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Dying to be normal

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Summary

The first chapter introduces us to the topic of this thesis: normalization of euthanasia and physician-assisted suicide. The position of euthanasia and physician-assisted suicide in society and the medical domain is subject to an ongoing discussion, which is related to the question of possible normalization of these practices. Exploring the concept of normalization in relation to euthanasia and physician-assisted suicide in the Netherlands is the research aim of this thesis. Each chapter studies one or more possible aspects of normalization.

The second chapter studies normalization as related to de-professionalization. It answers the question what the aims and expectations of people visiting consultation hours on advance directives are, what advice is given by the consultants, and how is acted upon this advice. This study is connected to the topic of normalization of euthanasia and physician-assisted suicide because the consultations happen outside the professional medical context. This de-professionalization can be seen as part of normalization. To answer the research question I conducted an observational study on consultation hours on advance directives. A total of 29 appointments with 36 members and eight consultants were observed. The results show that the main reasons for visiting the consultation hours were a need for assurance, and the feeling of control over future death. The consultants stress that euthanasia and physician-assisted suicide is in no way a right of the patient, and that it is exceptional practice for physicians. This is also the reason why they emphasized the greater importance of refusal of treatment — because this *is* a patient's right — over an euthanasia directive. The consultants encouraged the visiting members to go talk with their physician about their last wishes.

The third chapter shows insights into the possible normalization of euthanasia and physician-assisted suicide from the physicians' perspective: what changes have they encountered, (how) have they perceived the influence of the public debate on the practice of euthanasia and physician-assisted suicide? The chapter presents the results of a secondary analysis of semi-structured in-depth interviews among 28 physicians, who have experience with complex cases of physician-assisted dying. The interviewed physicians reported they experienced a change in what (family of) patients would expect from them: from a role as an involved caregiver to being the mere performer of euthanasia or physician-assisted suicide. Next, interviewees said that requests for euthanasia and physician-assisted suicide based on non-medical reasons came up more frequently and wondered if physician-assisted dying was the right solution for

these requests. Last, respondents had the impression that the standards of physician-assisted dying are shifting and that the boundaries of the euthanasia and physician-assisted suicide regulation were stretched. This chapter explicitly shows a difference in wants and expectations between physicians and patients, and shows that physicians can sometimes feel being put under pressure.

The fourth chapter answers the same question as the third chapter, namely what important developments in the practice of euthanasia and physician-assisted suicide are, however now from the perspective of Dutch experts in the field of euthanasia. Twelve semi-structured in-depth interviews were conducted to answer this question. The experts described both signs and causes of normalization as well as the opposite: euthanasia and physician-assisted suicide remaining exceptional practices. They also described a tension between the wishes of the general public and the willingness of the physicians regarding euthanasia and physician-assisted suicide. Legally, euthanasia and physician-assisted suicide remain exceptional, while on a social-ethical level normalization is at hand. It was said that physician-assisted dying has become a normal way to die.

Chapter five addresses the fear that, because of normalization, physician-assisted dying has become too easy. It describes complex cases of euthanasia and answers the question what causes a case of physician-assisted dying to be more complex than another. Results were based on semi-structured in-depth interviews among 28 physicians who have experience with complex cases of euthanasia or physician-assisted suicide, combined with in-depth interviews with 26 relatives of patients who had died by euthanasia or physician-assisted suicide. Complexities can be categorized into relational difficulties — such as miscommunication, invisible suffering, and the absence of a process of growth toward euthanasia and physician-assisted suicide — and complexities that arise from unexpected situations — such as the capricious progress of a disease or the obligation to move the patient. The course of the process toward euthanasia and physician-assisted suicide is not only influenced by the patient and his/her attending physician but also by the relatives who are involved.

Chapter six studies normalization in the context of specialization. It shows the results of a study into the End-of-Life Clinic, a facility for people whose own physician is not willing to grant their request for euthanasia or physician-assisted suicide. It answers the question which patients register themselves at the clinic, what the outcome of these requests for physician-assisted dying are and which factors are associated with granting or rejecting a request. The clinic can be seen as a sign of normalization, because it is a specialization of the practice of physician-assisted dying, while the opposite is also true: it also is a sign that physician-assisted dying remains so exceptional

and difficult for physicians that they are often not willing to perform it. All application forms and registration files from the first year of the clinic were analyzed, which came down to a total of 645 requests. Of the 645 requests made by patients, 162 requests (25.1%) were granted, 300 requests (46.5%) were refused, 124 patients (19.2%) died before the request could be assessed, and 59 patients (9.1%) withdrew their requests. Patients with a somatic condition (113 of 344 [32.8%]) or with cognitive decline (21 of 56 [37.5%]) had the highest percentage of granted requests. Patients with a psychological condition had the smallest percentage of granted requests. Six (5.0%) of 121 requests from patients with a psychological condition were granted, as were 11 (27.5%) of 40 requests from patients who were tired of living. These results show that the medical staff working for the End-of-Life Clinic are more willing to grant a request for euthanasia or physician-assisted suicide based on less common reasons — such as requests founded upon psychological conditions, and being tired of living — than physicians in the Netherland in general. The physicians and nurses employed by the clinic, however, often confirmed the assessment of the physician who previously cared for the patient; they rejected nearly half of the requests for euthanasia and physician-assisted suicide, possibly because the legal due care criteria had not been met.

Chapter seven, the general discussion, starts off with methodological considerations of the research presented in this thesis. Next, the results of these studies are summarized in reference to normalization on a legal level and on a societal level. In all chapters a certain duality can be found: elements of normalization combined with elements that indicate that euthanasia and physician-assisted suicide remain exceptional practices. Then, the possible meaning of normalization on an ethical level is described. In the closing part new questions which the research has raised are addressed and ideas for further research are mentioned.