occur less. With this client [i.e. who had a euthanasia request], she could not think about anything else, so it was really persistent. There were no good moments anymore, or a free moment, a moment where she would experience a will to live. (psychiatrist - R13)

Another respondent stated:

Yes, there is a big difference. People who for example are overwhelmed by heartbreak throw themselves in front of a train, hang themselves, take pills or slit their wrists. That is suicidality. I believe that you have to get them admitted, hold them, talk to them. And three weeks later, they're better. And then they live happily ever after. That is something different than a deeply felt death wish in case someone has a persistent, chronic depression or anxiety disorder. (GP - R16)

As a third factor, respondents mentioned that suicidality can have a communicative meaning rather than actually wanting to end one's life:

Look, most of these cases are a cry for help. Most suicide attempts are a cry for help. The real rational suicides, in which people have been weighing 'do I really want this, or don't I want this' are far less common.. (psychiatrist - R13) So if you have been neglected, never got something in life, and you want something, but the system is unwieldy and does not move, you can appeal to the system by speaking their language, which is risk-avoidant. The mental health care system is risk avoidant, so if you are saying 'I'm going to commit suicide', the system comes into action.. (psychiatrist R2)

Although respondents indicated that in their opinion the cause and meaning of impulsive suicidality differ from the cause and meaning in case of a request for EAS, they remarked that also not all EAS requests involve an authentic wish to die. Respondents described how a request for EAS might also have different meanings:

People are exploring how they can get their way, and yes, people with a lot of experience in the mental healthcare as a patient know that you can scare a psychiatrist with questions about life and death. They can assure themselves of special attention to that. But whether you should give that

attention, or go along with that line of thinking, takes professional skill to find out. (psychiatrist R4)

That happened multiple times, that is the same process that I had in the elderly home, that it is more of a question for improvement of the quality of life and care and attention, than it is directed at the end of life. (psychiatrist R1)

It was indicated that most patients who are suicidal are ambivalent until the end, whereas someone with a consistent and well-considered death wish is not:

We know that about suicidal people. In the majority of cases, there is ambivalence until the end. And whether that is ambivalence (...). It can be that you have your reasons to want to die, but also have fear and are afraid of dying. With your reason you want to die, with your heart you are afraid. Those are two different instruments, you could say, that go against each other. So that is also ambivalence. (...) But you often see that people who are suicidal do things in very mixed states.. (psychiatrist R4)

Physician-Assisted Death as Less Traumatic

Suicide was considered to be a complicated, violent, and lonely way to die:

If someone jumps in front of a train, that is an extremely harmful way to die, or don't die, because I also saw someone whose legs got ripped off after jumping in front of a train. That was horrible. There is so much violence in it, it's the violence that makes it so unpleasant. (GP - R17)

That you offer an alternative. Suicide is a very unpleasant intervention for the patient, for themselves, it is a very lonely road to take. (psychiatrist - R5)

EAS is, however, considered less traumatizing for the patient and his relatives, and it provides a possibility to say goodbye:

It (i.e. suicide) is horrible for the bereaved, they are left with a lot of questions and guilt. And it is also hard on the therapists. In short, it burdens the environment. And I think that euthanasia offers a better alternative for that.

I: Why?

R: Because you discuss the problem in the preliminary phase, the patient feels taken seriously, treatments are discussed seriously. Family is involved, in general. So, the end doesn't come as a surprise. And there are no, in the best case, questions left and the goodbye can be experienced in a much better way. The grieving process, well, it precedes the euthanasia. So I think it is a more humane way to die than suicide.. (psychiatrist - R5)

Treatability of the Condition

Another factor that distinguishes suicidality from EAS is the treatability of the condition. This respondent indicated that suicidality is considered treatable, while in the case of EAS the situation is without the prospect of improvement:

I: We were discussing the difference between suicidality and a lasting wish to die, how to differentiate and whether that difference is relevant.

R: Yes, it is very relevant, because it revolves around the question 'is it without prospect of improvement'. Because with suicidality, as a part of the disease, it is by definition not untreatable, because it is treatable. Actually, that is very important, that if someone continues to be suicidal despite you having done everything you can, that distinction [i.e. between suicidality and a lasting wish to die] becomes relevant, because you have done everything you possibly can. (GP - R13)

Consistency of the Death Wish and the Suffering

A final important difference was the fact that with EAS, the patient has a consistent death wish as a result of persistent suffering:

I: I believe I already asked, but what about the difference between suicidality and a lasting death wish, you would call in a psychiatrist?

R: Yes, I can imagine that I would do that. And, how consistent is someone, that is something I would find very important. And how much the image varies. If you talk to someone multiple times, maybe there are moments in which I think ‘Well, someone’s mood is pretty okay’, or it seems to go better. Or does someone stay very consistent in his suffering? (GP - R15)

Discussion

We have conducted this study to gain insight into how Dutch psychiatrists and general practitioners differentiate between suicidality and EAS.

It seems that physicians distinguish between impulsive death wishes and considered death wishes. Impulsive death wishes are not seen as justified reasons for EAS and should be treated. Moreover, it matters whether the death wish is consistent over time and whether the physicians qualify the death wish as a symptom of the disease and therefore as a part of the psychopathology, or as a consequence of the disease (but not part of it), as is the case for somatic diseases. If the death wish is seen as part of the psychopathology, EAS will be less conceivable for the physicians. Another important factor is whether they think the death wish is treatable or not. If so, the patient is not seen as a candidate for EAS. Those whose death wish is seen as a consequence of their disease (but not a symptom of it), for instance, because they feel exhausted after having coped with their difficulties for years and years, and whose wish is irremediable, are seen as potential candidates for EAS. Their death wishes are compared to

‘balance suicides’, or ‘rational suicides’. The physicians indicated that the option of EAS offers a dignified ending: death by EAS is less traumatic for the patient and their environment.

These criteria tie in with the due care criteria in the Dutch euthanasia law, which demand that the death wish is well considered, meaning the patient does not merely have the capacity to choose, but is able to reflect on his wish to die. Two of the other criteria also seem to play a great role, and to be interconnected: the irremediableness and the unbearableness of the suffering.

Regarding the well-considered death wish, when patients use their death wish as a way to provoke attention from the therapist, or even as a form of blackmail, as an appeal to improve the quality of mental healthcare, or when it arises out of an emotional response, it is hard to see these as well-considered death wishes. These are, as commonly is said, ‘cries for help.’ Despite this, it is argued that wanting to end one’s life can be a rational choice also for psychiatric patients.(9, 10, 13, 14) The decisional capacity is not affected all the time in all patients; some may have periods in which their capacity for understanding, reasoning, and communicating is intact. We believe that although certain psychiatric disorders can increase the risk of incapacity, this does not mean that all patients with psychiatric disorders should be considered incapable of making rational choices concerning their own death.(15) The other two criteria for EAS in the Dutch law relate to the suffering that the patient experiences, and demand that it is without the prospect of improvement and unbearable. This of course excludes patients for whom treatment is expected to improve their suffering. This is completely in line with what the interviewees stated, that if there is still the possibility of improvement, EAS should not be an option.

However, there also seems to be a group of patients whose death wish may well be part of their disease and at the same time the cause of

their irremediable suffering (i.e., the chronically suicidal patients). In these cases, physicians seem to struggle with judging how voluntary and well considered their death wish is, i.e., what the influence of the psychopathology is. Even if the death wish is part of the psychopathology, the patient is heavily burdened. These patients suffer extensively as a result of their psychopathology and from their persisting wish to die. It is the chronicity of the wish to die that is an important part of the unbearable suffering, and it is unsurprising that physicians struggle with this group.

We wondered whether EAS can be a justifiable option in the case a patient is chronically suicidal, suffers unbearably, and without the prospect of improvement, but cannot reflect well enough upon his death wish anymore because it is so entangled with his psychopathology? It is clear the physicians struggle with this group. First of all, we need to make clear that the patient does need to request EAS, we are not discussing a category of patients who cannot make a request due to their condition or do not want EAS. The question then is whether it is acceptable to lower the threshold for the ‘well-considered and voluntary’ criterion in some cases. The suffering of these patients is undeniable, and after several (or even many) failed treatments can be considered as untreatable. If we stick to the demand that the patient should be able to reflect on his death wish, and that the death wish should be well considered, EAS would not be possible. However, if the patient clearly suffers so unbearably and their situation is without treatment options, we suggest it is worth considering that the physician may plead force majeure as he or she can have good reasons to perform EAS, because it is the only option left to end the patient’s suffering. Although controversial, we would think this could provide a humane solution for patients who suffer unbearably and who are without the prospect of improvement from psychiatric illnesses.

Strengths and Limitations

To our knowledge, this is the first qualitative study that covers the question about how physicians view the relation between suicide and physician-assisted death. In-depth insight into this topic is of meaning for the debate around EAS, as it is an important consideration for doctors with regard to the acceptability of EAS. A limitation of this paper is the fact that the relation between suicidality and physician-assisted death was only one of the topics covered in the interviews, and not the main focus of an entire study. This could have led to a limitation in answers. Another limitation is the fact that the interviews were held by two interviewers, RP and NS. Although NS was trained by RP to do the interviews, this could have led to a difference in questioning.

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Chapter 5

Feeling Seen, Being Heard: Perspectives of Patients Suffering From Mental Illness on the Possibility of Physician-assisted Death in the Netherlands

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Abstract

Physician-assisted death (PAD) for patients suffering from a mental illness is allowed in the Netherlands under certain conditions, but is a very controversial topic, mainly discussed by ethicists and physicians. The voice of the patient is rarely included in the debate, so we know little about what their views on the topic are.

We aim to understand the views of patients with mental illness and wish to die with regard to the possibility of PAD in the Netherlands. The data for this qualitative study were collected through 21 in-depth interviews with Dutch patients who have a wish for PAD as a result of suffering from a mental illness.

We identified four themes in relation to the meaning of PAD for the patients suffering from mental illness and wish to die. These themes are: 1) Autonomy and self-determination, 2) ending the suffering, 3) recognition, 4) a dignified end-of-life.

The option of PAD for patients suffering from mental illnesses was considered of great importance to the patients who have a wish to die. We highlight the importance of 'recognition' for the situation of the patient, as this could lead to new perspective. We argue that psychiatrists need to reflect on providing this recognition in earlier phases of treatment; taking seriously and discussing a wish for PAD in treatment is beneficial to patients. It provides space for the patient to discuss their wishes, and could cause them not wanting to die anymore.

Introduction

Physician-assisted death (PAD) remains a very controversial topic (the term ‘Medical Aid in Dying’ (MAID) is also used, predominantly in Canada and the US). Few countries in the world allow PAD under certain conditions, and the Netherlands is one of these countries. The Dutch euthanasia law has regulated PAD since 2002, and allowed for PAD in case of a medical condition and if physicians act in compliance with the criteria of due care. These criteria can be found in box 1.

Patients suffering from mental illness are not excluded from eligibility for PAD, if their physician can comply with the due care criteria. Since the enactment of the law, the number of patients that received PAD based on suffering from mental illness is small, but increasing. Before 2008, mental illness was not registered as a separate category, but from 2008 to 2019, the number of cases rose from 0 to 68 (with a peak of 83 in 2017) (1)

Dutch physicians are reluctant to perform PAD in case of mental illness (more so than for PAD in case of somatic conditions), and psychiatrists are becoming more reluctant over the years.(2, 3) Most requests are received and performed by Expertise Centre Euthanasia (formerly known as End-of-Life Clinic).(2, 4) To guide physicians, various guidelines were drafted to provide clarification on how to handle a request for PAD from patients suffering from a mental illness, and on how to interpret the criteria of due care. The Regional Review Committees (RTE) and the Dutch Association for Psychiatry both issued guidelines on how to deal with a PAD request by a patient suffering from mental illness. (5, 6) These guidelines state that in these cases, a ‘second opinion’ should be given by a physician specialized in the condition of the patient, over and above the second-opinion already mandatory by law (SCEN consult). Points of discussion in the debate include the difficulty of interpreting the criteria of due care in case of mental illness, the complexity of establishing whether the death wish is part of the psychiatric disorder (7, 8), the assessment of mental capacity (9), irrational beliefs held by the

patient about chances of recovery (8, 10) the vulnerability of psychiatric patients, and their need for protection (8, 11, 12), and the concept of hope in treatment (13, 14). While scholars discuss these issues, the voice of the patient is rarely heard.(15) Therefore, we set up a study that investigates the views of patients suffering from mental illness, who have a wish for PAD.

Methods

We held 21 in-depth interviews with patients who suffer from mental illness and who have a wish for PAD. These interviews were conducted between November 2019 and July 2020. We used a topic list that can be found in box 2.

One researcher (RP) conducted all the interviews. Because of the situation around Covid-19, 4 interviews were held through video-calling, but the remaining 17 could be held face-to-face, in conformity with the rules issued by the Dutch government. The researcher has a degree in Psychology and Philosophy. She had considerable experience with interviews from doing other studies. A psychiatrist from the project group with experience in evaluating PAD requests of persons suffering from mental illness was on standby for coaching RP. They for example discussed how to ask questions, how to handle suicidal remarks or how to deal with an emotional respondent.

This study was evaluated and approved by the medical ethics committee (METC) of the Amsterdam UMC. To create conditions that were both safe for the respondent and the researcher, we asked the respondents to choose a care provider whom we would inform of his/her participation. We only shared that the respondent was going to participate in the study, and that we would contact the care provider if needed. The content of the interview remained confidential. We emphasized that respondents could always contact the researcher in case this was needed. Some respondents did so after the interview, to tell the researcher that their request was granted. No follow-up of participants was performed after

the interview. The interviews were held at the location of the patient's choice and lasted between 30 minutes and 2 hours. Patients signed an informed-consent form, that included statements on confidentiality and the voluntary character of participation. The patients who were interviewed via video-calling were read the informed-consent form and agreed verbally.

The protocol of this study was evaluated and approved by the METC of the Amsterdam UMC.

