Dutch doctors & dying

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Katja ten Cate

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

ACADEMISCH PROEFSCHRIFT

ter verkrijging van de graad van doctor
aan de Universiteit van Amsterdam
op gezag van de Rector Magnificus

Prof. dr. ir. K.I.J. Maex

ten overstaan van een door het College voor Promoties ingestelde commissie,
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geboren te Nijmegen

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Table of contents

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?

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* 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.

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Part 1

Chapter 2
End-of-life decisions for neonates

Previously published as:
Ten Cate K, van de Vathorst S, Onwuteaka-Philipsen BD, van der Heide A. End-of-life decisions for children under 1 year of age in the Netherlands: decreased frequency of administration of drugs to deliberately hasten death. *J Med Ethics*. 2015;41(10):795-8.

Abstract

Objective To assess whether the frequency of end-of-life decisions for children under 1 year of age in the Netherlands has changed since ultrasound examination around 20 weeks of gestation became routine in 2007 and after a legal provision for deliberately ending the life of a newborn was set up that same year.

Methodology This was a recurrent nationwide cross-sectional study in the Netherlands. In 2010, a sample of death certificates from children under 1 year of age was derived from the central death registry. All 223 deaths that occurred in a 4-month study period were included. Physicians who had reported a non-sudden death (n=206) were sent a questionnaire on the end-of-life decisions made. 160 questionnaires were returned (response 78%).

Findings In 2010, 63% of all deaths of children under 1 year of age were preceded by an end-of-life decision – a percentage comparable to other times when this study was conducted (1995, 2001, 2005). These end-of-life decisions were mainly decisions to withdraw or withhold potentially life-sustaining treatment. In 2010, the percentage of cases in which drugs were administered with the explicit intention to hasten death was 1%, while in 1995 and 2001, this was 9% and in 2005, this was 8%.

Discussion and conclusion There has been a reduction of infant deaths that followed administration of drugs with the explicit intention to hasten death. One explanation for this reduction relates to the introduction of routine ultrasound examination around 20 weeks of gestation. In addition, the introduction of legal criteria and a review process for deliberately ending the life of a newborn may have left Dutch physicians with less room to hasten death.

Introduction

Sometimes an ill newborn may suffer so severely or its prospects are so grim that an end-of-life decision is made. Such end-of-life decisions include decisions to withhold or withdraw potentially life-sustaining treatment, decisions to alleviate pain or symptoms with possibly life-shortening drugs and decisions to administer such drugs with the explicit intention to hasten death. The latter decision is the most far-reaching and controversial.

In the Netherlands, two potentially influential changes have taken place recently. In 2007, ultrasound examination around 20 weeks of gestation was introduced as part of the routine prenatal screening programme. In the same year, the Dutch government set up a legal provision that makes it possible for a physician to deliberately end the life of a severely ill newborn without being prosecuted if certain criteria of due care are met. (1)* This legal provision has come about in close collaboration with the field of paediatricians and stems from the so-called Groningen protocol. (2) Deliberately ending

life is defined as 'the use of drugs by a physician with the explicit intention to end the life of a severely affected newborn'. A newborn is taken to be a child under 1 year of age. (3) The criteria of due care are as follows: the child is suffering unbearably and hopelessly, the parents are fully informed about diagnosis and prognosis, the paediatricians and parents together have reached the conclusion that there are no other reasonable ways to relieve the suffering of the child, the parents have given consent, an independent physician has been consulted and the ending of life will be performed lege artis. (1) In addition, the legal provision requires that a physician who performs this act reports this to an expert committee (consisting of three paediatricians, a lawyer and an ethicist) that reviews these cases based on the criteria of due care. The expert committee has to inform the public prosecutor of its assessment, and the public prosecutor ultimately decides whether to prosecute (for murder or manslaughter) or not. (1)

We have repeated a nationwide questionnaire study that was previously conducted in 1995, 2001 and 2005 to assess whether the introduction of

