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A dialogue on death

On mental illness and physician-assisted dying

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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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