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Snijdewind, M.C.

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This is my last stop
Gonna take a long walk
Before I take my boots off
I'll see ya round the way

The Last Hawk – Shovels & Rope

7

General discussion

The final chapter of this thesis highlights the main findings of the former chapters, reflects on the ethical aspect of normalization, describes the implications and looks ahead towards further research. First however, I'll discuss some methodological considerations.

METHODOLOGICAL CONSIDERATIONS

The central concept of my thesis is normalization, which has not been defined beforehand because I made a choice to both study the concept as well as trying to answer the question if and in what way normalization applies to EAS. Not defining the concept beforehand made it possible to include a wider range of views on normalization, and to give a more nuanced answer to the question how normalization applies to EAS. It can be understood as exploring a landscape and at the same time making a map of it.

Qualitative research

In qualitative research, the persons carrying out the research are the research instrument and, as such, they are “an integral part of the process and final product”.⁽¹⁾ Researchers should deal with this by being open and reflexive about their role and position in the study and its subject.

So, what is my own point of view, where do I stand? When I first started, I had a rather strong and positive opinion on EAS. I would position myself being pro-choice, thinking from the perspective of the patient: if someone wants to die, why not help him/her with that? For me, EAS was normal. Soon after being appointed I started interviewing physicians on complex cases of EAS and by gaining more knowledge on the subject, my sympathy for the position that the physician is in grew and I learned EAS was far from as normal as I presumed it to be. The patient was not the only one for whom something was at stake. In public I found myself defending the physician's perspective, of EAS being difficult. Slowly, my position on EAS in relation to normalization grew into a nuanced view where both exceptional and normal aspects were intertwined.

This brings me to the question if I, as part of the Dutch society and culture, can study an aspect — the possible normalization of EAS — that is part of that same culture. Even though this may have the advantage of inside knowledge, was it possible I was too much involved? As a researcher I tried to be aware of this possibility and to limit the consequences, I took notes about what I saw, what caught my eye and what I thought of it. By actively reflecting on these notes, I learned to make a separation

between what was the respondent's point of view and what were my own assumptions. Discussing my data and my findings with colleagues further enriched and deepened this reflectivity. I kept questioning my own interpretations throughout the process and tried to prevent rash conclusions.

Limitations in perspectives

Although both patients and bereaved are potentially vulnerable respondents in the context of end-of-life research, it is important to do justice to their views by including them in research.(2) A limitation of my study is that the patient's perspective is only included in the observational study. In this study, the participants were mainly inquiring about EAS and none of the participants had an actual present EAS request — they were mainly looking for assurance in case of future suffering and for ways to organize their end of life in a way that suited them. Since they did not have an actual EAS request, it can be questioned if they truly represented the patient's view. Other than this, the patient's perspective is represented by their bereaved. It is difficult to establish the reliability and validity of after-death interviews with bereaved for patient views.(3) Although their perspective might not quite cover the expectations and experience of the patients themselves, nevertheless it remains the only one that is available after the patient's death.

Another limitation is the possibility that the memory of the respondents who talked about their experience of the process towards EAS and the performance of it, might be subject to distortion. This applies to the physicians' as well as the bereaved' interviews. Stories people tell about a lived experience are always subject to reinterpretation and change.(4-5)

One could argue that my selection of participants was biased, because in selecting physicians for the interviews I looked specifically for complex cases, not representative for all EAS cases, and included members of the NVVE, whose thoughts and experience are not necessarily representative for the Dutch population. However, my research was not meant to be representative for all EAS cases let alone the general population. I studied normalization and thought it was most likely to be found at the boundaries of the EAS practice and discussion: the NVVE and complex cases fitted this description. I thought that if there would be signs of normalization it could be found with the members of the NVVE. And, in contrast, if there would be signs of normalization of the complex cases of EAS, then the more common cases of EAS would be subject to normalization as well. My results showed something else: it turned out that the difficulties surrounding EAS were not as much about the condition a patient

was suffering from but about issues concerning the relation between physician and patient — issues that can play a role in suffering from cancer just as in suffering from a psychiatric condition.

Despite my effort to follow the participants of the observational study to the conversation about end-of-life preferences with their physicians, in a large number of cases I did not manage to do so. I wanted to hear firsthand how patients would formulate their future wishes and their expectations in the very first conversation with their physician on this topic, because I thought the different perspectives of patients and physicians would be best visible at this point in time. I see it as a challenge for future research to find that right timing where patients and physicians first meet to talk about EAS.