* In 2016 the legal regulation on DELN has been changed. In the new regulation (that can be found here: Ministerie van Veiligheid en Justitie en Ministerie van Volksgezondheid Welzijn en Sport. Regeling beoordelingscommissie late zwangerschapsafbreking en levensbeëindiging bij pasgeborenen. *Staatscourant.* 2016;3145.) the criterion of actual unbearable and hopeless suffering has been widened somewhat in the sense that when the suffering is not unbearable yet but is foreseen to become unbearable in the near future, this can also be a legitimate reason for DELN. The other criteria have not been changed.

the ultrasound at 20 weeks of gestation as part of the routine prenatal screening programme and the legal provision for deliberately ending the life of a newborn have affected the frequency of end-of-life decision-making practices for children under 1 year of age. (4,5)

The research questions of this study were as follows: 1) How frequently are different types of end-of life decisions made for children under 1 year of age in the Netherlands in 2010? 2) Has this practice changed since 2007? 3) What are the characteristics of cases where physicians used drugs with the explicit intention to hasten death?

Methodology

In the Netherlands, all deaths are reported to Statistics Netherlands. In 2010, a total of 695 deaths of children under 1 year of age were reported. All 223 deaths that occurred between August and November 2010 were included in our sample. Based on the reported cause of death, cases were divided into those cases where death had come suddenly and unexpectedly (n=17) and cases where death could have been preceded by an end-of-life decision (n=206). Physicians who had reported a non-sudden death (n=206) were sent a questionnaire by mail. The questionnaire included questions about whether the death of the child could have been hastened (intentionally or unintentionally) by decisions to forego potentially life-sustaining treatment or by the use of potentially life-shortening drugs. A total of 160 questionnaires were filled in and returned (response rate 78%). Each case was weighted to ensure that the sample adequately reflects the proportions of infants by gender and place of death (at home, or in a hospital at a neonatal intensive care unit (NICU) or not at a NICU). This means that if the response rate for female infants was, for example, lower than the overall response rate, female infants in the sample weigh for somewhat more than one case to correct for that. This makes the data representative for all deaths of infants under 1 year of age in 2010 in the Netherlands.

Findings

End-of-life practices in 2010

We found that, in 2010, 63% of all deaths of children under 1 year of age were preceded by an end-of-life decision (table 2.1). The vast majority were decisions to withdraw or withhold potentially life-sustaining treatment.

Half of these cases also involved the use of possible life-shortening drugs to alleviate pain or symptoms. In 4% of all deaths, the administration of drugs with a possible life-shortening effect to alleviate pain or symptoms was the only end-of-life decision. In 1% of all deaths, drugs were given with the explicit intention to hasten death. All of these cases also involved a decision to withdraw or withhold life-sustaining treatment; there were no cases where death was intentionally hastened by the use of drugs without an accompanying decision to withhold or withdraw potential life-sustaining treatment.

Table 2.1 End-of-life decisions for children under 1 year of age in 2010, 2005, 2001 and 1995 in the Netherlands

	2010 n=177*	2005 n=122	2001 n=233	1995 n=299†
	%‡			
Total end-of-life decisions	63	59	68	62
Life-sustaining treatment withheld or withdrawn	58	55	63	57
No possible life-shortening drugs given	31	27	26	26
In combination with drugs with possible life-shortening effect to alleviate pain or symptoms	26	20	29	23
In combination with drugs given with explicit intention to hasten death	1	8	8	8
No life-sustaining treatment withheld or withdrawn	4	3	4	5
Drugs given with possible life-shortening effect to alleviate pain or symptoms	4	3	3	4
Drugs given with the explicit intention to hasten death	0	0	1	1

* A total of 160 returned questionnaires on deaths that could have been preceded by an end-of-life decision plus 17 sudden and unexpected deaths for which the physician did not receive a questionnaire.
† The large difference between the numbers in 1995 and 2010 can be explained by differences in number of deaths during the study period and response rate; 1995: 338 deaths in study period, response rate 96% versus 2010: 223 deaths in study period, response rate 78%.
‡ Rounded and weighted percentage of all deaths of children under 1 year of age in the Netherlands in that year.