Respondents

Respondents were selected through purposive sampling, and were selected using these criteria: they were above 16 and had a wish for PAD because of the suffering from their mental illness. We wanted to yield a broad variety of experiences, so we did not select based on age or status of the request. We excluded patients who also suffered from somatic illness, or who were involuntarily admitted to a psychiatric hospital/facility. After 21 interviews, data saturation was reached as the last interviews did not yield any new information, and the inclusion was stopped. We interviewed mostly females (16) who were between the ages of 50-70 years old (12). The main diagnosis was a mood disorder, but many respondents had multiple psychiatric diagnoses. In addition to suffering from a mood disorder, respondents often suffered from traumatic events in their past.

Almost all respondents suffered from their mental illness for more than a decade (even respondents who were 30 years or younger). Most respondents were still in the process of evaluation of their PAD request (11), but we also interviewed respondents with granted requests (4) or with a denied request (2). Others were 'on hold' while still in treatment, or were on the waiting list of Expertisecentre Euthanasia.

We recruited the respondents through patient federations and the Dutch Dying with Dignity Foundation (NVVE). The researchers wrote a

call, to which potential respondents could respond; we did not actively approach potential respondents individually. The call was initiated by the Amsterdam UMC, and only distributed by the NVVE and patient federations.

Data analysis

All interviews were transcribed verbatim by a third party, who had signed a confidentiality statement. One interview was lost due to technical problems, which means that 20 interviews were included in the analysis. Analysis of all interviews was done by RP, and methods and results (the code trees and themes that were identified) were discussed with the supervisors of the study (SV and DW). SV also read two interviews, to check whether the interviews were undertaken correctly.

We carried out thematic analysis, and coded inductively (codes were identified and code trees were created). Analysis was performed with the use of a qualitative coding program: MAXQDA2020.

Results

PAD can take two forms in the Netherlands: ‘euthanasia’ and ‘physician-assisted suicide’. Euthanasia means the administration of life-ending drugs by a physician at the patient’s request and physician-assisted suicide is when a physician prescribes and provides life-ending drugs to the patient, at their own request, to self-administer. In the interviews, we use the term ‘euthanasia’ for both, because this is the most commonly used term in the Netherlands.

We identified broadly four themes concerning the meaning of the possibility of PAD for persons suffering from mental illness. These themes were 1) autonomy and self-determination, 2) ending the suffering, 3) recognition, 4) dignified end-of-life. We also asked respondents about how they experience suicidality concerning PAD. These themes will be discussed below.

Autonomy and self-determination

'I think it is really important that it is a possibility. What I said before, you did not choose to be here, so why can't you decide yourself when to get out of life. 'That's not possible here', what do you mean? You can choose about everything yourself, but not that? And yes, what I said, I am very much in favor of being able to do that. Not only for me, some people are even worse off than me.' R5 (request status: 'on hold')

Respondents stressed that they consider it important to be able to make decisions about their end of life. They indicated that they wanted to decide whether or not they die, and when and under what conditions their death should take place. Some considered themselves to be constantly living for others, and therefore found self-determination even more important:

'I'm very busy with that in my mind, that in this, others are not as important as I am. All my life I have been taking others into account, whether they liked it or not, whether it turned out well or not, half of it is meant well but does not come across like that. But I do have the feeling that...that I can choose myself in this.' R3 (request status: 'denied')

Ending the suffering

'And I thought about whether to apply [i.e. for PAD] for months, because I have wanted to die all my life. I have so much sadness, and am in so much pain, I cannot take it anymore, I am tired, exhausted, I have to fight every day so hard to get through the day, to get to the next day. I am tired, I do not want to do this anymore.' R9 (request status: 'has not made official request yet')

Although it was stated by some respondents that they just wanted to die, most respondents indicated that they did not necessarily want to die, but that the life they live is just not bearable anymore.

Respondents mentioned that they had been thinking about the decision to request PAD for a long time, and concluded that fighting their mental illness was just too much, and that they could not take it anymore. PAD was considered to be a way out of the pain and suffering that respondents experienced.

While some respondents wished to end their suffering as soon as possible, others considered PAD an option in case the suffering became even greater in the future. The option of PAD in case nothing works anymore would give peace of mind to the respondent and could potentially even help in their treatment.

R: 'I called the End-of-Life Clinic, (...) and they said that it [i.e. requesting PAD] was pointless, don't even bother to try.

I: Okay, and how do you feel about that?

R: It is frustrating. I think, it would help me psychologically...in my treatment, psychologically it would help me a lot when it is always a possibility. In case it won't work anymore, if you think it won't work anymore. It always gave me a lot of peace of mind to find out, at the time, to find out how to kill myself, if I would. I believe it gives you a certain peace of mind to know you do not have to do it anymore in case it is really finished, if you believe that nothing works anymore.' R11 (request status: 'discusses request with GP')

When asked what made the suffering so unbearable and impossible to deal with, respondents indicated that there was not just one reason; it was a convergence of reasons. Although the symptoms of the mental disorder played a role, respondents also mentioned other reasons that made their suffering unbearable. These reasons were often related to relations with other people; patients felt lonely, unable to feel a connection and/or have meaningful relations with other people:

R: And just, not wanting to do anything, nothing yields pleasure. And it has been the case, for a very long time, that I...well, no intimacy of whatsoever, that has never developed. I have been together with my partner for 27 years (...) but it does not come to me, I do not feel it. Also with friends, that is very difficult, if friends for example say to you that they like seeing me or talking to me, or do something together with me...I always had the feeling, from a young age, like 'that is not true', like it is not right, that they rather spend their time with someone else.' R8 (request status: 'granted')

In addition to this, respondents did not want to feel like a burden to others, which they sometimes did. Also, they felt as if their life was without meaning or goals, which left them feeling worthless and empty. Another important reason related to the unbearableness of the suffering was that they considered their suffering to be without an end. This respondent explains how the fact that the suffering has to go on for such a long time makes it unbearable.

'Nothing is left, really, nothing. And I cannot live with that. Maybe that is different for someone else (...) but for me that is too much. (...) If you cannot develop yourself, cannot evolve, and the only thing is sadness and misery. (...) I just want that to end, I believe it is enough like this. And yes, to me it is always so weird that with euthanasia, not necessarily with mental suffering, but with most people that receive euthanasia, these are patients in the terminal stage of their disease, often cancer patients. And I always find that a bit lame, because they get to hear that they have 3 more weeks to live, and that is not without a prospect of improvement to me, because it is 3 weeks. If somebody would tell me that this would take 3 more weeks, I would easily get through that.' R21 (request status: 'request is being evaluated by own psychiatrist')

Recognition

Some respondents acknowledged that even though they did have a wish to die, their request for PAD was meant as a ‘cry for help’, they wanted to be seen and heard, as they felt that no one did so.

R: I think, I see now, in hindsight that the euthanasia request was some sort of cry for help. ‘Up to here, and not further’. ‘And please do something, listen to me about what is going on’. So I can get on for a while, until that wish appears again. I mean subliminal, under the surface’

I: Latently

R: Yes, it is latently present’ R17 (request status: ‘discusses request with GP’)

Recognition was thought of in two different ways: recognition of their situation and their suffering, and recognition in the form of an affirmation by the physician that their suffering is indeed unbearable and without a prospect of improvement. Recognition of their suffering and wish to die as a result of that suffering was of utmost importance to some respondents. This perceived recognition gave them peace of mind, which paradoxically could create the possibility of not wanting PAD anymore. Recognition was considered not only important to the patient himself, but also for their environment.

‘So it would, that is the most important thing to me, that it would offer me the possibility to, for the people who have distanced themselves from me because it got too complicated, to reassure them, like, ‘okay, it goes along the official ways’. ‘Apparently, there is nothing we can do for her anymore’. (...) But if doctors say so and want to guide me through it, then it is not only me who is saying it, but also the expert. That is an important back-up that I have, so that it can happen in a normal way. That would be the nicest for me, yes.’ R21 (request status: ‘request is being evaluated by own psychiatrist’)

They explained that they considered that they might have a ‘tunnel vision’ about their own situation, and to have a physician to ‘objectively’ evaluate their situation meant that they could view their suffering as indeed unbearable and without a prospect of improvement.

I: ‘Okay, and what does it mean to you to be able to make an euthanasia request?’

R: Well, it gave me quite some peace of mind, because, well, that is what I feel, that it is nice to have some sort of approval. That you, well, because you have been in the midst of it for such a long time, and that causes you not to be objective anymore, with regard to the unbearableness and irremediableness of it. And it is nice that they can check independently whether that is correct or not. Because if you decide it all on your own, then you are stuck with the feeling of ‘that is how I decided it, and I believe it is unbearable and irremediable, but perhaps it is not’. And that approval, I think for me is very important. Maybe not for others, but I think that is part of my character. So it might not be the case for others, but for me it is very nice to receive that confirmation.’ R7 (request status: ‘granted’)

Many respondents indicated that they did not feel heard by the mental health care system (GGZ) in the Netherlands; they felt that the quality of the GGZ was lacking. This respondent for example mentioned how she felt a victim of the mental healthcare system:

R: When I was 17, I ended up in the mental healthcare system

I: How did you experience that, how did that work out for you?

R: Well, I would not recommend it to anyone to enter the mental healthcare system.

I: Okay...

R: I say this with a smile, but it has been one big nightmare. After ten years, the past ten years...well, the system is just, I feel a victim of it, to be honest, more than I was helped by them. With a sick management

culture and jargon, and perverse incentives because of the power of the health insurer, nothing is right about the entire system. And people blundered with me, all those years. And I, especially since 2016, 2017, I had to say 'listen to me finally, take me seriously!' And that was a turning point for me, that I got the feeling like 'you are not with me, you are my enemy now'. R21 (request status: 'request is being evaluated by own psychiatrist')

Reasons for speaking negatively about the GGZ were the following: they did not feel as if the GGZ took responsibility in taking up a request for PAD, as the treating psychiatrist left this to EE. Treatment did not seem accessible for those with a wish for PAD and they felt they were denied therapy-options because this was considered by the mental-healthcare professionals as incompatible with a wish for PAD. Others state that the GGZ focuses too much on curation and too little on personal recovery from the psychiatric condition. Others complained about the lack of continuity with regard to therapists; that aftercare is not well taken care of, and that protocols are too rigid and that mental health care is not accessible enough.

Some respondents indicated that they did not want to die, but just wanted to talk to the physician to feel heard by them. It was suggested that not feeling heard by mental-healthcare professionals can result in starting a conversation about PAD.

'Yes, and maybe, maybe it is also...well, that I just want to talk to those people, maybe also to just feel heard. If you look deep into my heart, I do not want to die...and yes, the process can take up to a year. And you can always say 'no', but I just wanted to start the trajectory. (...) I just want to talk to those people.' R1 (request status: 'request status: 'waiting list')

It seems as if in some cases, not feeling heard by mental healthcare professionals can provoke the patient into a wish to discuss PAD.

However, this does not mean that the patient is not suffering from their mental illness; it shows how important it is to the patient to feel recognized in their suffering by mental healthcare professionals and what the patient is willing to consider and discuss to feel heard.

Dignified end-of-life

An important theme that we identified involved references to a ‘dignified’ or ‘humane’ end-of-life. Respondents provided us with different aspects which, to them, are essential to a ‘dignified’ or ‘humane’ end-of-life. The first aspect of a dignified death was that PAD provided an ‘open and honest’ way of dying, involving others and without the risk of legal persecution for the relatives.

‘I believe it is a dignified way to say goodbye. (...) And that there are people that grant me to do it like this, with relatives, completely open, in a way that is 100% sure. That they won’t intervene, (...), that you don’t have to do secretly or illegally. That it can happen in such an open and honest way. Yes, that is a big difference with other ways.’ R8 (request status: ‘granted’)

A second aspect was the prevention of suicide. Suicide was perceived as insecure and inhumane, for both the patient and others. Not succeeding while trying to commit suicide, with all the possible consequences (for example disability) was something that the patient wanted to avoid, for himself, and their loved ones.

‘But if it does not work out...(...) there are a lot of consequences, for myself, because I damage my body, or cannot do things anymore and life will become even more unbearable. You break things, cut things up that cannot heal anymore or will be painful, that you make you suffer even more. So that is a hard consideration. And, I don’t have to take that step with an euthanasia request(...) It doesn’t matter really how they kill me,

as long as they do, and that the wish is accepted, that they don't stop you.'
R19 (request status: 'request is being evaluated by EE')

Suicide and PAD

As suicide was considered not to be a part of a dignified or humane death, many respondents spoke about how they wished to prevent this from happening. One of the reasons that physicians struggle with PAD for patients who suffer from mental illness, is that they have trouble distinguishing suicidality from a wish for PAD. Our respondents clearly distinguished 'impulsive suicidality' from PAD. They recognized that impulsive suicidality was part of their psychopathology.

R: 'But the attempts were in a period when I was depressed

I: Okay, and was it the sombreness that made you suicidal?

R: Yes, and the voices. The orders and not wanting life anymore.

I: So the voices gave you the order to kill yourself?

R: Yes, they have only one goal: to destroy me, they are only negative.' R1
(request status: 'waiting list')

Respondents experienced impulsive suicidality as different from a request for PAD; suicidality, although sometimes also planned, was perceived as an act out of desperation and crisis; a state of mind in which there is no more room for other thoughts or control over actions. A wish for PAD was seen to be more well-considered.

'Being suicidal is often despair and panic. And of course that you want it, but at that moment when you have those thoughts and want to carry it out, or think about that, then you are at a low. While with a euthanasia request, of course you also have those moments, it can be any moment, it can happen any time, but the euthanasia trajectory is very long, and there are moments that you are not suicidal anymore, that you are just left with 'I am done with life, I want the suffering to end, and to die' That can be a

difference with the euthanasia trajectory.’ R19 (request status: request is being evaluated by EE’)

In addition to the decision-making process being more well-considered in the case of PAD, another distinguishing factor identified was that PAD was perceived as more humane than suicide, because the way that the death wish was carried out was more ‘friendly’, also for others that otherwise may be confronted with a gruesome suicide.