Quantitative:

The quantitative part of this thesis also has its strengths and limitations. A strength of the study into the End-of-Life Clinic is that I included all application forms the clinic received in the first year of existence. Using the application files also had its limitations. I did not have access to the medical files of the patient, so I had to use the information on the application file to classify the medical condition a patient was suffering from. The application file is most often filled in by the patient or his/her relative, and therefore information on the medical condition was sometimes very concise or incomplete, while other times it included a detailed description of all ailments the patient had suffered from since childhood, of which (probably?) many were no longer relevant for the EAS request.

MAIN FINDINGS

This thesis describes developments in the field of EAS in relation to the question of normalization. Different perspectives are presented: that of patients, of bereaved, of physicians, and of experts. Because the results of the separate studies have already been discussed in the previous chapters, I will use the two levels of normalization that I have found in the study on views of experts (chapter 4) as reference points to reflect on the other study outcomes.

I have described the societal level as the degree of acceptance and incorporation of EAS in society, and the legal level as the place EAS takes within (or out of) the law. The legislation concerning EAS has not changed since the enactment of the Euthanasia Law. Therefore, EAS is still a criminal act and, at least legally, it remains an

exceptional medical act. For EAS to become a normal medical act, it would have to be taken out of the criminal law. However, this does not mean that the legal level only opposes normalization. The legal level and the societal level also influence and interact with each other. The fact that the legal due care criteria include ‘open norms’(6) is the most obvious mix of the two different terrains. A concept like unbearable suffering is subject to interpretation of the physician(7) which is, at least partly, shaped by the Review Committees’ decisions, and society’s understanding of it.(8) And the other way around, the legal level influences the societal one by slowing its normalization down, because it sets boundaries. This is also why the goal of an initiative like Out of Free Will(9), or the recent draft law proposal of Dijkstra(10), was to realize a change or addition in the law — for some people the law is no longer sufficient and further societal acceptance needs to be reflected in an attunement of the law. At the same time, there are reports of physicians wanting to avoid performing EAS(11); physicians often do not use the full extent of the law(12), and in chapter 4 the experts also mention the possibility that physicians become more reserved. This might be confirmed by the latest study of the evaluation of the Euthanasia Law, which reported that the group of physicians that is not willing to grant an EAS request seems to have grown slightly (19% in 2016, compared to 15% in 2011 and 2005).(13) However, when asked about conceivability to grant an EAS request based on specific types of suffering, no such changes were found compared to previous years(13).

With the regulation of euthanasia, obstacles have been taken away. More openness, more shared knowledge on methods and what falls within the boundaries of the law. This does not mean that EAS has become easy. Regulation cannot offer solutions for the complexities that seem to be inherently linked to EAS, like the emotional burden the physician feels, or the fact that sometimes the disease catches up upon the patient — Chapter 5 shows the practice remains difficult. However, being difficult does not mean that it is still exceptional. A medical act can be extremely difficult, but still normal, again think about amputation. How would EAS be any different? The difficulty of EAS is not so much found in the performance itself, as is with amputation, but in the moral way. EAS demands a consideration of one’s own values and what is understood by being a good caregiver.

We have already established that the needs and wants of patients (and their relatives) do not always coincide with those of the physicians (chapter 4). When comparing the societal level of normalization with the legal one, one could say that patients have expectations of EAS that exceed the legal boundaries, while physicians are sometimes

not willing to grant an EAS request even if it is within these legal boundaries. This difference can cause friction. This friction is supported by the findings in chapter 3, where physicians mentioned they felt pressure from patients and family members to perform EAS. Also, other studies confirm that physicians sometimes feel being put under pressure.(14-16) However, it is not known if these feelings are stronger than before or that they are inevitably linked to EAS. Chapter 2 shows that in the consultation hours on ADs, consultants make an effort to stress the importance of early communication on end-of-life care preferences between patient and physician, in order to bridge the differences in expectations and avoid miscommunication between physician and patient, and for them to be on the same track in an early stage. Earlier research also reported that timely communication between physician and patient concerning the end of life still needs improvement(17-19) and found that both physicians and patients saw the value of clarifying expectations in these conversations.(20)