Comparison with earlier years

In 1995, 2001 and 2005, comparable percentages (62%, 68% and 59%, respectively) of deaths of infants under 1 year of age were preceded by an end-of-life decision (table 2.1). (4,5) As of 2010, these end-of-life decisions were mainly decisions to withdraw or withhold potentially life-sustaining treatment. In 1995, 2001 and 2005, the percentage of cases in which drugs were administered with the explicit intention to hasten death, in combination with another end-of-life-decision, was 8% (95% CI 5% to 12%). In 2010, this percentage has decreased to 1%, (95% CI 0% to 4%). In 1995 and 2001, 1% of all deaths involved an isolated decision to use life-shortening drugs with the explicit intention to hasten the death of an infant (without another preceding end-of-life decision). In 2005 and 2010, no such cases were found.

Characteristics of 2010 cases where death was intentionally hastened by using drugs

The 2010 sample included only two cases where physicians indicated that they had administered drugs with the explicit intention to hasten death. The text box presents some details of these two cases, based on the responding physicians' answers to the questionnaire.

Case 1

An infant that died at a neonatal intensive care unit (NICU). Information on the child's diagnosis is missing. The involved physician indicated that artificial respiration was withdrawn with the explicit intention to hasten death. The child's future quality of life was estimated to be so poor that prolonging life was deemed futile. The child also received morphine and a benzodiazepine with the explicit intention to hasten death. The physician indicated that the drug dosages used to alleviate symptoms had not been higher than necessary. During the dying process, a neuromuscular blocker was administered to stop gasping. The child was less than a week old when it died, and its life was estimated to have been shortened by a week at most. The responding physician labeled his act as a 'non-treatment decision' and the death was reported as a natural death.

Case 2
An infant that died at a pediatric ward in a hospital. The child was born with congenital abnormalities. It received morphine and was, during 8 weeks, continuously sedated with midazolam until death. The child had received artificial fluids and nutrition during this period. The responding physician indicated that artificial respiration and cardiovascular medication were withdrawn with the explicit intention to hasten death. The child was thought to have no realistic chance of survival. The physician indicated that death was caused by the administration of morphine with the explicit intention to hasten death. The physician indicated that the drug dosages used to alleviate symptoms had not been higher than necessary. The child was between 1 and 3 months old when it died, and its life was estimated to have been shortened by a week at most. The physician labeled his act as 'palliative sedation' and the death was reported as a natural death.

Discussion and conclusion

The Dutch practice of end-of-life decision-making for children under 1 year of age has changed little compared with 2005, 2001 and 1995. However, the frequency of using drugs to deliberately hasten death decreased in 2010. We believe that the routine ultrasound examination around 20 weeks of gestation and the legal provision for deliberately ending the life of a newborn, both introduced in 2007, can provide plausible explanations for this decreased frequency. We will explain why.

All 22 cases of deliberate ending of life that were reported to the public prosecutor between 1997 and 2004 concerned cases of children with severe spina bifida. (6) After 2007, however, only one case of deliberate ending of life was reported to the new expert committee that has to review these cases. (3) This one case did not concern a newborn with spina bifida, but it concerned a newborn with the lethal form of epidermolysis bullosa, for which no alternative could be found to relieve its severe pain and suffering. (3,7) It seems that spina bifida is no longer a reason to end a newborn's life. It has been demonstrated in earlier research that the introduction of the ultrasound examination around 20 weeks of gestation resulted in significantly fewer children with spina bifida (or other congenital abnormalities) being born, because many parents opt for termination of the pregnancy. (8) In the period between 2004 and 2006, in 44% of the cases of women carrying a foetus with a neural tube defect (e.g. spina bifida), the pregnancy was deliberately terminated; in the period between 2007 and 2009, this percentage was

70 and in the period between 2010 and 2012, this percentage was 73. For foetuses with chromosomal abnormalities, the same trend can be seen; in 2004–2006, 30% of these pregnancies were terminated, in 2007–2009, 46% were terminated and in 2010–2012, 48% were terminated. (8) Parents of children with major congenital abnormalities (diagnosed antenatally) who are born alive today are likely to have already made a decision in favour of provision of life-sustaining treatment and are thus less likely to ask for deliberate ending of life. The moment of deciding to end a child's life is shifted to pregnancy. This does not imply, however, that this decision has become easier or ethically less problematic; late termination of pregnancy has its own ethical and emotional complexities, but those are beyond the scope of this paper.

