Dutch doctors & dying

*Do doctors’ personal views influence their professional care at the end of life – and should they?*

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Chapter 1
General introduction

This thesis is a reflection of my study into physicians' views on end-of-life care and end-of-life decisions in general, and physician assisted dying in particular. When I started this thesis I had no experience with death and dying. However, I was very interested to learn if and how physicians' personal views shape the way they care for patients at the end of life, because I suspected that, despite of the many rules, regulations and guidelines on this topic, this was a part of medicine where physicians' personal views and values would come to the surface and would play a role, perhaps even more than in any other part of medicine. Physicians' personal views and values on death and (assisted) dying might even come into conflict with the views and values of patients and their relatives. The combination of this possible tension between physician and patient with the delicate and loaded setting I could imagine a deathbed is, made me think of this as a very interesting topic and a great opportunity for ethical reflection.

This thesis aims at providing more insights into the viewpoints of physicians on death and (assisted) dying, and an ethical reflection on the influence these viewpoints have on the care physicians provide at the end of life. The increasing involvement of medicine in death and dying and the increasing appeal of patients on physicians to help them die (well), make these insights and reflection all the more relevant.

In modern Western societies death and dying have become ‘medicalised’. (1-4) Some figures can illustrate this. Van der Heide and her team have studied end-of-life practices in the Netherlands for more than 25 years. (5) They show that: ‘in the Netherlands the percentage of patients in whom an end-of-life decision had preceded death increased from 39% in 1990 to 58% in 2015. In 1990 1.7% of all deaths were the result of euthanasia; in 2015, this percentage was 4.5%. In 2015, physician assistance in dying was requested by 8.3% of all deceased persons. The use of morphine to alleviate symptoms while taking into account possible hastening of death as a result increased from 19% of all deaths in 1990 to 36% in 2010 and 2015. Continuous deep sedation was provided in 8.2% of all patients in 2005 and in 18.3% in 2015.’(5) Van der Heide concludes: ‘the use of potentially life-shortening medication and continuous deep sedation to relieve end-of-life suffering has become common practice in the Netherlands.’(5)
Death and dying are now seen as matters medicine in general, and palliative care in particular, has an important role to play in. (1-4) There are several developments, which began in the sixties and seventies of the twentieth century, that had an influence on the way Western medicine deals with death and dying today. In Britain for example Cicely Saunders laid the foundation for the hospice movement, which enabled patients to prepare for their coming death, in contrast to earlier times when confronting the patient with his coming death was deemed too burdensome for the patient. (6) In the United States psychiatrist Weisman wrote the influential book ‘On dying and denying’, and psychiatrist Kubler-Ross published her studies on the experiences of the terminally ill. (7-9) These authors too emphasized the importance of awareness and acceptance of death and assigned professional caregivers a prominent role in helping the patient to achieve these. (7-10)

Palliative care was also a reaction to medicine’s expanding possibilities to prolong life. In various countries people asked themselves if this ideal of prolonging life should not be limited when the quality of that life would fall beneath a certain limit. Prolonging life sometimes seemed futile with regard to quality of life. (11,12) The patients’ rights movement came up; medical power and paternalism were challenged and had to make room for informed consent in the various domains of medicine, e.g. cure, care and research. This growing recognition of patient autonomy is also reflected in the increasing number of people that want to have something to say about the moment and the way they die and the increasing rights and opportunities they have been given to do so. (5,13,14) In the last decades many countries around the world have altered their legislation on termination of life, most countries with regard to withdrawing life-sustaining treatment but some with regard to euthanasia on request of the patient as well. (14,15) The Netherlands was the first country in the world to pass a law on assisted dying, which came in effect in 2002, after a long societal, political and professional debate that already began in the seventies. (16) The Netherlands is also the first (and only) country in the world that has a legal regulation on deliberately ending the life of severely ill neonates. (17,18)

However, even in a country in which assisted dying seems so generally accepted, there will always remain differences in how people – physicians as well as patients – view life, death, the role of medicine, suffering, decline and dependency. That these differences, as I already suspected, may come to the surface and play a role in the practice of end-of-life care and decision-making I experienced personally. During my work on this thesis my grandfather died. Unfortunately his death did not match his or his family’s preferences, views and values. This experience gave me extra
fuel for the ethical discussion on what I believe to be the ethically justified role for physicians’ personal viewpoints in end-of-life care. I hope that with this thesis I can make a contribution to better medical care and assistance for all of us who will die in the future.

Methods

This thesis is a mix of empirical research and ethical reflection and discussion. The empirical research is quantitative (chapter 2) but mostly qualitative (chapter 3, 4 and 5) in nature, since qualitative research is the most appropriate method for gaining insight into physicians’ personal views. In-depth interviews with physicians were regarded as the most appropriate form of qualitative research in this case because this thesis is about very personal and deeply held beliefs and values and deals with a sensitive topic. (19-21)

A total of 63 Dutch physicians were interviewed for this thesis. The empirical research focuses on the Dutch practice only, however, the ethical reflection on the empirical findings (chapter 6) is also relevant outside the Netherlands, since physicians everywhere deal with dying patients.

A more detailed description of the used methods can be found in each chapter.

Outline of the thesis

This thesis consists of three parts.

Part 1 (chapter 2 and 3) is about end-of-life decisions for severely ill neonates (children 0-1 year) in general, and the decision to deliberately end their life in particular.

Chapter 2 presents figures from a nationwide study from 2010 on end-of-life decisions for neonates and elaborates on the decreased frequency of the decision to deliberately end life (DELN). Chapter 3 zooms in on this issue of DELN. It presents the results of an interview study on the views of paediatricians on DELN – especially in the case of a dying neonate whose dying process takes very long – against the background of the legal regulation for DELN that exists in the Netherlands since 2007. In essence the difference in views boils down to the question how ‘good dying’ for a neonate (and its parents) would look like.

Part 2 (chapter 4 and 5) is about Dutch general practitioners (GPs) and the care they provide at the end of life.
Chapter 4 presents the results of an interview study on the considerations that play a role for GPs when they have to decide on a request for euthanasia or assisted suicide (EAS). Some of GPs’ considerations have little to do with the due care criteria of the Dutch law on EAS or the interpretation of these criteria, but are related to their personal views on good dying. Chapter 5 zooms in on these views on good dying. It presents the results of another interview study on GPs’ views on good dying and discusses the way these views influence the care GPs provide at the end of life.

Part 3 (chapter 6) is an ethical discussion in which the findings presented in the previous chapters are reflected upon and this chapter thereby forms the general discussion of this thesis. In this chapter I seek an answer to the question: ‘is it ethically justifiable that a physician’s personal viewpoints influence the care he provides for patients at the end of life, and to what extent?’ An additional question I address is whether the answer to this question changes in case of an assisted death (EAS and DELN) in comparison with care surrounding a ‘normal’ death, and if so, why?

References


* In this thesis I use ‘he’ and ‘him’ to refer to patients as well as physicians, however, this can also be read as ‘she’ and ‘her’ of course.