R: ‘Most of the time, suicide is very gruesome. And euthanasia is possible, but from my perspective it is so much more respectful and friendly. So, there is a difference, being suicidal, and ending your life is different from euthanasia.

I: And is the main difference then the way it is performed, like, suicide is gruesome and euthanasia can be peaceful?

R: Yes, a humane manner. A quiet, humane, loving and respectful way.’ R20 (request status: request is being evaluated by EE’)

A final difference between suicide and PAD mentioned, was that a request for PAD comes more ‘from the core’ than suicidality does.

4.13 I: ‘How do you see that relation? How does that work for you? Is it the same, or different?’

R: Suicide is different from a wish to die, I think. Suicidality tends towards crisis and panic, and a wish to die is more ‘deep’.

I: Okay, and with ‘deep’ you mean?

R: From your true core, that you cannot take it anymore...the wish to die.

I: Yes.

R: And suicidality can be more random.’ R13 (request status: ‘granted’)

Also, the term ‘self-euthanasia’ was also mentioned, as a sort of intermediate form between impulsive suicidality and PAD. ‘Self-euthanasia’ was not only considered a less impulsive form of suicide,

but had more distinctive elements to it: there is no physician involved who has to decide over the patient's fate, self-euthanasia can be carried out when the patient wants it, one can involve relatives and loved ones, and it is less aggressive than suicide as it is carried out with for example medication or the helium-method instead of jumping in front of a train or off a high-rise building. Other respondents did not consider self-euthanasia a proper alternative to PAD, as it is not sure whether one will definitely die from self-euthanasia; there is the risk of failure, and relatives may be confronted with legal issues.

'What I see as a difference for myself, because I saw this also in my surroundings, in therapy and also in work, is the acute impulsive suicidality, taking action impulsively, and that is not the case with me. My brain does not work like that. With me, it would always be a planned, well-prepared action. So in that sense, and that is a term that I found at the NVVE [i.e. Dutch Dying with Dignity Foundation], it would be more like a 'self-euthanasia' than a suicide, in an impulsive form that you see a lot when people tried multiple times. That is not the case with me. (...). For me, that is the difference. So there would be a suicide wish in the sense that I rather die today than tomorrow, but I would never leave impulsively and leave everyone with the misery that brings along.'

R8 (request status: 'granted')

Discussion

We conducted this study to gain insight into the question of what the possibility of PAD means to patients suffering from mental illness who have a wish to die. We identified four themes: autonomy and self-determination, ending of the suffering, recognition, and a dignified end-of-life. The respondents considered it very important that they can choose a humane death, to end their suffering or to prevent a gruesome suicide or an unsuccessful suicide attempt that may cause disability. Although not all patients necessarily wish to die, the fact that their suffering is so unbearable and does not seem to have a foreseeable end is too much for them to handle. They choose death over living their lives like this. The unbearable nature of the suffering has several elements that altogether make it unbearable to the patient: suffering from the symptoms of the mental illness, not having satisfying relationships, difficulty giving meaning to life, and perceived endlessness of the suffering. Verhofstadt et al. found the same domains (medical, intrapersonal, interpersonal, societal and existential) in their study on the unbearable nature of suffering of patients with mental illness and a request for PAD in Belgium.(15) Dees et al. found that also in the case of somatic suffering, existential or psycho-emotional components contributed significantly to the unbearable nature.(16) This shows that regardless the condition that people suffer from (mental or somatic), unbearable nature is a complex phenomenon. Healthcare primarily focuses on symptom-reduction, but if we take into account that unbearable nature is not only determined by medical issues, one can question whether we should turn to healthcare in order to solve these issues?’

We also showed that patients make a clear distinction between suicidality and PAD; although both revolve around wanting to die, suicidality is recognized, also by them, as being a part of the psychopathology and as a state of despair. From the perspective of the patients, the difficulty in differentiating between suicidality and a request for PAD, seems to be a theoretical problem, and not a problem that they recognize or experience.(17)

What is remarkable is that across the themes we identified, ‘peace of mind’ plays a significant role in relation to PAD. For some, the possibility of PAD in the future is enough to make it possible for them to continue living for that moment (and it may even help them in therapy). Thienpont et al. already showed that a significant number of patients continue living after they received approval from their physician to receive PAD.(18) We now established that not only a granted request may bring in a new perspective that helps to continue living, but that the presence of the option of PAD in itself already creates peace of mind, and that it may even prevent suicide because it helps patients in their treatment and to keep their mind off of suicide. Having the option of PAD and being able to discuss this with a physician is thus very important to the patient. We want to highlight this point, as it has been argued that physicians should not discuss PAD with patients as this would take away hope from the patient.(10, 13) Patients say they benefit from discussing their wish to die and PAD request with their physician. This is also reflected in the fact that patients attach importance to ‘recognition’. Respondents feel acknowledged if the physician takes their request for PAD seriously and discusses it with them., which possibly could lead to new perspectives. This provides a strong argument in favor of discussing PAD with a patient. In our view, discussing a death wish with a patient should be a part of treatment, even if the physician him/herself does not want to perform the PAD. The treating physician knows the patient best. In addition, being able to talk about your inner world and wishes is an essential part of psychological treatment. It is problematic if a patient cannot talk about their wish, because the physician is not open to it; it ignores a big part of the patient’s life and longing. Also, talking about the death wish can open up the possibility of new perspectives on treatment. If the patient is assured that his/her wish is taken seriously, our study shows that the patient can experience enough ‘peace of mind’ to think about new possibilities. This could increase the willingness of the patient to try out new treatment options that could lead to an improvement of their situation.

Remarkably, respondents mentioned that they wished to receive this recognition specifically from their mental healthcare provider, and not for example from their spouses, friends or other important persons in their lives. This study could not answer the question of whether they did or did not wish for recognition from their immediate surroundings, or whether they already did. Fact is, they do explicitly mention this wish in relation to their mental health-care provider. It could be argued that acknowledging a patient's suffering is always part of a good treatment. The question remains whether a 'formal' discussion about PAD is the right or only way to provide it. Maybe, if mental healthcare providers take death wishes seriously in an earlier phase of treatment and are willing to discuss these, patients do not need to ask for PAD in order to receive that recognition.' In our view, mental healthcare in the Netherlands (in collaboration with patients) needs to reflect on how to better meet the needs of the patient. Recognition of their suffering and discussing their death wish in an earlier phase of treatment could perhaps prevent patients with mental illnesses from considering PAD.

Conclusion

We believe that the main take-home message from this study is that it is beneficial to patients to discuss their wish for PAD with a physician, because it provides them with recognition and may even cause them to not want to die anymore. We would suggest that the patient's own treating physician takes up this role. It seems many of our respondents only were able to discuss their death wish with a physician from EE. Discussing a death wish should be part of treatment, even if the physician decides he/she does not want to perform a PAD request

Strengths and limitations

One of the strengths of this study is that we included the voice of the people that this debate revolves around: patients that suffer from mental illnesses and who have a wish to die. It would be paternalistic to only talk about the patient, and not with the patient. Persons with mental illness are often excluded from debates as they are perceived to be especially vulnerable or not capable to discuss their experiences. Although we took precautionary measures in order to provide safety for both the patient and the researcher, partly on our own initiative, partly on request of the medical ethics committee, these were not needed during or after the interviews.

The general response from the respondents was that they finally had a voice, that they were listened to, that they found meaning in being listened to and that it was important to do this research. One respondent even indicated that because of the interview, she could find meaning again in her life and wanted to do something with her experience as a person who has a mental illness; her story had worth.

A limitation of this study is that it could be the case that respondents who responded to our call are patients who are disproportionality dissatisfied with the mental healthcare system in the Netherlands, and wanted to talk to us to express that dissatisfaction. This could have led to

a bias in our results. Another limitation is that the coding was performed by only one researcher (RP). Although she has considerable experience with interviewing and coding from other studies, this could have led to a bias in our results. We limited this by discussing code trees and themes with both supervisors. Also, two transcripts of interviews were read by one supervisor (SV).

The variation in the patients' phases of decision making with regard to their PAD wish could be seen as a limitation to the study. We recruited respondents in various stages of their trajectory for the following reason: there are not that many patients with mental illness and a PAD wish who also want to share their experiences, and this has provided us with the opportunity to include a substantial amount of respondents. In addition, although they differ in phase, their wishes remain the same, namely to receive PAD because they suffered from a mental illness. A final limitation could be that we did not ask for marital status, occupation, educational level or other characteristics, which could complicate the replication of the study.

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Chapter 6

What About Us? Experiences of Relatives Regarding
Physician-assisted Death for Patients Suffering From
Mental Illness: A Qualitative Study

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Abstract

Physician-assisted death (PAD) for patients suffering from mental illness is legally permitted in the Netherlands. Although patients' relatives are not entrusted with a legal role, former research revealed that physicians take into account the patient's social context and their well-being, in deciding whether or not to grant the request. However, these studies focused on relatives' experiences in the context of PAD concerning patients with somatic illness. To date, nothing is known on their experiences in the context of PAD concerning the mentally ill.

We studied the experiences of relatives with regard to a PAD request by patients suffering from mental illness. The data for this study were collected through 12 interviews with relatives of patients who have or had a PAD request because of a mental illness.

We show that relatives are ambivalent regarding the patient's request for PAD and the following trajectory. Their ambivalence is characterised by their understanding of the wish to die and at the same time hoping that the patient would make another choice. Respondents' experiences regarding the process of the PAD request varied, from positive ('intimate') to negative ('extremely hard'). Some indicated that they wished to be more involved as they believe the road towards PAD should be a joint trajectory. To leave them out during such an important event is not only painful, but also harmful to the relative as it could potentially complicate their grieving process. Professional support during or after the PAD process was wanted by some, but not by all.

Introduction

Dutch law has regulated the practice of physician-assisted dying since 2002. Physicians may be exempted from prosecution if, and only if, they meet the legal criteria of due care. Relatives of patients who request PAD have no legal role before, during or after the process. We do, however, know that family members often are active participants in the decision-making process of PAD in case of somatic diseases. In general, the family of the patient plays an important role for physicians when deciding whether to grant a PAD request.(1, 2) The well-being and future bereavement of the family members are often taken into account when physicians decide whether to grant the PAD request or not.(3) Whether relatives should be involved during a PAD trajectory is debated. Various authors claim that the practice of PAD needs to be understood in terms of a patient-physician-family triad, instead of just the patient and the physician, because physicians often already engage relatives anyway.(1, 2) On the other hand, physicians need to make sure that the request is not made under the undue influence of relatives, so that the request can be considered voluntary.(4) The majority of PAD requests are made by patients whose suffering is caused by a somatic illness, such as cancer.(5) The Dutch euthanasia law, however, does not exclude patients who suffer from mental illness. PAD requests on the grounds of suffering from a mental illness are mostly performed by Expertisecentrum Euthanasie (EE) (formerly known as the 'End-of-life Clinic')(5, 6) They often receive the more complex requests, and patients for whom a mental illness is the underlying reason for requesting PAD are considered complex by physicians.(7-9)

Empirical research in which the relatives participate as a research subject are relatively scarce(1) and former studies on relatives and PAD mainly focused on relatives of patients who suffer from somatic illnesses, revealing that these relatives are often involved during PAD trajectories. Therefore, we set up this qualitative study to examine the experiences of the relatives of patients that requested PAD because they suffer from

a mental illness. In this study, the term ‘relatives’ refers both to family members, and also to close friends of the patient.

Methods

We chose to address the questions by using qualitative methods, as this would provide the best opportunity for respondents to elaborate on their experiences and would lead to rich data.

We held 12 interviews with relatives from patients who had requested PAD because of their suffering from a mental illness. These interviews were held between June 2019 and June 2020. The interviews had an open character but were structured by the use of a topic list, with topics such as: how do they experience the death wish of the patient, how does the PAD request impact them, do they support the PAD request and why, how do they experience the procedure of the PAD request, are they involved during the procedure and how do they experience this (lack of) involvement, what do they think about how the physician handled the PAD request, how do they feel about the decision of the physician, are they in need of support during or after the trajectory, where would they like to find this support?

One researcher (RP) conducted all the interviews. Because of the situation around Covid-19, 3 interviews were held by video-call, but the remaining 9 could be held face-to-face.

The interviews were held at the location of the respondent’s choice and lasted between 1 and 3 hours. Respondents signed an informed-consent form, that included statements on confidentiality and the voluntary character of participation. We also promised confidentiality on information given about the patient and his situation. The respondents who were interviewed via video-call were read the informed-consent form and agreed verbally.

This study did not need ethical approval of an ethics committee under Dutch law (WMO).

Respondents

We recruited the respondents through the Dutch Dying with Dignity foundation (NVVE). We wrote a call, that was published in the newsletter of the NVVE, to which potential respondents could respond. These relatives had actual experience with their relative requesting PAD, so for them it was not just a hypothetical situation. Unfortunately, we could not find more than 12 respondents that wanted to give an interview. Characteristics of the respondents can be found in box 1. One person was not interviewed, but responded through email about the PAD of her son. Passages of this email were also used in this paper.

Data analysis

All interviews were transcribed verbatim by a third party, who had signed a confidentiality statement. Analysis of all interviews was done by RP, and methods and results were discussed with the supervisors of the study (SV and DW). We used open coding and inductive analysis to identify overarching themes. The codes were based on the content of the interviews. Analysis was supported by the use of a qualitative coding programme: MAXQDA2020.

Results

In the results, we will discuss the following themes: when a relative wants PAD, the process of requesting PAD, and support for the relatives.