What happens when patient and physician are not on the same page is shown in chapter 5: complexities arise and the process towards EAS becomes difficult. The examples that are given by respondents also show that these relational difficulties often lead to a patient that is ready to have his request for EAS fulfilled and a physician that needs more time. The patient is a few steps ahead of the physician. Rising difficulties are not always due to the type of suffering which the request is based on — think for instance about dementia or psychiatric suffering — however the conditions in which difficulties occur are more often present in these cases. What we have also learned from this chapter is that relatives play a role in the process towards EAS as well, so it's good to take their views and opinion into account. Previous studies confirm this(15-21), however in guiding documents it is overlooked — perhaps because it is not part of the legal requirements.

The End-of-Life Clinic can be seen as one of the possible solutions when patient and physician are not on the same track and cannot resolve this together. The clinic itself reports that the relationship with the patient is in 7% of their admissions the reason for the physician not to be willing to grant the EAS request.(22) The End-of Life Clinic is specifically founded for patients whose request is rejected by their treating physician and who seek another physician who has less reservations than their own physician.(23) The results in chapter 6 describe that the medical staff working for the End-of-Life Clinic turned out to be more willing to grant EAS requests based on less common reasons, such as psychological conditions and being tired of living. This is in accordance with their goal to help patients with an EAS request based on more uncom-

mon reasons.(24-25) The yearly reports of the End-of-Life Clinic show that since the foundation, every year the clinic receives more applications and their medical staff is also steadily growing in number.(22)

ETHICAL REFLECTION ON NORMALIZATION

We have seen different levels of normalization: on a societal and on a legal level. In this section I will show what implications normalization might have on an ethical level. Then, I'll defend the position that the subject of normalization is not EAS — what is being normalized is that dying is something you should actively engage in.

In the introduction we have seen that 'normal' can be understood as "ordinary or usual; the same as would be expected".(26) The word 'expected' holds some normative value — something that is expected often also ought to happen. The teachings of Foucault on power, (self)discipline and the norm inspired me to take one step further. I won't discuss his work in detail, but will only pick out one small aspect of his ideas: the relation between normal(ization) and the norm.(27-29) According to Foucault, what happens to the normal, is that it becomes the norm in itself. The statistical normal tends to become the moral normal. It becomes desirable to be included in the norm(al).(27) People make an effort to conform, they want to belong to the main group. If you deviate from the normal, you want to adjust, because otherwise you are left out.(27) At the same time, it is also expected from you to adhere to the norm, so it is not only willingly that people comply, they are also pushed to do so and are left out if they don't. This is normalization and self-surveillance at work.(27) This is also what is meant when Foucault says that normalization *produces* new subjects. The norm is not enforced on subjects, they are not forced into this new norm, instead they want to fit in because they value the norm(al), it is something that they themselves have incorporated, they have become subjects who truly *want* this. The motivation to adhere to the norm is therefore both intrinsic as well as extrinsic: it comes from within individuals (self-surveillance) as well as from the outside world. As normalization produces new subjects, it *changes* the subjects in a society.

So, what is the norm in our society? I do not want to suggest that it is EAS. EAS is not something to strive for, it is not normal in the sense that it is the default way to die. In this respect, Foucault's understanding of normalization looks somewhat like the slippery slope argument, because it appeals to our idea that something — EAS as exceptional practice — will lead inevitably to another situation — EAS as norm. As

we already pointed out, it is not that people assume or expect that someone will want to die by EAS. If EAS is not subject to normalization, can we distinguish something else that is? In my opinion, what has become the norm is choosing the way you want to die. Dying is no longer unruly, it is something that you can have a say in, and not only that, you are expected to have a say in it, to have an opinion about your last phase in life, about the way you want to go. A good death constitutes dying in the way you have chosen. This is a norm that does not solely depend on the occurrence of EAS — even if EAS would no longer be an option, people would still be expected to make up their mind about what they value in the end of life. However EAS does have (had?) its influence on this norm, because EAS is one of the practices that makes us into subjects that have a say in how they die. Talking about EAS is a way for people to state what they find important, what they can't live or die without, what makes life worthwhile, what they fear, what they would like to avoid. Euthanasia has become a popular discourse in the Netherlands to talk about what you do and do not want in the last phase of life. Previous research showed that a wish to die does not necessarily imply a genuine desire to hasten death⁽³⁰⁾ and from Norwood's study we have learned that talking about euthanasia is part of the Dutch culture, and often does not result in euthanasia.⁽³¹⁾ What EAS has introduced and promoted by its existence is the element of choice. EAS may be the obvious example of a choice you can make at the end of life, but it is definitely not the only thing people are expected to have an opinion on, having a say in how to arrange your death is not limited to EAS. To name a few other areas: advance care planning, (non)treatment decisions, and place of death. The focus on and importance of patient preferences and involvement has turned into an obligation to be engaged in and have an active say in the care you receive. Not having end of life preferences or not wanting to be involved in decision making on this topic might be on its way to become, in the wording of Foucault, deviant.⁽²⁷⁾