End-of-life decision-making at today's NICUs will mainly concern children who are born prematurely or who suffered from severe asphyxia during birth. In both these situations, the use of drugs with the explicit intention to hasten death is not likely to be regarded as acceptable by the expert committee. The argument to end the life of a severely asphyxiated child mainly relates to an expected poor quality of life or a future without perspective. Although some paediatricians regard this as an acceptable reason to deliberately end life, the expert committee does not. This is because the legislator has made clear that the child must suffer unbearably at the moment the decision is made, so its bleak prospects are not seen as an acceptable reason for deliberately ending life. (1,9)

For prematurely born children, life-shortening drugs will not often be used to hasten death either, since these children are likely to be dependent on life-sustaining treatment that can be withdrawn in case physicians and parents think that continuing treatment is no longer beneficial to the child.

Life-shortening drugs to hasten death might then be used to end a protracted dying process. (10,11) Recently, the Royal Dutch Medical Association (KNMG) has published a report with recommendations on end-of-life decisions for newborns, in which they express the opinion that the use of lethal drugs (i.e. neuromuscular blockers) to end a protracted dying process (whether to relieve the suffering of the patient or the parents) should be seen as acceptable. (12) According to the KNMG, this act should be reported to the expert committee who should review it as acceptable. Although the report – stating the official opinion of the medical profession – may be considered to have a normative status in the Dutch medicolegal context, the due care criteria of the official legal provision do not (yet) allow for the use of lethal drugs to relieve the suffering of the parents and/or without consulting an independent physician. (1,9)

Differences in interpretations of the legal provision

In addition to the finding that the frequency of the use of life-shortening drugs with the explicit intention to hasten death has decreased, the details of the cases presented in the text box suggest that physicians may classify their acts differently than the expert committee would. Further, the relation between the physician's reported intention and his actual acts appears to be not self-evident. In case 1, the life-shortening drug used was a neuromuscular blocker, which certainly will hasten death if not administered with artificial ventilation. According to the expert committee's definition of deliberately ending life, this act would classify as such and should be reported. (3) The KNMG also states this act should be reported as deliberately ending life, but they disagree with the expert committee about how it should be reviewed. (12) The physician in case 1, however, classified this death as a 'natural' death and did not report it to the committee. There are other paediatricians who share this viewpoint and who do not regard this act as deliberately ending life. (11)

In case 2, the physician indicated to have administered a life-shortening drug with the intention to hasten death, but the drug given was morphine, in a dose that was reported not to be higher than necessary to alleviate pain and symptoms. The use of morphine in a dose that is not higher than necessary to alleviate pain and symptoms is, at least from a legal point of view, regarded as symptom management and falls under 'normal' medical practice. This physician may have had the intention to hasten death when he used morphine (although this was probably not his sole aim, since there was also a need for alleviation of pain and symptoms), but it is questionable whether the use of morphine indeed had a life-shortening effect. (13,14)

Limitations and strengths

The limitations of this study are its retrospective design and the fact that the study is based on physicians' own perception of their actions and intentions rather than on a report of the actual drugs used and the clinical details of the patients. The strengths of this study, however, are the large number of respondents, its nationwide character, the high response rate and the fact this study has been conducted approximately every 5 years since 1995. This makes it possible to monitor the Dutch practice of end-of-life decision-making through the years and to signal changes in practice.