If a relative wants PAD

Although the interviewed relatives eventually supported the decision of the patient requesting PAD, they often did so with ambivalent feelings and their support was often the result of a process. Respondents mentioned various aspects of their process; they understand the wish of the patient, but also hoped for another solution. Understanding

the suffering of the patient, or ‘compassion’, was an aspect that the respondents often mentioned. They saw how hard life was for the patient and how deep their suffering was. They understood that this was just not bearable anymore for the patient: they wanted the patient to have peace. This respondent describes the ambivalence of understanding the wish to die on the one hand, and wanting to grow old with the patient on the other:

‘And I understood her suffering, I understood her burden and wish, but I wanted to grow old with her. We fought some fights about that during the summer. (...) After that, we sort of went on a two-track approach, she went on the track of the Expertisecentrum Euthanasie and I went on the track of wanting to keep her. So, ‘I will follow, but I won’t go along’... and that led to more friction and clashes. So eventually I had to make the choice, either I keep doing this and I lose her, or I get beside her and walk with her, still hoping I could turn her. I did the last thing. But that got me in an exceptional position. (...) During that time she informed a couple of people, some friends, who had all kinds of questions about it and came to me with those questions. And I had to defend her, or explain her, while I did not want this to happen at all.’ R6-partner

In some cases, the respondents understood the wish to die from their own experience, as they also suffered from a mental illness and had had periods in which they wished to take their own life. They explained that their own experience with wanting to end their life as a result of a mental illness contributed to a deeper understanding of why the patient wished to end their suffering, but also led to their hope that the patient would also be able to recover. Respondents on the one hand understood the patient’s wish to end their life, but they feared that they would do so by means of a gruesome suicide. Respondents wished that the patient did not have to die because of suicide, because they wanted them to have a humane and peaceful death, also without possible legal consequences for the relatives.

Finally, some respondents spoke about their belief that the patient should be able to make decisions about their own life, and that the respondent thought that the patient was capable of doing so. Some respondents believed the patient still had potential to recover from their mental illness. They believed that more or a different treatment for the patient's mental illness would result in the patient wanting to continue his life. Another aspect of the struggle with the wish to die of the patient was related to religious beliefs of the respondent. This respondent for example speaks about how his Christian beliefs do not allow for a self-chosen end-of-life:

'And I come from a Christian background. The idea to end her life, actively end her life, was not done in our family culture. From the perspective of the Bible...well, you get a death sentence when you try to end your life. And people who end their own life, they cannot be buried in the cemetery, they used to be buried next to the cemetery. (...) It is sort of a desecration of the ground if you end your own life. So that cultural, or religious determination, or the little space that you have as a human being...whether that is because you are gay, or mentally ill, if you could not bear life anymore and would take your own life, you were condemned to an eternal burning in hell, so to speak.' R5 - brother

The process of requesting PAD

All respondents were involved with the patient's request for PAD in one way or another. Some respondents only discussed the PAD wish and request with the patient. Others were also present during conversations with the physician. Some were even present at the moment that the patient died. Not all respondents were satisfied with the extent to which they were involved in the PAD process, some mentioned how they were not present during conversations with physicians even though they had wanted to be, because they wanted to understand how the patient and physician viewed the situation. Respondents who were friends with

the patient understood why they were not involved in a way that for example a partner or mother was. Not all patients wished their relative to be present during process, e.g. because the patient and relative had a disturbed relationship. Not being a part of the conversations between patient and physician was problematic for some respondents, because they felt they could offer valuable information about the situation and wanted to express their view on the matter. Also, being part of the process was considered by the respondents to be better for the relative, because they believe that it should be a joint trajectory.

Some respondents felt left out by the physicians of Expertisecentrum Euthanasie, even though they were present at the conversations the physician had with the patient:

I: And do you have the feeling that you were involved in the process?

R: By her: yes. Not by Expertisecentrum Euthanasie. I was there during all conversations, except that one conversation with her own psychiatrist, all other conversations were here at home, so I was present at all of them.

I: okay.

R: But that is also a thing of the team [i.e. of Expertisecentrum Euthanasie], I understand it at the one hand, but not on the other. They are here for the patient, and not for the relatives that go with that. That is the idea that they gave me.

I: And how did you feel about that?

R: I cannot judge whether this is how it normally goes, or just with this team. (...) Let's say that I can imagine that for some survivors it would be nice. Yes. (...) would I have wanted that? Yes, I actually do. It is still something that you do together, this trajectory.' R8 – partner

I: Did you feel involved by Expertisecentrum Euthanasie?

R: No, No. I goes past you. They never asked us anything. Partly, I understand it, because it has to revolve around the one making the request, but I do think 'well, it is a road that you walk together', in the best case of course. (...) If you ask me, I understand that it goes like this, but I think

that for the survivors or relatives it would be better if it is a more joint trajectory, if that is possible within the family ties.’ R3 – mother

Some patients made the choice to keep the PAD request secret from other relatives. Respondents mentioned how keeping the PAD request secret from other relatives can provoke feelings of unsafety amongst families:

‘Eventually after two years, I was able to accept it, and my brother was also able to accept it, but my sister was very troubled by it. And my other brother, who was very much against it, believed it [i.e. PAD] just should not have happened. So everyone had their own position. But fact was that it was a huge blow for everyone, that was unbalancing for all of them. And I mean, people who consider this [i.e. PAD] should not keep it a secret for so long, because it is horrible for the relatives, it undermines your feeling of safety. You can just hear out of the blue that your brother or sister is going to die a month later...and is getting help doing so, the Dutch government, mental healthcare facilities are helping with that. ‘it should not get any crazier’ those thoughts are present. If you are not part of that process (...) if you do not do that, it is a blow for the relatives that leaves them insecure for a very long time. R5 - brother

A lack of involvement was not always perceived as problematic, as some respondents indicated that it is the patient who can make the decision about whether and how their relative should be involved, and not them. It depended on the relationship with the patient whether the respondent found this problematic or not. For example, friends did leave more room for the personal decision of the patient. Family or partners were more inclined to be troubled by a lack of involvement.

Some respondents experienced the process of requesting PAD and the trajectory with the physician as hard, lonely or bizarre. One mother wrote to us in an e-mail (she was not interviewed) that it took a lot from her and her child to stay alive until the PAD was performed:

'Everything around the self-chosen end-of-life of R. [i.e. name patient] was as he wanted it, but the road towards it was extremely long and hard. There were moments in which R. almost could not hang on any longer and we had to do everything with help, care and support with medication to make sure he would not hurt himself. It was literally keeping someone alive so that he could die with dignity.' - mother

And a partner said:

'And the whole trajectory, well, I think it is bizarre. It is bizarre to stand next to someone who is on a road to death, and longs for death. Who during the process (...) gets a very narrow view, while I did not want to lose her.' R6 – partner

Other respondents described the PAD trajectory in positive terms, such as this mother, who experienced the process as 'intimate':

'R: And you know, it is the worst thing that can happen to you as a parent, and yet I consider myself lucky that it happened like this. I went through worse grieving-processes. I mean, I am not cheering, and it hurts on a daily basis, but I do not want to miss that pain anymore, it is part of it [i.e. her life] now, and it is bearable out of love. It makes you a different person, I hope a better person, I do not know.

I: So it was also a positive experience, even though it was really hard?

R: Yes, absolutely, yes. Very intimate.' R3 - mother

Support for the relatives

Some relatives experienced a sense of burden in having to care for their loved one. Although they loved the patient a lot, and did not wish for him to die, they considered the care to be burdensome. This respondent explains how he experienced less stress and more freedom now that the patient has passed away:

'And I was in peace with that. I thought, if she dies, that will also be some sort of relief, because I also lose a lot of stress and care. I have more freedom to do things again, until Corona happened, because now I cannot go anywhere.' R9 – partner

During the process of PAD, they received support mostly from people in their surroundings. This respondent mentioned how he finds support with friends and neighbours:

'I have good friends in W. [i.e. town] and we have very nice neighbours, they listen to us, offer us things. But I would not have the slightest idea what people could have done. No one can fix the head of M. [i.e. name patient]. So, yes, support, like last Sunday, we went to a good friend of M., we had a reasonable day. Just some distraction, that is the support I need, yes.' R2 - partner

Some found professional help, from for example their general practitioner or a mental healthcare provider. In some cases, the mental healthcare provider of the patient also was a source of support for the relative. They appreciated this a lot, also because the care provider knew the patient.

We asked whether the relatives were in need of more support during the process of requesting PAD, perhaps also organized in a more structured way; for example by means of peer-support. The respondents reacted differently to this idea: some would have liked this; others did not want this at all. Reasons for wanting an organized structure were that they could find recognition and information from others. On the other hand, respondents indicated that peer-support would be too much, as they were still taking care of the patient. Also, as the patient was so well-informed about the trajectory, they could share the information with their relative, hence there was no need for more information.

We asked the respondents whether they received some type of professional support after the patient died, whether they would have liked to receive support, and in what form. Most respondents mentioned that they sought support with friends and family. Some respondents indicated that they sought psychological treatment themselves, or participated in peer-support groups with a focus on grief (not necessarily related to PAD)

For some respondents, finding support with friends and family was enough, but some were in need of more support. This respondent for example talks about how his brother-in-law (the partner of the patient) would have liked to hear something from the treating physician of the patient:

R: There is one thing I have noticed, not during the process, but after it ended. The relatives, my brother-in-law never heard anything, never, not a phone call, no visit, nothing.

I: From the physicians, you mean?

R: From the treating physician, who treated his wife for 15 years.

I: Okay, yes.

R: While he walked on eggshells for years, always with a fear of 'is she still there?' and 'how is she?'. So it was horrible for him, his wife that he loved, that he was married to for 30 years, to lose her like this. (...) And a sign of sympathy from the mental healthcare system, yes, he needed that, and he missed that a lot.

I: Yes.

R: Why did they not reach out to him? That is the only thing that I can think of: 'professionals should pay more attention to that, the aftercare'"

R5 – brother

We also asked whether a peer-support group for the moment after the PAD was performed would be an option for the respondents. For some, a peer-support group would not be an option, as they indicated that they

do not want to listen to other people's stories. So, although peer-support groups are not for everyone, some liked the idea of help with overcoming or coping with the grief and loss of the patient. This respondent spoke about how she would like to have support to fill the void and create some order in the chaos that the death of the patient leaves:

I: And what would aftercare mean to you, what are you in need of?

R: Structuring, structuring within the context of...well, structuring the chaos. And how it is best arranged, I have to think about that. But this is something really intense, whether it [i.e. PAD] happens or not. It is a measuring moment, that is how I see it, a milestone that absorbs everything. And after that, there is nothing, nothing, just chaos. And I really look up to that. (...) it concerns me. I think 'yes', I would like that [i.e. aftercare]. I think that is a good thing. But I cannot think of something other than a black hole, and the chaos. That it [i.e. aftercare] is important in some form or another.' R10 – mother

Discussion

We performed this study to investigate the experiences of relatives of patients with a PAD request as a result of suffering from a mental illness. We show that the process of requesting PAD and the following trajectory comes with ambivalence. It involves understanding the wish to die, but at the same time hoping that the patient would make another choice. Aspects of understanding the wish to die were compassion, respect for autonomy, having experience with the same mental illness as the patient, and the fear that the patient will commit a gruesome suicide. On the other hand, respondents had personal beliefs (such as religious beliefs) or beliefs about the situation of the patient (perhaps they can get better with more or different treatment?) that conflicted with understanding the PAD request. Respondents' experiences regarding the process of the PAD request varied, from positive ('intimate') to negative ('extremely hard'). These results may be relevant for other areas in the world where either

PAD for patients suffering from mental illness is already permitted (such as Belgium), or heavily debated (Canada).

One of the results that stood out was the ambivalence all respondents experienced with regard to the PAD request; not one simply just agreed with the wish of the patient. This ambivalence is a known phenomenon, that is also present in the context of PAD for patients suffering from somatic diseases.(1) Although respondents indicated that they felt ambivalent, they did not mention that they suffered from this ambivalence. What they did suffer from was that the physician and patient did not take their views into account when evaluating the request. Some respondents did not understand why the physician would help the patient to die, and were very much against it; they were not part of the trajectory. Keeping the PAD a secret from other relatives meant a huge emotional blow for all involved. It seems important to the relatives that the PAD is a joint trajectory. This relates to a second important result of our study: although most respondents were involved in the process in one way or another, some of them were not satisfied with how much or the way they were involved. Multiple respondents mentioned that they did not feel engaged by EE during the process. Although they understood why not, they did wish for more involvement, as they preferred that the process towards PAD should be a joint trajectory. We asked EE what their policy is on involving relatives when evaluating PAD requests. Their statement can be found in box 2.

So, although EE explicitly has the intention of involving the relatives of the patient during the PAD process, our results show that relatives still sometimes do not feel involved (enough). Engaging relatives in the PAD process seems to have a positive effect on the grieving process of the relatives.(10, 11) General practitioners and nursing home physicians often do so, and physicians in general describe a positive experience with involving the family members during a PAD process in context of somatic illness.(12, 13)

This may raise the question whether it is the responsibility of the physician to involve the relatives and organize support for them. Expertisecentrum Euthanasie (EE)- that handles most requests from patients suffering from mental illness – assumes no task in taking care of the relatives. These physicians are not the treating physician of the patient and this may complicate the communication with the relatives. We expect similar patterns in other countries: even if PAD for persons suffering from mental illness is allowed by law, practice will show that most physicians are reluctant to evaluate and perform such requests.(14) If a country does not have an institution like EE to handle requests, it is possible that it comes down to a few physicians who are willing to grant those requests. Although EE calls the relative 6 weeks after the PAD is performed, they do not support the relative during or after the trajectory. Our study shows that relatives want to be taken into account when the patient's wish is evaluated by a physician. It is not so much that they want to impose their views on patient and/or physician; they want to be acknowledged and to be a part of a trajectory. This is an understandable wish, since relatives often have been part of the patient's life for a long time (sometimes even from birth) and care for the patient a lot. To leave them out during such an important event is not only painful, but also harmful to the relative as it could potentially complicate their grieving process. In end-of-life care generally, bereavement care of the family at the end-of-life is an important aspect.(15, 16) Taking care of relatives after the PAD trajectory could be a task for the general practitioner, or another professional care giver. However, most respondents relied upon friends and family for support. Also, follow up care is not necessarily medical care. Perhaps it would therefore be better suited to not rely upon general practitioners or other care professionals for this care, but to organize support groups for relatives; as some mentioned that they could benefit from this. It would be greatly appreciated by some of our respondents if there would be a peer-support group especially for relatives of patients that have a PAD request because they suffer from mental illness.

