A dialogue on death

On mental illness and physician-assisted dying

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Chapter 1

General introduction

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'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 believes 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 or 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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