Conclusion

We conclude that the Dutch practice of end-of-life decision-making for children under 1 year of age has changed little between 1995 and 2010. The frequency of the use of life- shortening drugs with the explicit intention to hasten death, however, has decreased after the introduction of ultrasound examination at 20weeks of gestation as a routine prenatal screening procedure and of the legal provision for deliberately ending life, including the installation of an expert committee to review these cases.

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Katja ten Cate interpreted the data and wrote the first draft of this article. Suzanne van de Vathorst was her supervisor; she made a substantial contribution to the conception and design of the article and revised it critically. Bregje D Onwuteaka-Philipsen and Agnes van der Heide were involved in the design of the study and the collection and analysis of the data. Both revised the article critically.

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Chapter 3
Paediatricians' views on good dying for neonates

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Abstract

Objective To assess Dutch paediatricians' views on neuromuscular blockers for dying neonates.

Study design Qualitative study involving in-depth interviews with 10 Dutch paediatricians working with severely ill neonates. Data were analysed using appropriate qualitative research techniques.

Result Participants explained their view on neuromuscular blockers for neonates with a protracted dying process. Major themes were the interpretation of gasping, the role of (the suffering of) the parents, the need for judicial review and legislation's impact on the care participants provide for dying neonates.

Conclusion The interviews show no consensus between paediatricians and provide insights into the points of disagreement. Interviews also suggest friction between the convictions of paediatricians and legislation, which seems to have an undesirable impact on Dutch care for dying neonates and their parents. This study raises important questions for paediatricians worldwide to reflect upon, such as: 'what constitutes 'dying well'?' and 'what role should the parents' perspective play?'.

Introduction

In the Netherlands, a legal provision exists to allow for deliberately ending the life of a neonate (DELN). (1) This is defined as: the administration of a drug by a physician with the explicit intention to end the life of a severely ill neonate. (2) This legal provision, however, does not function well.

Paediatricians do not report cases of DELN and the desired transparency about the practice of DELN is not realized. (2,3) More insight into the practice of DELN and paediatricians' views on it may provide explanations for the lack of cases being reported.

The Dutch have a long history of public debate about (legislation on) medical decisions at the end of life in general, and about end-of-life decisions for neonates in particular. (4-7) Due care, transparency and accountability have been keywords in this debate. In 2006, the debate about DELN for severely ill neonates resulted in a legal provision that makes it possible for a physician to perform DELN without being prosecuted in case certain criteria of due care are met. (1)

These criteria of due care entail that the child is suffering unbearably and hopelessly, that the parents are fully informed about diagnosis and prognosis, that the paediatricians and parents together have reached the conclusion that there are no other reasonable ways to relieve the suffering of the child, that the parents have given consent, that an independent physician has been consulted and that the DELN will be performed 'lege artis'. In addition, the legislation entails that a physician who performs DELN has to report this to an expert committee (with three paediatricians, a lawyer and an ethicist) that was installed to judge cases of DELN by assessing the criteria of due care. The expert committee will inform the public prosecutor, who ultimately decides whether to prosecute (for murder or manslaughter) or not.

This legal provision, however, appears not to function in practice; in seven years just one case of DELN has been reported to the expert committee, while based on earlier research the estimated number of cases was much higher. (8-10) One possible explanation for the lack of reported cases is that it is not clear what actions should be classified as 'deliberate ending of life'. This seems to apply to the use of neuromuscular blockers (NMBs) to end a protracted dying process. (2,11,12) From earlier research, we know that the NMBs are sometimes used in the Netherlands to hasten the death of a gasping neonate whose dying process takes long. (11,13,14) Although these cases, strictly interpreted, might be classified as DELN, paediatricians have not reported these cases to the expert committee. This might be because paediatricians do not perceive the use of NMBs as DELN. Practice and legislation do not match in this respect. (2,11,12) The aim of this study is to gain more insight in paediatricians' views on the use of NMBs for dying neonates against the background of the current legal provision for DELN and to find explanations for the mismatch between practice and legislation. This insight can be a step to let legislation and practice be better aligned.