Strengths and limitations

A strength of the study is that this is the first time relatives of patients with mental illness and a PAD request have been investigated.

Other studies mainly focused on relatives of patients with somatic illness. We succeeded in finding these relatives, and getting them to speak openly about this emotionally charged issue. Another strength is that we conducted a qualitative study, with in-depth interviews, which provided respondents to elaborate on their views and experiences. A final strength is that all the respondents had actual experience with a patient requesting PAD, so they did not discuss hypothetical situations.

A limitation of the study is that we only found relatives through the Dutch Dying with Dignity Foundation (NVVE). This may have led to selection bias, as members of the NVVE often have a positive attitude towards PAD in general.

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Chapter 7

General Discussion

General discussion

Reflection on the main research findings

This thesis discusses physician-assisted death (PAD) in the context of mental illness. The literature cites concerns with regard to PAD in general, but specifically for patients with a mental illness, such as concerns about decisional capacity of the patients, problems physicians experience with the evaluation of the central legal criteria of due care (the physician must be convinced that the request is voluntary and well-considered, and that the suffering is unbearable and without prospect of improvement), and issues with (counter)transference, hopelessness and vulnerability.(8, 10, 12, 30-32) Most of these studies are however non-empirical medical-ethical or quantitative in nature and do not provide us with in-depth information about experiences and considerations of the stakeholders directly involved (physicians, patients and relatives) We wanted to gain insight into the practice of PAD for the doctors involved, patients suffering from mental illness and their relatives.

We addressed three main questions:

- 1. What are the views and considerations of the physicians involved in requests for assistance in dying from a person suffering from mental illness (psychiatrists and general practitioners)?*
- 2. What are the experiences, views and considerations of persons suffering from mental illness with regard to their own wish for assisted dying?*
- 3. What are the experiences, views and considerations of the relatives of persons suffering from a mental illness that have (or have had) a request for assistance in dying?*

In order to answer the abovementioned questions, we performed various studies: an interview study with 17 psychiatrists, a questionnaire

among 500 general practitioners, an interview study with 20 general practitioners, an interview study with 21 patients suffering from mental illness who have a wish for PAD, and an interview study with 12 relatives of patients with mental illness who have a wish for PAD.

Below, I will discuss the first and second research question together. After that, I will turn to the third and final question.

Our studies show that physicians have many considerations with regard to PAD in context of mental illness, regardless of their own position in the debate. Even physicians principally in favour of the practice of PAD for persons with mental illness, could see that there are also problems attached. The interview study with psychiatrists, shows that the main difference between being a proponent or opponent of the possibility of PAD in case of a mental illness lies in the way psychiatrists view the nature of mental illness. On the one hand, some physicians view mental illness as fundamentally different from somatic illness. For them, the very nature of mental illness makes it impossible to evaluate a PAD request; a death wish is always a symptom of psychopathology, the criteria of due care are therefore more difficult, some even said impossible, to evaluate and mental illness is wrought with more diagnostic and prognostic uncertainty than somatic illness. On the other hand, there were psychiatrists who only saw a gradual difference between the two. They argued that patients who suffer from mental illness are equal to patients suffering from somatic illness in relevant aspects; they can also suffer unbearably and without prospect of improvement and can have a rational wish to die. Equality between patients in these regards, to them, also implies equality in access to PAD.

However, psychiatrists were also of the opinion that there is a societal commitment to suicide prevention, and it is therefore important to differentiate between suicide and PAD.⁽⁷⁾ The death wish of the patient with a PAD request can be a symptom of the mental illness, and in that case should be considered and treated as suicidality. We studied if and

how physicians distinguish between suicidality and a wish for PAD. Our studies show that physicians who are involved in PAD trajectories of patients with mental illness, psychiatrists and general practitioners, differentiate between three types of death wishes: 'impulsive suicidality', 'chronic death wishes' and a 'rational wish to die'. An impulsive suicide was characterized as a temporary wish to die, often related to emotional events, and a symptom of the psychopathology of the patient. Chronic suicidality was characterized as being more persistent and frequently occurring, but still a symptom of the psychopathology of the patient. A rational death wish was characterized as a well-considered persistent wish to die, unrelated to emotional events, and not an expression of the psychopathology. According to the interviewed physicians, PAD should be an option only if the patient has a rational wish to die. Physicians can relatively easy identify an impulsive suicide, but they considered discerning between chronic suicidality and a rational wish to die to be complicated. To distinguish between these categories, psychiatrists and general practitioners evaluate whether the death wish is seen as part of the psychopathology, whether it is consistent over time, and whether they consider it treatable. On the basis of the interview data, we argued that physician-assisted death can be justified also in some cases in which the death wish is part of the psychopathology, as the patient's suffering can also in those cases be unbearable and irremediable. Physician-assisted death in these cases may remain the only option left to relieve the suffering.

Another example of a difference between mental illness and somatic illness in relation to PAD is the factor 'life-expectancy', also explicitly mentioned in our study amongst general practitioners. To them, the fact that a patient with mental illness is often relatively young, and not expected to die from his/her mental illness, is an important factor for being cautious about PAD requests. The majority of PAD requests involve patients suffering from cancer, and in these cases, the patient is likely to die within a relatively short period of time. The certainty

that comes with terminal somatic illness seems to take away some fear of misinterpreting the criteria of due care (predominantly the criterion of ‘no prospect of improvement’). Also, they indicated that helping a relatively young person to die feels unnatural to them. Although understandable, we argued that another aspect remains underexposed; because patients suffering from mental illness often have decades to live, their suffering could go on for all that time. Although physicians retrieve hope from the fact that their patients have a relatively long life ahead of them, the patients view this differently. Patients in our study indicated that the fact that they have a relatively long life-expectancy only adds to the unbearableness of the suffering. This is also illustrated by the fact that some patients postpone or retract their PAD request after their request got granted; knowing that they have a way out relieved their suffering. (18) So, refusing a PAD request on the basis of life-expectancy may keep open the possibility of recovery, but may also prolong and add to the suffering of the patients.

The insecurity that comes with factors such as diagnostic and prognostic uncertainty, and with the concern about how to differentiate between suicidality and a rational death wish, influences whether physicians are open to the option of PAD in case of mental illness, or not. Physicians showed that part of their reluctance also lies in difficulties in interpreting the criteria of due care. In particular the criterion of ‘irremediability’ seems troublesome; how can a physician decide that treatment options are exhausted? Irremediability can be understood as having no treatment options left, but can also be understood as the absence of ‘hope’; a state of mind of the physician and patient.(10, 14, 33) A systematic review by van Veen et al. shows that a clear answer to the question of irremediability cannot be found, and that a certain level of insecurity is inevitable.(34) It seems as if physicians will always have to deal with a state of ‘not knowing’ when confronted with a patient with a PAD wish resulting from mental illness, especially concerning the evaluation of the ‘irremediableness’ criterion of the law. We saw that for some physicians this meant that they would never perform PAD as they want to be sure

about all criteria of due care. For other physicians, the question is how to deal with the insecurity when faced with a PAD request. So, how can physicians deal with a state of 'not knowing', that inevitably comes with a request for PAD from a mentally ill patient?

Verhofstadt et al. already showed that unbearableness and irremediableness are interconnected; hopelessness is an important factor when it comes to unbearable suffering.(15) What becomes clear in our study amongst patients, is that for patients it is of great importance that the physicians at least discuss the option of dying; this can even result in the patient gaining new perspectives. Thienpont et al. showed that a number of patients continue living after they received approval to receive PAD; the option of PAD gave them enough strength and hope to continue their lives.(18) Also, a study by Expertisecentrum Euthanasie (EE) found that 20% of the initial requests for PAD by persons with mental illness were retracted. The explanation that EE gave was that being taken seriously in their wish to die created enough peace of mind and caused patients not wanting PAD anymore.(4) Our study confirms this idea, and adds that not only a granted PAD request can induce hope, also the mere discussing it with a physician can create 'peace of mind'. This is an important finding, because it is argued by other authors that discussing a PAD wish with a patient should be avoided, as this would take away hope.(10, 13) To come back to the question what physicians can do about the insecurity concerning treatment options and hope, the answer is talk to their patient about their wish to die. Not only can treatment options only be discussed by understanding the perspective of the patient (are treatment option reasonable to the patient?), the mere fact that a physician discusses the wish to die with a patient and takes them seriously may cause the patient to choose life instead of death. Also, the patients in our study understood the complexity that comes with a request for PAD, they do not view this as an easy decision either for themselves or for the physician. Talking about an existing wish to die is an essential part of treatment; it provides space to discuss the inner world of the patient, and to recognize their suffering. The study amongst

patients highlights the importance of recognition, and indicated that patients do not always feel recognized by physicians that work in the mental healthcare system (GGZ).

The psychiatrists we interviewed also mention problems with regard to the mental healthcare system; they raise concerns with regard to long waiting lists, reduced quality of treatment, a focus on short-term treatments that leaves patients who need long-term care without appropriate treatment options, and a dominant 'biological view' on the nature of mental illness. The suboptimal functioning is an issue that both patients and doctors raise. We need to ask the question why the GGZ does not provide a solution to the suffering that these patients experience?

One answer might be that mainstream mental healthcare services often seem to be focused on limitations that are associated with mental illness, and not on possibilities for living a good life with mental illness.(35) Another concept of what mental health is, and what mental healthcare should aim for could improve this. Huber et al. already proposed a new conceptualization of health. In this view, health should not be defined as the presence or absence of illness, but as the ability of persons to deal with physical, emotional or social challenges. 'Positive health' is a broad concept, consisting of six dimensions: bodily functions, mental well-being, existential meaning, quality of life, social and societal participation and daily functioning.(36) In the context of mental healthcare, a 'recovery-oriented model' would be in line with this new conception of health. In recovery-oriented mental healthcare one strives for a 'way of living a satisfying, hopeful, and contributing life even with any limitations caused by illness.'(37) It does not necessarily include symptom-remission, but it is seen as a 'process of personal growth and development, and involved overcoming the effects of being a mental health patient, with all its implications, to regain control and establish a personally fulfilling, meaningful life.'(38, 39) This surely deserves further investigation.

However we should not be blind to the option that also a recovery oriented framework may not provide a solution to the suffering of these chronically ill patients. For some patients a recovery-oriented model could induce false hope about recovery. Some patients simply will not recover from their mental illness, and the question can be asked ‘when is enough, enough?’. If we take the perspective of healthcare for somatic illnesses, it can of course be said that we also cannot cure all somatic illnesses. However, we do have palliative care to relieve the suffering and improve the quality of life of patients. The World Health Organization defines palliative care as an approach that improves the quality of life of patients and their relatives when faced with a life-threatening illness by preventing and relieving suffering of physical, spiritual and psychosocial nature.(40) A patient does not need to be in a terminal stage of their illness; palliative care is appropriate for all stages of a chronic and/ or ultimately life-threatening illness. It is an approach that ‘improves the quality of life of patients and their families in facing the problems associated with life-threatening severe persistent mental illness through the prevention and relief of suffering by means of a timely assessment and treatment of associated physical, mental, social, and spiritual needs.’(41) Palliative psychiatry acknowledges that some patients have an incurable mental illness, offers support and integrates various aspects of well-being, uses a team approach and will enhance quality of life and may also positively influence the course of the mental illness.(41) It is worthwhile to mention that palliative care in psychiatry does not exclude other treatment approaches; it is compatible and consistent with principles of the recovery-model of psychiatry.(42, 43) However, a clear conception of palliative psychiatry is lacking, and it is unsure how it should be applied in mental healthcare.(44)

Now the questions presents itself what the differences are between recovery-oriented care and ‘palliative psychiatry’. One difference could be that in the context of palliative psychiatry, you accept that the patient will also not recover anymore (and may even decline further)

and you commit to quality of life instead. Another difference could be that a recovery-oriented model still is directed at leading a productive life, and reintegration in society. In my view, the curative framework, the recovery-oriented model and palliative psychiatry can be seen as complementary to each other and can be seen as a continuum (with some overlap). The question remains where the option of PAD can be placed on that continuum. Although there are initiatives in the Netherlands like Active Recovery Triad (a long term mental healthcare model)(45), palliative psychiatry is not yet thoroughly developed and implemented, as the same time the option of PAD exists for patients suffering from mental illness. I consider this to be problematic, because it leaves patients without options to choose from. For a significant number of patients suffering from severe mental illness, curation is not within reach; their mental illness will always be part of their lives.(46) This does not have to be an insurmountable problem; it is possible to live a satisfying and meaningful life even with mental illness. However, we do need proper care for patients who wish to choose life with severe mental illness instead of PAD. Having to choose between a curative framework (that does not work for all) or PAD is a poor choice. We need to provide enough good options to choose from; that way the patient can make an informed decision not based on a lack of (palliative) care, but because none of these options provided enough alleviation of their suffering.

Whether a patient needs to have received palliative care before he/she can turn to PAD is a next question. I would say that that depends on how one balances different aspects. One could argue that the patient should have tried all possible solutions available (including palliative psychiatry) to make life more bearable before one may request PAD. On the other hand, if one more strongly values the principle of autonomy, one could say that it is up to the patient whether he/she considers alternatives reasonable. In somatic care, we also do not expect a patient to have undergone all possible curative treatments and palliative care before he/she can choose PAD. To make a distinction based on the illness of the

patient (somatic vs. mental) seems to be discriminatory and arbitrary, so I would be inclined to argue that also in case of mental illness, patients may have the option to say ‘no’ to more treatment or care. However, as argued earlier, we do need more palliative care options for patients suffering from mental illness so that they can choose life with proper care.