That being said, this statement also needs nuancing. It is not something that has become reality already. If we look at the effort that physicians and researchers put in the promotion and study of advance care planning^(18,32), this shows that it is not something that all patients do already. Some patients or family members lack initiative and openness to advance care planning. However that this is not accepted as is, but seen as something that is needed to be overcome⁽³³⁾, shows that our society is working hard to get there, to get to the point where we are expected to have end of life care preferences and to make decisions on this topic.

IMPLICATIONS AND FURTHER RESEARCH

In this section I'll address the new ethical questions that are raised by our exploration of normalization.

The first question to ask ourselves: how is normalization related to the slippery slope? I briefly touched upon this point in the above section. The slippery slope arguments reasons that if you allow one thing, that is morally acceptable in itself, it will gradually evolve into another thing, that is no longer morally acceptable.(34-35) It addresses a fear of abuse of the law: often used when talking about vulnerable groups, for instance people suffering from dementia or psychiatric patients. In the Netherlands some authors have expressed their concern about the practice of EAS for people suffering from dementia or a psychiatric illness(36-37), however this possibility is also seen as emancipation of the patient. The law always intended to include these groups of patients, so it cannot be seen as stretching the law, let alone abuse. Is it part of normalization that we interpret it this way?

The next question is on the subject of inclusion and personal freedom. Should we help everyone with an EAS request that falls within the boundaries of the law? This question relates to the freedom the physicians have to reject requests based on personal considerations or principles. There has been a development that physicians need to justify why they reject a request (chapter 4), which I think, contributes to a more prudent practice. However, if normalization continues, personal reasons might no longer be considered a substantiate motivation to reject a request: we do not accept that a physician rejects a normal medical act because he/she experience it as burdensome. I think it is time to renew the societal discussion about the physician's personal freedom to reject request.

If EAS is subject to normalization, it may also have implications for the current review system. It might be too extensive and therefore needs reconsideration. Normalization of EAS could imply bringing it under the same review system as other medical acts: disciplinary law.

Above, I have given some thought on what I think are the important ethical questions which need to be debated . Next I'll describe my ideas for further research.

My first recommendation for research would be to conduct a qualitative in-depth interview study into the reasons for the medical staff of the End-of-Life clinic to reject or to grant EAS requests. The goal of the clinic is to help patients whose requests fall within the legal boundaries but are rejected by their own treating physician. A previous

study into the considerations of physicians on EAS requests reported that physicians have considerations that are unrelated to the legal criteria.⁽¹²⁾ It would be interesting in the context of normalization to study if the physicians working for the End-of-Life Clinic also have considerations unrelated to the legal criteria when they are assessing an EAS request. If personal ideas or values are left out, it could be interpreted as a sign of normalization: using the due care criteria as a sort of indication for EAS.

Next, I would recommend a second evaluative study into the End-of-Life Clinic. In the first year of its existence the clinic was closely watched by the Review Committees, the clinic received heavy criticism, and maybe the people working for the clinic had to get used to working in this new environment and system. I wonder if that might have had influence on the way requests for EAS were handled. Another reason for a second evaluation is the possibility to include the medical files of the applications this time for a more reliable and unified understanding of the underlying conditions the patients are suffering from.

The qualitative study into difficulties that can occur in a process towards EAS has shown the scope of possible complexities, but I would now recommend a quantitative follow-up study to see how often these difficulties occur in practice and on what aspects support could be provided.

Last, I would recommend conducting a study into how the discussion and tuning between physician and patient happens: how do they manage to get on the same track? The outcomes of this study into 'good practices' could help us guide both parties when the process becomes difficult.

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