The research question of this study was: what do Dutch paediatricians think about the use of NMBs to end a neonate's protracted dying process accompanied by persistent gasping? More specifically, we wanted to know: 1) Would paediatricians find the use of an NMB in the dying phase acceptable and for what reasons? 2) Would paediatricians classify the use of an NMB in the dying phase as DELN (and why or why not)? 3) Do paediatricians think the use of NMBs in the dying phase should be subject of judicial review (and why or why not)? 4) What is, in the paediatricians' view, the influence of the current DELN legislation on the care they provide for dying neonates? To answer these questions we have conducted qualitative interviews with Dutch paediatricians working in the care for severely ill neonates.

Methods

Participants and data collection

We held in-depth interviews with 10 paediatricians working in the care for severely ill neonates. Nine are neonatologists, working on a neonatal intensive care unit (NICU), one is a paediatric neurologist working in a large children's hospital. Because we assumed that practices might vary depending on the affiliation of the hospital and its policies on end-of-life matters, we wanted to interview a neonatologist from every Dutch NICU. We managed to do so, apart from one NICU; unfortunately, it was not possible to arrange an interview in time with a neonatologist from this NICU. We also interviewed a paediatric neurologist, because neurologists are often involved, as well, in the decision-making process for severely impaired infants.

The interviews were part of a larger study; an evaluation of the legal provision for 'late termination of pregnancy and deliberately ending the life of a neonate'. As a result, the paediatricians in this study were asked about the practice of and the legal provision for DELN, a subject with a broader scope than what is discussed in this article. With regard to the subject of this article the following topics were covered during the interviews: interpretation of gasping, possible suffering of the child who gasps, role of the (suffering of the) parents, the acceptability of NMBs (and the conditions for that), the use of NMBs in relation to the DELN legislation, participants' view on the DELN legislation and its impact on practice. The interviews were held in the paediatricians' own offices and each lasted approximately one hour. All participants consented to the interview being recorded with an audio recording device and transcribed verbatim. Many open-ended questions were used in order for participants to tell us about their experiences and

perceptions in their own words. Two researchers conducted the interviews (KC and IB). The first interview was conducted together and was reflected upon to refine the topic list. During the period the interviews were held both researchers met several times to talk about the interviews to stay attuned. Both the researchers are trained in medical ethics, KC also has a medical background.

Analysis of the data
The interviews were systematically analysed with techniques for qualitative data analysis by KC. Several measures were taken to increase the validity of the analysis. (15) KC read the interviews several times and every fragment was given a code (open coding). After this initial round of coding, IB read all the interviews, as well, and looked into the codes to make sure that no important themes were missed. Further analysis was done by KC. The focus was on the fragments that had to do with the topic of this article; the use of NMBs in the dying phase and its relation to the DELN legislation. These fragments were further analysed during several phases of coding (axial and selective coding); codes were refined, sub codes and overarching codes were assigned and relationships between codes were explored. (16) Interviews were also analysed as a whole, to look for patterns and inconsistencies in reasoning. Part of the analysis and the methods used were discussed in an intervision group of PhD students, all doing qualitative research.

Results

Paediatricians on the acceptability of NMBs in the dying phase
In the interviews we encountered proponents, as well as opponents of the use of NMBs to end a protracted dying process accompanied by persistent gasping. (See figure 3.1 for the variety of opinions encountered in the interviews). Proponents gave different reasons why they would find the use of NMBs acceptable. The two main reasons that were mentioned were relieving the suffering of the child and the parents. Proponents of the use of NMBs did not agree on the question whether a dying child could suffer from the gasping. Some said that it is not possible for the child to suffer because of the comatose state it would be in.

> 'The child will not suffer from gasping because it will be comatose owing to the high level of carbon dioxide.' (R9)

> 'Gasping is a very basic function that remains for a long time, but at that point the child will be brain dead and cannot suffer.' (R6)

Others said that the suffering of the child could not be dismissed off hand, and that therefore it is assumed to be present.

> 'We do not know if the child suffers from gasping, that is why we interpret it as such.' (R10)

All the interview participants who believed the child might be suffering from gasping would find the use of NMBs acceptable if the suffering could not be relieved in other ways (with a higher dose of analgesics and/or sedation).