Now we turn to the third, and final, research question of this thesis:

What are the experiences, views and considerations of the relatives of persons suffering from a mental illness that have (or have had) a request for assistance in dying.

So far, I have discussed issues concerning the physician and the patient, and this is representative for the position of the relative during a PAD trajectory: they are involved, but have no official role. As they are involved in and affected by the PAD request of the patient, we decided that it was worthwhile to include their voice in this thesis. Relatives are often ambivalent with regard to the wish for PAD, and a PAD request, but wish to offer support to the patient. They find it important that the patient is comfortable with the amount of involvement, but relatives also indicated that they think it should be a joint trajectory towards a possible PAD. This would be beneficiary for them, and it would help them in their grieving process. As it is now, the relative often does not feel included by the physician who handles the PAD request; some indicated that they felt left out. This may raise the question whether it is the responsibility of the physician to organize support for the relatives, but this would be difficult. Expertisecentrum Euthanasie - that handles most requests from patients suffering from mental illness – has no task in taking care of the relatives. Although they call the relative 6 weeks after PAD, they do not support the relative during or after the trajectory. The focus lies on the patient, which is justified by a focus on the principle of autonomy. However, the principle of autonomy does not need to exclude taking into account the views and preferences of relatives. Autonomy

may be thought of in mainly two different ways: as a relational and non-relational concept. A non-relational way of understanding autonomy focuses much on independence and control, whereas a relational way includes an understanding of a patient's personal views and relationships. (47, 48) Although it goes beyond the scope of this thesis to thoroughly discuss these two ways of understanding, it is important to understand that these two ways influence how we today view the involvement of others on medical decision-making such as PAD. It seems physicians mostly have a non-relational view on autonomy; relatives feel left out during a PAD trajectory. However, from a relational stance towards autonomy, one could argue that physicians do need to take the relatives into account. Respect for the wishes of the patient could also implicate respecting the wishes of the relatives, as they are often connected. From a relational autonomy perspective, relationships with relatives are a big part of the autonomy of the patient. In that light, one could argue that physicians also need to take the relatives into account when confronted with a PAD request: it is part of taking care of the patient. On the other hand, involving relatives in a trajectory towards PAD could be problematic. For example, what if the views of the relatives contradict the views of the patient? I would say that our study shows that the problem is not that the patient and relative necessarily have different views (although this could of course occur). Although ambivalent, interviewed relatives could understand the patient's wish. They did not want the patient to die, but they understood their suffering and why they chose to request PAD. The important thing that our study shows is that relatives want to be taken into account when the patient's wish is evaluated by a physician. It is not so much that they want to impose their views on patient and/or physician; they want to be acknowledged and to be a part of a trajectory. I would say that this is an understandable wish, relatives often have been part of the patient's life for a long time (sometimes even from birth) and care for the patient a lot. To leave them out during such an important event is not only painful, but also harmful to the relative as it could potentially complicate their grieving process. In case of somatic

illness, physicians already often include the patients' family during the decision-making process of PAD. In general, the family of the patients plays an important role for physicians when deciding whether to grant a PAD request or not.(19, 20) I see no reason why, in case of overlapping views and if the patient wishes so, a relative should not be included in the trajectory in case of a PAD request based on mental illness. Of course, it proves to be more difficult when views conflict. I would say that, ultimately, it is up to the patient to request PAD and to decide if a relative may be included. Persons may make autonomous decisions about their end-of-life and about who they wish to be a part of it. Although unfortunate and undesirable from the perspective of the relatives, in the end it is and should be a patient-physician affair.

Now, I will turn to the ethical justification for PAD in context of mental illness.

The four normative foundations of the Dutch euthanasia law are: the physician's duty to relieve suffering (compassion), respect for autonomy, dignity and protection of life.(49) Are the ethical foundations different for mental illness, compared to somatic illness?

I think we would all agree that also in case of mental illness, patients may suffer severely. Mental illnesses are considered to fall within the medical realm, hence are the responsibility of physicians. Relieving suffering is one of the primary goals of medicine, so physicians have the duty to relieve suffering (compassion). Whether mental illness should be considered a medical condition is debated. Foucault has already shown that the way we think about mental illness is subject to change; up to the Renaissance we thought about madness in terms of the supernatural. This changed into a view that related madness to (a lack of) morality, and ended with what is now widespread in psychiatry: a medical view on mental illness.(50) This is also what some psychiatrists mentioned; they indicated that the dominant view in psychiatry is still the 'biological' view, which can influence the way the patient views him- or herself and

the possibilities of future improvement. Although the ‘medical model’ is now prevalent in psychiatry, other models exist, such as for example the psychological model or the social model of mental illness.⁽⁵¹⁾ Which model (or models) explains mental illness best is beyond the scope of this thesis. For now, patients with severe mental illness turn to physicians for care, and it is up to the physician to provide care and relieve suffering. Whether respect for autonomy can be a foundation for PAD in case of mental illness is debated; some authors raise the concern of decisional capacity in relation to mental illness.^(8, 52-54) Even though some authors address the risk of incapacity, they also admit that mental illness should not be equated with incapacity.⁽³¹⁾ Hewitt et al. show that patients with mental illness can have a rational wish to die, even in case of schizophrenia.^(55, 56) Dembo et al. argue that cognitive distortions may also occur in patients without mental illness, and hence that the existence of cognitive distortions alone cannot justify excluding patients with mental illness from PAD.⁽⁵⁷⁾ What becomes clear is that although mental illness risks causing incapacity, it is not the case that all patients with mental illness are incapable of making rational decisions about their wish for PAD. In my opinion, this risk, then, justifies evaluating capacity extra carefully, but it would not justify a priori excluding all patients with mental illness from PAD. Respect for autonomy was also considered of importance for the patients. Patients indicated that the option of PAD meant that they themselves could make decisions about their own end-of-life. They indicated that they wanted to decide whether or not they die, and when and under what conditions their death should take place. Respect for dignity is also important to patients suffering from mental illness. The patients from our study discussed ‘loss of dignity’ in relation to how they died, and not for example in the context of their life and suffering. Respect for dignity is a multi-faceted and complex concept, and can be understood in different ways. It goes beyond the scope of this thesis to discuss all these interpretations, but Pans shows that in the context of the Dutch euthanasia law, the Regional Review Committees Euthanasia (RTE) often understand ‘loss of dignity’ as a concept related

to physical deterioration and care-dependency. According to Pans, this is remarkable, as the literature on dignity often relates the concept to the decline of mental functions.(49) Only in case of dementia, the loss of mental functions seems to be clearly linked to loss of dignity. Pans, however, does not explicitly raises the issue of dignity in relation to suffering from mental illness. For the patients I interviewed, PAD offers the possibility of dying in an ‘open and honest way’, without the possibility of legal persecution for their relatives. To them, PAD could prevent a gruesome suicide, which could be traumatizing to others, or -in case the suicide is unsuccessful- can cause disability.

A fourth, and final, normative principle that underlies the Dutch euthanasia law is the ‘right to protection of life’. The right to protection of life is a leading principle with regard to all medical treatments. Some argue that in case of PAD for patients suffering from mental illness, patients’ lives should be protected because they are especially vulnerable. The main focus of papers concerning vulnerability is on decisional competence of patients.(8, 12) Above, I concluded that a risk of incapacity due to mental illness may justify taking extra precautionary measures, but cannot justify excluding all patients with mental illness from PAD. Therefore, PAD may also be a legitimate option for them. Still it is in principle forbidden for physicians help a patient die, even if he/she asks for it.(49) The extensive criteria of due care are necessary because of the strength of the principle; only if the physician judges there is a voluntary and well-considered request, and the suffering is unbearable and without prospect of improvement, a physician may assist in death. There are circumstances in which the duty to relieve suffering weighs heavier than the duty to protect life. If confronted with a conflict of duties (protection of life, autonomy and compassion), a physician should act in accordance with the most important interest, and this also holds for patients with mental illness.

Concluding, the normative foundations of the Dutch euthanasia law seem not to be fundamentally different in case of mental illness, compared to somatic illness; the same principles uphold. However, even if we can ethically justify PAD in case of mental illness, the practical identification of those patients who are eligible for PAD remains problematic.

Methodological considerations

This section discusses the strengths and limitations of the research methods used in this thesis.

Both the limitations of the ‘qualitative research methods’ and of ‘quantitative research methods’ will be addressed, but directly below I will discuss some overall strengths of the methods used in this thesis: we included all stakeholders regarding physician-assisted dying for patients suffering from mental illness. Not only did we include the physician’s perspective, but also that of the patient and his or her relatives. We predominantly used qualitative research methods, which provides in-depth knowledge. Also, we performed a mixed methods study with regard to the experiences, views and considerations of general practitioners, thus developing a broad view on this subject.

We made use of a pilot-tested, validated questionnaire that was also used in a previous study amongst psychiatrists and in earlier evaluations of the Dutch euthanasia act. This allowed us to compare results our to these other studies. Finally, confidentiality was guaranteed for all respondents, in the questionnaire and in the interviews. This allowed respondents to freely talk about this controversial, personal and delicate subject matter.

Quantitative research methods

We used a cross-sectional design in the form of a survey in order to answer questions about the experiences of general practitioners with physician-assisted suicide in case of psychiatric suffering. Surveys are often used in health-related professions and are an appropriate

research method for studying human phenomena, such as opinions regarding a subject.(58) However, surveys also have several limitations. A first issue with a survey-study is the high risk of non-response, which could lead to bias in the study results, and can cause problems with validity and generalizability of the findings. Reasons for not responding to questionnaires are often a lack of time and concerns about confidentiality.(59) We took several measures to increase the response rate: we minimized the length of the questionnaire, ensured anonymity regarding the results and also sent a reminder after several weeks. Despite these actions, the response rate of the survey study amongst general practitioners in this thesis was relatively low: 22%. The results of this study were, however, fairly consistent with findings from other studies on the subject.(22, 23)

Another limitation with regard to the use of questionnaires is the fact that they contain predefined questions and answering options. This may lead to misinterpretation of the questions, skipping questions, and a lack of clarity of answers. Respondents also do not have the opportunity to provide answers that are not already predefined. For this reason, in-depth interviews were also held with general practitioners. This has provided us with a more complete picture of what the experiences and views are of general practitioners regarding assisted dying in case of mental suffering.

Qualitative research methods

Not everyone is convinced of the reliability and validity of qualitative research.(60-62) Bias could occur as the researcher plays an important role during the gathering, interpretation and presentation of the data. One of the ways to ensure that qualitative research is reliable, is to have an open and reflexive attitude during the process:

‘Those carrying out qualitative research are an integral part of the process and final product, and separation from this is neither possible nor desirable.

The concern instead should be whether the researcher has been transparent and reflexive (i.e., critically self-reflective about their own preconceptions, relationship dynamics, and analytic focus) about the processes by which data have been collected, analysed, and presented.’ (61)

Can we identify potential influences that could lead to bias with regard to the research conducted in light of his thesis? And if so, how did we make sure we minimized the chances of bias?

One of the important factors is the fact that I myself was not new to the field of mental healthcare. Before I took on the role as a researcher in the field, I saw mental healthcare from the opposite perspective: that of the patient. Besides having a long history of therapy during my teens and adolescence, I also received intensive treatment before and during the course of my research. So, how did this affect my views on the matter and the way I carried out my research? Firstly, I believe it got me interested in the topic of assisted death in case of mental suffering. How someone deals with a wish to die is a question that is not unknown to me and having the opportunity to study the phenomenon from another perspective really connected with what I find interesting. Finishing a PhD thesis heavily relies on continuing to be motivated, and I experienced that connecting on a personal level with the subject matter ensured motivation. A second example of how it affected my research is that I really wanted to include the patient’s voice in the debate. Instead of talking about patients and their experiences, I wanted to talk with them. This has caused me to decide to interview patients with a wish for assisted suicide as a result of their mental suffering. It also helped me to be empathetic to the experiences of the patients that I interviewed. Mental suffering is highly stigmatized and the stigma prevents people from sharing their experiences. (63, 64) By being aware of the difficulties one can experience in talking about mental suffering, I did my utmost to keep a non-judgemental attitude and respond in a caring way, hoping to provide a safe space for sharing.

On the other hand, I had to be careful not to identify with the

respondents too much. I tried to be conscious of the possibility of over-identification with the patients, or bias in the interpretation of my results. During my interviews I had to develop a stance in which I was listening to the respondent, asking the questions, while keeping track of and containing my own (emotional) responses. After each interview, I actively reflected on this process. I also made sure to involve another perspective on the matter by asking my supervisors and a psychiatrist from my research group for advice on how to deal with this. They gave me advice, kept an eye on how the research progressed and discussed the outcomes with me. By means of this reflective attitude, offering transparency about the issue, discussing the results with my supervisors and the psychiatrist from my research group, I tried to minimize the chances of bias in my results.

Implications for practice

In this section I will discuss the implications for practice, and discuss new questions raised.

Although it is not a result of this thesis, it cannot be ignored that we need a solution for the current waiting list for patients with mental illness of Expertisecentrum Euthanasie, which is up to two years.⁽⁶⁵⁾ Having to wait more than two years when you experience your suffering as unbearable is inhumane, and should not be accepted. On the one hand this might mean that we are in need of more physicians who are willing to perform PAD in case of mental illness. On the other hand, we need an understanding of why all these patients see PAD as an option. In this thesis, I conclude that physicians (psychiatrists and general practitioners) need to actively engage in a conversation about a wish to die with their patient (who might already consider to ask for PAD). As said above in relation to the recovery approach and palliative care, we do need to think about what the focus of mental healthcare should be for patients suffering from severe and refractory mental illness. It seems the current curative framework does not provide a solution to these patients.

In light of these conclusions, I suggest the following:

Physicians (psychiatrists and general practitioners) should be trained to evaluate PAD requests from patients suffering from mental illness.