For the participants who did not think the child could suffer from gasping, but would find the use of NMBs acceptable, it was the suffering of the parents that made it acceptable. These participants said that a protracted dying process accompanied by persistent gasping could be too burdensome for some parents. Therefore, these participants would find the use of NMBs acceptable in case the parents would indicate that they could no longer cope with the situation and would ask the doctor to put an end to the dying process.

All opponents of the use of NMBs believed that the child could not suffer from gasping. For them, the suffering of the parents did not make the use of an NMB to end the dying process an acceptable option.

Proponents of the use of NMBs at the request of the parents argued that the suffering of the parents could be taken into account because the child no longer has any interest in what happens to him as he is in an irreversible coma.

> 'Almost all parents will accept gasping if they are well prepared in advance. But sometimes it takes so long, twelve hours or so, and then parents become exhausted. Then I wonder what is the use of continuing this for another couple of hours. Why should we make these parents wait until that gasping finally stops, while we know for sure that the child is in an irreversible process and will die within a day? I know it is problematic in a legal sense to take the suffering of the parents into account, but for the child it does not matter anymore. And otherwise parents are left with a very bitter taste about something that is supposed to be a humane and dignified goodbye to their child.' (R9)

> 'The suffering of the parents should definitely count in such a situation. Not in decisions to withdraw treatment, then it is all about the child's interests, but when that child is not there anymore actually, it should be about the parents.' (R6)

For opponents of the use of NMBs on the other hand, it was precisely their conviction that a child does not suffer from gasping that was the reason not to use NMBs.

> 'Yes, there are parents who ask me to put an end to the dying process because of the gasping, but unless the patient suffers I am not going to do something about it.' (R5)

They favoured a more natural course towards death and did not want to 'cover up' a dying process artificially for the sake of the parents.

> 'I tell parents it is up to the child to choose the moment it dies. (…) Because we tried to hide death, we are not used to it anymore and we are scared of it. We should not cover it up, it is a normal part of life.' (R5)

> 'Gasping is just a natural part of the dying process. If you explain that to parents and prepare them very well in advance I do not see any reason to use NMBs. I am more a proponent of good counselling for parents, including help from psychologists, spiritual counsellors and social workers. And I see all parents six weeks after their child's death, I have never heard any complaints.' (R4)

Ending the dying process: DELN or not?

All the interview participants made a clear distinction between ending the life of a child who is already dying and ending the life of a child who would otherwise not be dying. The first situation, so participants explained, applies to the situation already described above; the child in a protracted but undeniable and irreversible dying process accompanied by persistent gasping that receives an NMB to end the process. The second situation then would apply to a child who is not depending on life support (except for maybe artificially given fluids and nutrients) and is not dying, but whose life is terminated deliberately with a lethal drug for reasons of severe suffering that could not be relieved otherwise and/or a very poor prognosis. Although all the interviewed paediatricians regarded the use of NMBs in the dying process (which some would call 'help with dying') as a separate issue, distinct from termination

of life of a stable child, participants thought differently about the question whether to regard the use of NMBs as deliberately ending life (DELN).

Most of the interview participants did not regard the use of NMBs as DELN; they would restrict the use of the term DELN for the situation of the child who would not be dying if it would not be given a lethal drug.

> 'The DELN legislation was designed for the active ending of life, which in my view refers to a severely damaged but stable baby whose death will be arranged; 'tomorrow morning 9 o'clock'. That is a totally different situation than a gasping baby in a dying process whose parents cannot cope with the situation any longer. That is not about ending life, it is about facilitating good dying, good dying in the eyes of the parents.' (R3)

Other participants did regard the use of NMBs as DELN.