Physicians do not frequently receive PAD requests from patients suffering from mental illness, only almost half of the psychiatrists have ever received such a request, and 4% has ever performed on a request. (3) This could provide an argument for not making PAD part of the general training of psychiatrists and GPs. However, the impact of a request on the physician, the patient and his relatives is great, hence an approach is needed that is characterized by sensitivity and knowledge. By making PAD in case of mental illness part of general training, a physician might feel less unease, and might be more inclined to take up a request themselves, without necessarily granting it. This would mean less pressure on Expertisecentrum Euthanasie and more patients who have their request evaluated by a physician who knows them.

Physicians should actively engage in talking to their patients about a possible wish to die.

Although it is suggested in literature that physicians should not initiate conversations with their patients about their wish to die, because it is supposed to induce hopelessness, my research suggests the opposite. The patients we interviewed appreciate an open dialogue about what goes on in their inner world and wanting to die can be a big part of that inner world. In addition to the fact that it is essential for the patient to be able to talk during therapy about what is going on in their lives, discussing a wish to die may paradoxically create space and peace of mind and thus offer hope and new perspectives on treatment. PAD is not a right of the patient and a physician cannot be forced to grant and perform a request. However, an open conversation about the subject is already helpful to the patient and should –in my view- be part of good care.

For patients with severe refractory mental illness mental healthcare in the Netherlands should focus more on a recovery oriented framework and palliative psychiatry instead of working from a curative framework.

For some patients with severe mental illness, curation is not possible. Focusing on curation could leave them feeling hopeless about the future and could lead them to consider PAD. While there are local initiatives that focus on recovery, some psychiatrists indicated that the mental healthcare system still focuses too much on curation, and too little on recovery. A focus on 'recovery' could help patients find meaning and new perspectives, while still being confronted with mental illness.

Future research

Finally, I will address some ideas about future research, that in my opinion are needed to improve how we can deal with abovementioned issues.

First, I would recommend a study into how persons with mental illness give meaning to their lives after initially requesting PAD. A study by Expertisecentrum Euthanasie shows that 20% of patients with mental illness retract their request after being able to discuss it with a physician. (4) It would be important to study how they continue their lives after initially believing that their suffering was unbearable and irremediable. A similar study could be performed with patients with mental illness whose request was denied by a physician (60% of requests at Expertisecentrum Euthanasie)(4). Although some patients commit suicide after a denied request, most continue living. How do they give meaning to their lives? And, how does this relate to a concept of 'recovery'? If we can understand how patients with severe mental illness and a wish for PAD continue their lives and find meaning again, we could use these results to improve mental healthcare for other patients.

Secondly, a qualitative study into the experiences of physicians with regard to granted and performed requests. Physicians are reluctant regarding PAD for patients with mental illness, and it would be important to find out what the experiences of physicians actually were with evaluating, granting and performing a PAD request. Was it as complicated as many people think, and if so, what made it that complicated? Was the trajectory burdensome for physicians, or not? Would they consider doing a PAD trajectory again, and if not, why not? If we get a clearer view on what issues of physicians are that actually undertook the journey of a PAD trajectory, we might be able to identify issues that can be solved, hence, could make physicians more inclined to consider a request.

A final recommendation would be a study into the possibilities for palliative psychiatry in mental healthcare. What would palliative psychiatry mean in the context of Dutch mental healthcare? Are aspects of palliative psychiatry already in place? Should this be an option for patients with severe refractory mental illness, or not? How should this be implemented?

A clear conception of palliative psychiatry could mean a big step in the direction of good care for patients with severe refractory mental illness. PAD should always be an option only if nothing else helps.

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Summary

Summary

Chapter 1 provides an introduction to the main theme of this thesis, namely physician-assisted death (PAD) for patients suffering from mental illness. In the Netherlands, PAD is not only regulated for patients suffering from somatic illness; patients suffering from severe and refractory mental illness may also request PAD. However, this is a controversial issue, and many raised concerns against the practice. Although physicians have become more reluctant towards PAD in case of mental illness, the number of patients that request PAD has risen during the years. So far, studies regarding PAD for mentally ill patients were predominantly medical-ethical or quantitative in nature and in-depth qualitative studies into the views and considerations of all stakeholders were lacking. We therefore decided to study the views and considerations of physicians (psychiatrists and general practitioners), patients suffering from mental illness who wish for PAD, and their relatives. The main questions that this thesis aims to answer are:

1. What are the views and considerations of the physicians mostly involved in requests for assistance in dying from a person suffering from mental illness (psychiatrists and general practitioners)?
2. What are the experiences, views and considerations of persons suffering from mental illness with regard to their own wish for assisted dying?
3. What are the experiences, views and considerations of the relatives of persons suffering from a mental illness that have (or have had) a request for assistance in dying?

Chapter 2 explores the views and considerations of psychiatrists with regard to PAD for patients suffering from mental illness. It answers the question what reasons psychiatrists give to be in favour or against the practice. We held in-depth interviews with 17 Dutch psychiatrists. Irrespective of their own views, psychiatrists consider both reasons for and against PAD for mentally ill patients. These reasons are of a moral (justice and equality, professional responsibility and compassion), epistemological (how can one determine the suffering is without prospect of improvement), practical, and contextual (mental healthcare provisions) nature. The variety in views seems to be related to a difference in the view on the nature of mental illness. Some psychiatrists stress the difference, whereas others point out the similarities between somatic and mental illness. We argue that these opposing views could be bridged by a more pragmatic view, such as a two-track approach.

Chapter 3 discusses the experiences and views of general practitioners (GP) regarding PAD for mentally ill patients. Can GPs conceive ever performing PAD in case the patient suffers from a mental illness only? What reasons are to support or not support PAD for mentally ill patients? The data for this study were obtained through a survey amongst 500 randomly selected GPs, and by 20 in-depth interviews with Dutch GPs. We show that Dutch GPs are less likely to consider a request for PAD from a patient suffering from mental illness, compared to patients suffering from a somatic illness. Reasons for supporting PAD for patients suffering from mental illness had to do with responsibility, compassion, fairness and preventing suicide. Reasons for not supporting PAD for patients suffering from mental illness related to the scope of medicine, a perceived lack of experience, uncertainties regarding the criteria of due care, and life-expectancy. We argue that by applying a criterion such as life-expectancy for patients with mental illness, the possibility of recovery stays open at the expense of prolonging the suffering and adding to the unbearableness of it.

Chapter 4 provides insight into the relation between suicide and PAD. Do physicians differentiate between suicidality and a request for PAD? We held interviews with 17 psychiatrists and 20 GPs in order to answer this research question. We conclude that the physicians distinguish between three types of death wishes: impulsive suicidality, chronic suicidality and rational death wishes. To discern between the categories, they evaluate whether the death wish is seen as part of the psychopathology, whether the death wish is consistent over time and whether they consider the death wish treatable. Some considered PAD an alternative to a rational death wish, because this was perceived as a more humane manner of dying for the patient and their relatives. However, we argue that PAD can also be justified in some cases where the death wish is part of the psychopathology, as the patient's suffering can also be unbearable and without prospect of improvement. PAD may be the only option to relieve the suffering.

Chapter 5 offers insight into the experiences and perspectives of patients suffering from mental illness on PAD. This study answers the question what the option of PAD means to them. We interviewed 21 patients who have a wish for PAD because they suffered from a mental illness. We identified four themes in relation to the meaning of PAD for these patients. The themes are: a) autonomy and self-determination, b) ending the suffering, c) recognition, d) a dignified end-of-life. The option of PAD for patients suffering from mental illnesses was considered of great importance to the patients who have a wish to die. We highlight the importance of 'recognition' of the situation of the patient, as this could lead to new perspectives and could possibly prevent suicide. We argue that the mental healthcare system in the Netherlands needs to reflect on providing this recognition in earlier phases of treatment, because this could prevent patients from considering PAD.

Chapter 6 addresses the experiences of relatives of patients suffering from mental illness who have a wish for PAD. We were interested in their experiences before, during and after a PAD trajectory. In order to provide us with insight, we interviewed with 12 relatives of patients who have had a PAD request because of suffering from a mental illness. The results show that relatives are ambivalent with regard to the PAD request of the patient. Their ambivalence is characterised by their understanding of the wish to die, while also hoping that the patient would make another choice. Their experiences with regard to the trajectory varied from positive ('intimate') to negative ('extremely hard'). Some wished to be more involved, as they believe the road towards PAD should be a joint trajectory. Some felt left out by the physician who handles the request. Professional support was wanted by some, but not by all, and we suggest that peer-groups could offer a possible solution.

Chapter 7 offers a reflection on the main research findings, methodological considerations and implications for practice and further research. In this chapter I discuss the results from the studies amongst physicians, patients and their relatives, in connection to existing literature. I then discuss the ethical justification of PAD in case of mental illness. The methodological considerations focus primarily on the limitations of the research methods (survey study and interview studies), I furthermore discuss personal experience with suffering from mental illness. After the discussion of the main findings and methodological considerations, I turn to three implications for practice, i.e.: a) physicians should be trained to evaluate PAD requests from patients suffering from mental illness, b) physicians should actively engage in a conversation with the patient about their possible death wish, and c) mental healthcare in the Netherlands should focus more on a recovery oriented framework and palliative psychiatry instead of working from a curative framework for patients with severe refractory mental illness.

Samenvatting

Samenvatting

Hoofdstuk 1 biedt een introductie tot het thema van dit proefschrift; euthanasie en hulp bij zelfdoding voor mensen die lijden aan een psychische aandoening. In Nederland is hulp bij zelfdoding niet alleen mogelijk wanneer een patiënt lijdt aan een somatische aandoening; ook mensen die lijden aan ernstige psychische aandoeningen komen in aanmerking hiervoor. Dit is echter zeer controversieel, en velen uiten hun zorgen hierover. Hoewel artsen steeds terughoudender worden ten aanzien van hulp bij zelfdoding voor mensen met een psychische aandoening, is er de afgelopen jaren een flinke stijging te zien van het aantal mensen dat om deze reden een verzoek doet. Onderzoeken over dit onderwerp waren tot nu toe voornamelijk ofwel niet-empirisch medisch-ethisch ofwel kwantitatief van aard. Kwalitatieve studies naar de opvattingen en overwegingen van alle betrokkenen misten nog, en daarom hebben wij besloten de opvattingen en overwegingen van artsen, patiënten en naasten te bestuderen.

De vragen die ik poog te beantwoorden in dit proefschrift zijn:

- 1. Wat zijn de opvattingen en overwegingen van de artsen die het vaakst betrokken zijn bij verzoeken om hulp bij zelfdoding in het geval van lijden aan een psychische aandoening (psychiaters en huisartsen)?*
- 2. Wat zijn de ervaringen, opvattingen en overwegingen van mensen die lijden aan een psychische aandoening ten aanzien van hun eigen verzoek om hulp bij zelfdoding?*
- 3. Wat zijn de ervaringen, opvattingen en overwegingen van de naasten van mensen met een verzoek om hulp bij zelfdoding vanwege lijden aan een psychische aandoening?*

Hoofdstuk 2 onderzoekt de opvattingen en overwegingen van psychiaters ten aanzien van hulp bij zelfdoding in het geval van lijden aan een psychische aandoening. Het hoofdstuk beantwoordt de vraag wat redenen zijn voor psychiaters om voor of tegen hulp bij zelfdoding in het geval een patiënt lijdt aan een psychische aandoening te zijn.

Om deze vraag te beantwoorden hebben we diepte-interviews gehouden met 17 Nederlandse psychiaters. We laten zien dat psychiaters zowel redenen voor als tegen hulp bij zelfdoding in het geval van lijden aan psychische aandoeningen noemen. Deze redenen die genoemd werden zijn moreel (rechtvaardigheid en gelijkwaardigheid, professionele verantwoordelijkheid en barmhartigheid), epistemologisch (hoe kan je bepalen of het lijden uitzichtloos is), praktisch en contextueel (geestelijke gezondheidszorg voorzieningen) van aard. Een verschil in opvattingen lijkt gerelateerd aan een verschil in visie op wat psychische aandoeningen zijn. Sommige psychiaters benadrukken het verschil, terwijl anderen de overeenkomsten tussen somatische en psychische aandoeningen benoemen. We beargumenteren dat deze tegenovergestelde visies overbrugd kunnen worden door een meer pragmatische benadering, zoals een twee-sporen beleid.

Hoofdstuk 3 gaat over de ervaringen en opvattingen van huisartsen ten aanzien van hulp bij zelfdoding in het geval van lijden aan een psychische aandoening. Kunnen huisartsen zich voorstellen dat zij ooit hulp bij zelfdoding uitvoeren in het geval dat de patiënt lijdt aan een psychische aandoening, en welke redenen hebben zij om wel of niet achter de praktijk van hulp bij zelfdoding te staan in het geval van lijden aan een psychische aandoening? De data voor deze studie zijn verkregen door middel van een vragenlijstsonderzoek onder 500 huisartsen, en door middel van diepte-interviews met 20 Nederlandse huisartsen. Nederlandse huisartsen zijn minder geneigd een verzoek om hulp bij zelfdoding te overwegen wanneer dit gedaan wordt door een patiënt die lijdt aan een psychische aandoening, vergeleken met patiënten die lijden aan somatische aandoeningen. Redenen om open te staan voor

verzoeken om hulp bij zelfdoding hebben te maken met opvattingen over de reikwijdte van de geneeskunde, met een ervaren gebrek aan ervaring, onzekerheden gerelateerd aan de wettelijke zorgvuldigheidscriteria, en levensverwachting van de patiënt. Wij beargumenteren dat doordat huisartsen een extra criterium, zoals leeftijdsverwachting, hanteren, zij wellicht de optie openhouden dat de patiënt geneest, maar dat dit er juist ook voor kan zorgen dat het lijden verlengd wordt en er bijgedragen wordt aan de ondraaglijkheid hiervan.

Hoofdstuk 4 geeft inzicht in de relatie tussen suïcide en hulp bij zelfdoding. We beantwoorden de vraag of, en hoe, artsen onderscheid maken tussen suïcidaliteit en een verzoek om hulp bij zelfdoding. We hebben interviews gedaan met 17 psychiaters en 20 huisartsen om deze onderzoeksvraag te beantwoorden. We concluderen dat de artsen onderscheid maken tussen drie soorten doodswensen: impulsieve suïcidaliteit, chronische suïcidaliteit en een rationele doodswens (balans-suïcide). Zij onderscheiden deze doodswensen door te evalueren of de doodswens een onderdeel is van de psychopathologie, of de doodswens consistent is over de tijd heen, en of ze de doodswens behandelbaar achten. Sommige artsen beschouwen hulp bij zelfdoding als een alternatief voor een rationele doodswens, omdat zij dit een meer humane manier van sterven vinden voor de patiënt en zijn/haar naasten. Wij beargumenteren dat hulp bij zelfdoding ook gerechtvaardigd kan zijn in sommige gevallen waarin de doodswens een onderdeel van de psychopathologie is, omdat in deze gevallen het lijden ook ondraaglijk en uitzichtloos kan zijn. Hulp bij zelfdoding kan dan de enige manier zijn om het lijden op te heffen.

Hoofdstuk 5 biedt inzicht in de ervaringen en perspectieven van patiënten die lijden aan een psychische aandoening betreft hulp bij zelfdoding. Deze studie beantwoordt de vraag wat de optie van hulp bij zelfdoding voor betekenis heeft voor deze patiënten. Om deze vraag te beantwoorden hielden wij interviews met 21 patiënten die een wens

tot hulp bij zelfdoding hebben omdat zij lijden aan een psychische aandoening. Wij identificeerden vier thema's in relatie tot de betekenis van de mogelijkheid tot hulp bij zelfdoding voor patiënten die lijden aan een psychische aandoening. Deze thema's waren: a) autonomie en zelfbeschikking, b) het lijden beëindigen, c) erkenning, en d) een humaan levenseinde.

De mogelijkheid van hulp bij zelfdoding in het geval van lijden aan een psychische aandoening werd erg belangrijk gevonden door en voor patiënten die een doodswens hebben. Wij benadrukken het belang van erkenning voor de situatie van de patiënt, omdat dit tot nieuwe perspectieven kan leiden en mogelijk suïcide kan voorkomen. Wij beargumenteren dat de geestelijke gezondheidszorg in Nederland zou moeten nadenken over hoe deze erkenning in eerdere fases van behandeling gegeven kan worden, omdat dit kan voorkomen dat patiënten hulp bij zelfdoding gaan overwegen.

Hoofdstuk 6 gaat over de ervaringen van naasten van patiënten die een verzoek om hulp bij zelfdoding hebben vanwege het lijden aan een psychische aandoening. Wij waren geïnteresseerd in hun ervaringen van voor, tijdens en na het traject rondom hulp bij zelfdoding. Om inzicht te verschaffen in hun ervaringen, hebben wij interviews gehouden met 12 naasten van patiënten die een verzoek om hulp bij zelfdoding hebben of hadden. De resultaten laten zien dat de naasten voornamelijk ambivalent staan tegenover het verzoek om hulp bij zelfdoding van de patiënt. Hun ambivalentie wordt gekarakteriseerd door het enerzijds kunnen begrijpen dat de patiënt wil sterven, maar anderzijds hopen dat de patiënt een andere keuze maakt. Hun ervaring met betrekking tot het traject varieerde van positief ('intiem') tot negatief ('extreem zwaar'). Sommigen wensten meer betrokken te zijn, omdat zij van mening waren dat de weg naar hulp bij zelfdoding een gezamenlijk traject dient te zijn. Sommigen voelden zich niet betrokken door de arts die het verzoek behandelde. Professionele steun werd door sommigen gewenst, maar niet door allen.

Wij suggereren dat lotgenotengroepen een mogelijke oplossing zouden kunnen bieden.

Hoofdstuk 7 biedt een reflectie op de onderzoeksresultaten, methodologische overwegingen en implicaties voor de praktijk en nieuw onderzoek. In dit hoofdstuk behandel ik de resultaten van de onderzoeken onder artsen, patiënten en hun naasten, en verbind ik deze aan de bestaande literatuur. Ook ga ik in op de morele rechtvaardiging van hulp bij zelfdoding in het geval van lijden aan een psychische aandoening. De methodologische overwegingen gaan voornamelijk over de beperkingen van de gekozen onderzoeksmethoden (vragenlijstonderzoek en interviewstudies), en ik bespreek persoonlijke ervaringen met betrekking tot het lijden aan een psychische aandoening. Na het bespreken van de onderzoeksresultaten en de methodologische overwegingen, ga ik over naar de implicaties voor de praktijk, namelijk: a) artsen zouden opgeleid moeten worden om verzoeken om hulp bij zelfdoding te evalueren, b) artsen zouden actief het gesprek aan moeten gaan met hun patiënten over een eventuele doodswens, en c) geestelijke gezondheidszorg in Nederland zou zich, als het gaat om mensen met ernstige en refractaire psychische aandoeningen, meer moeten richten op herstelgerichte zorg en palliatieve psychiatrie, in plaats van het werken vanuit een curatief kader.

Dankwoord

Dankwoord

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Mijn allerbeste collegae. Jullie aanwezigheid tijdens dit traject heeft het bijzonder aangenaam gemaakt. Het gaat te ver om jullie allen bij naam te noemen, maar graag noem ik toch een aantal in het bijzonder. Kasper, Xanthe en Marieke. Het ethiek clubje! We hebben ons georganiseerd, en vervolgens helemaal niks gedaan, behalve elkaar steunen in barre proefschrift-tijden (oke, en naar Artis, en biertjes drinken of uit eten).

Ik dacht dat ik iemand was die kon werken zonder mij bezig te houden met collega's, maar jullie hebben mij wel laten inzien dat dit niet het geval is. Wat ben ik blij dat jullie er waren en ik hoop dat we elkaar blijven treffen. Nog even een shout-out naar Marieke, hoe fijn was het om in Corona-tijden vaak samen toch een dag in de week op het AMC te werken. Altijd met wandelingetjes buiten, even koffie of gewoon hard aan het werk...dank je wel hiervoor, het maakte de vele maanden draaglijker. Mijn pre-Corona kamergenoten; Jelle, Ralf, Evert, Amalia en Lucinda. Ook al waren we met totaal verschillende zaken bezig, we konden elkaar altijd wel vinden voor een koffie of een klets-moment. Ik waardeer de gezelligheid die jullie meebrachten op het AMC, maar ook tijdens onze uitjes. @ Amalia: you are amazing! Thank you for the good times we have had and the amazing gifts you brought from Indonesia. I will miss you. Kirsten Evenblij, al even werken we niet meer samen, maar desondanks heb je in de beginjaren van mijn onderzoek een belangrijke bijdrage gehad. Als hulp met SPSS, of qua gezelligheid in bijvoorbeeld Canada. Het ga je goed!

Jolien Glaudemans, waar was je het laatste jaar? Ik heb je gemist. Gelukkig konden we elkaar voor dit jaar geregeld vinden voor een kletspraatje, koffie of een zeur-moment. Heerlijk! Natashe Lemos Dekker (Natte), dank voor de koffiemomenten en het kunnen bespreken van ons werk.

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PhD Portfolio

PhD portfolio

Education

Webinar Empirical Ethics (2021) – 0.4 ECTS

Basiscursus Regelgeving en Organisatie voor Klinisch Onderzoekers (BROK) (2019) – 1 ECTS

AMC World of Science (2019) – 0.7 ECTS

Scientific writing in English (2019) – 1.5 ECTS

Spring School Ethical Theory and Moral Practice, OZSW (2018) – 2 ECTS

Qualitative Health Research (2016) – 1.9 ECTS

(Inter)national conferences, workshops and symposia

Symposium *‘De nalatenschap van verlies en trauma voor individu, gezin en samenleving: implicaties voor psychische gezondheid’* Utrecht, The Netherlands (2020) 0.5 ECTS

The seventh annual OZSW conference (The Dutch Research school of Philosophy), Amsterdam, The Netherlands (2019) – 1 ECTS

3rd International Conference on End of Life Law, Ethics, Policy and Practice, Ghent, Belgium (2019) – 1 ECTS

NVVE symposium ‘Euthanasie als behandeloptie bij psychisch lijden’, Driebergen, The Netherlands (2018) – 0.5 ECTS

3rd Annual Meeting of the Amsterdam Public Health research institute, Amsterdam, The Netherlands (2018) – 0.5 ECTS

15 Years of Euthanasia Law in Belgium, Antwerp, Belgium (2017) – 0.5 ECTS

2nd International Conference on End of Life Law, Ethics, Policy and Practice, Halifax, Canada (2017) – 1 ECTS

NVvP Voorjaarscongres 2016, Maastricht, the Netherlands (2016) – 0.5 ECTS

International Euthanasia Conference 2016, Amsterdam, The Netherlands (2016) – 0.5 ECTS

NVVE congress “Complexe euthanasie”, Utrecht, The Netherlands (2016) 0.5 ECTS

Philosophy of Care meetings (monthly), Amsterdam UMC location AMC, Amsterdam, The Netherlands (2016-2020) – 1 ECTS

Various evenings with programmes about physician-assisted dying (in context of psychiatry) (for example at Spui25, de Balie, or Universiteit van Nederland) – 1 ECTS

Presentations

Oral presentation: Huisartsennetwerk Amsterdam UMC, locatie AMC: *'Euthanasie en hulp bij zelfdoding in de psychiatrie'* (2019) – 0.2 ECTS

Oral presentation: Spring School Ethical Theory and Moral Practice, OZSW: *'Physician-assisted suicide in psychiatry'* (2018) – 0.2 ETCS

Oral presentation: Quest, VUmc: *'Levensbeëindiging door psychiaters: de resultaten van de derde evaluatie van de Wet Toetsing levensbeëindiging op verzoek en hulp bij zelfdoding'* (2017) – 0.2 ECTS

Oral presentation: 2nd International Conference on End of Life Law, Ethics, Policy and Practice, Halifax, Canada: *'Psychiatrists Views on Assisted Dying and Psychiatric Patients: a Qualitative Study'* (2017) – 0.2 ECTS

Oral Presentations during Philosophy of Care (Ethics of Care) meetings – 0.2 ECTS

Teaching

Supervising Bachelor thesis medical student (2020) – 1 ECTS

Supervising Master thesis medical student (2019) – 1 ECTS

Ethics and infectious diseases (2019-2020) – 0.5 ECTS

Ethics and addiction (2019) – 0.5 ECTS

Moral Case Deliberation to Medical Students (Bachelor and Master) (2016-2020) – 1 ECTS

Publications

Onwuteaka-Philipsen, B. D., Legemaate, J., van der Heiden, A., van Delden, H., Evenblij, K., el Hammoud, I., Pasma, H. R. W., Ploem, C., Pronk, R., van de Vathorst, S., Willems, D. (2017). Derde evaluatie Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding. Den Haag: *Zonmw*.

Legemaate, J., Ploem, C., Pronk, R., van de Vathorst, S. Het functioneren van de toetsingscommissies euthanasie. (2017) Tijdschrift voor Gezondheidsrecht 41(4-5):342-350

Pronk, R., Evenblij, K., Willems, D. L., & van de Vathorst, S. (2019). Considerations by Dutch psychiatrists regarding euthanasia and physician-assisted suicide in psychiatry: a qualitative study. *The Journal of Clinical Psychiatry*, 80(6), 0-0.

Evenblij, K., Pasma, H. R. W., Pronk, R., & Onwuteaka-Philipsen, B. D. (2019). Euthanasia and physician-assisted suicide in patients suffering from psychiatric disorders: a cross-sectional study exploring the experiences of Dutch psychiatrists. *BMC Psychiatry*, 19(1), 1-10.

Pronk, R., Snijdewind, M. (2019). Euthanasie bij psychiatrisch lijden. *Algemeen Tijdschrift Voor Wijsbegeerte* 111 (2):253-257

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Snijdewind M., Pronk R. (2020) Euthanasie bij persoonlijkheidsproblematiek. *Nederlands Tijdschrift Geneeskunde*. 164:D4928

Pronk, R., Willems D.L. & van de Vathorst, S. (2021) Feeling Seen, Being Heard: Perspectives of Patients Suffering from Mental Illness on the Possibility of Physician-Assisted Death in the Netherlands. *Culture, Medicine and Psychiatry*, 1-15.

Contribution of co-authors

Contribution of co-authors

All authors read and approved the final version that was submitted. Rosalie Pronk, Suzanne van de Vathorst and Dick Willems were responsible for the design of all the studies.

Chapter 2:

Rosalie Pronk, Kirsten Evenblij, Dick Willems and Suzanne van de Vathorst

RP conducted the interviews, analysed the content and wrote the manuscript. KE, DW and SvdV reviewed the manuscript and revised it for important intellectual content. Jolien Glaudemans is acknowledged for her contribution as a second coder.

Chapter 3:

Rosalie Pronk, Nieke Sindram, Suzanne van de Vathorst and Dick Willems

RP and NS both conducted the interviews and analysed the content. RP conducted and analysed the survey-study. RP wrote the manuscript. SvdV and DW reviewed the manuscript and revised it for important intellectual content. Kirsten Evenblij is acknowledged for her contribution to the analysis of the survey-study.

Chapter 4:

Rosalie Pronk, Dick Willems and Suzanne van de Vathorst

RP conducted the interviews, analysed the content and wrote the manuscript. DW and SvdV reviewed the manuscript and revised it for important intellectual content.

Chapter 5:

Rosalie Pronk, Dick Willems and Suzanne van de Vathorst

RP conducted the interviews, analysed the content and wrote the manuscript. DW and SvdV reviewed the manuscript and revised it for important intellectual content.

Chapter 6:

Rosalie Pronk, Dick Willems and Suzanne van de Vathorst

RP conducted the interviews, analysed the content and wrote the manuscript. DW and SvdV reviewed the manuscript and revised it for important intellectual content.