> 'Yes, I would call this termination of life too, because it is still your action that determines the time of death.' (R5)

Judicial review

In the interviews it became clear that it is not the case that all participants who think positively about the use of NMBs to end the dying process would be against judicial review of this type of action in the context of current DELN legislation. The interviews showed that there is a range of opinions about this matter, as can be seen in figure 3.1. For example, some of the proponents of the use of NMBs argued that these cases meet the criteria of due care for DELN, because the suffering of the child could not be relieved otherwise. While other proponents suggest that some clause should be added to the current legislation to allow for the suffering of the parents to have a role in these particular cases (cases where the child is in an irreversible dying process and lacks consciousness).

> 'I am not against review. It seems like a good idea to me to have one central point where these cases can be reported and judged to see whether it is done carefully and 'lege artis', so it becomes clearer what everybody is doing. However, that means that the criteria should change for these particular cases. Moreover, it is my opinion that in case the expert committee gives a positive judgment, this kind of cases should be kept away from public prosecution. In contrast to the 'real' DELN, the active ending of the life of a stable baby; that is such an extraordinary situation, I do not mind that public prosecution looks into those cases.' (R2)

Other proponents of the use of NMBs were of the opinion that these cases should not be reported to the expert committee at all; they do not perceive them as DELN in the first place.

> 'This is not about ending life, but about facilitating good dying in the eyes of the parents. You should not make that subject of judicial review. That makes it a very heavy and complicated decision for a physician to make, due to the fears he then might have for his own position. That is not desirable in an acute situation of a dying baby and its parents who are in need. A physician should be able to do what he thinks is needed to make this a good, meaningful and humane experience.' (R3)

The current legislation's influence on care

Interview participants told us that they see an influence of the current legal provision concerning DELN and its interpretation by the expert committee on the care they provide for dying neonates. Some proponents of the use of NMBs, including some who believe the child might be suffering from the gasping, told us that the fear of legal consequences was the reason they refrained from the use of NMBs.

> 'I am not against NMBs, it could be a sound solution to stop persistent gasping. But I think I do agree, actually, with those who say NMBs cause an unnatural death and should be seen as the active ending of life. As long as we do not know for sure that we will not get legal trouble with it, we will not use them. So we tell the parents legislation forbids us to make an end to the gasping.' (R10)

Other proponents reported that they still use NMBs, but less frequently; only when they believe it to be absolutely necessary to prevent severe suffering for the child or its parents. They do not report this as DELN, in the first place because they do not perceive it as DELN, and secondly because they fear legal consequences if it would be judged as such.

> 'The expert committee has a rather strict reputation. I think that makes paediatricians reluctant to use NMBs and when they do use them they will not report it.' (R2)

All proponents of the use of NMBs to end the dying process indicated that they would use them more often if that were permitted. Some participants conclude that the current legislation and the expert committee's

interpretation of it have made the care they provide less optimal than they would want.

> 'A good death, I think that is very important, but I do not fancy 2 years of legal trouble. So yes, I think this influences practice, if you know you could be judged strictly, you will be inclined to 'play it safe', but sometimes that will be disadvantageous to the child and its parents.' (R3)

Besides the alleged negative effects of the legislation, participants also acknowledge that the legislation has led to more awareness of the fact that the use of life-shortening drugs in the dying process will lead to an unnatural death and can therefore be problematic in a legal sense. Participants saw it as a positive thing that, in general, a child is given more time to die in a natural way now, owing to this increased awareness and thus decreased use of drugs that could hasten death, because they believed this to be beneficial to the parents' grieving process. They were also positive about the fact that the current legislation has urged them to involve the parents more and to prepare them well for what they can expect when their child dies.

> '25 years ago when I did my training, the boss would go home after the decision was made to withdraw treatment and the fellow would pull the tube out and gave the child a huge dose of morphine to be sure it died quickly. With this discussion on DELN, the awareness increased that this, of course, would not be a natural death and thus would be problematic in a legal sense. It is good that we are far away from that type of practice now. (…) Being born takes some time, so does dying.' (R10)

> 'I see in practice that, as the expert committee made clear that they would judge negatively about the use of NMBs, we have taken this into account and only use NMBs when absolutely necessary to prevent trauma for the parents. I have to admit, most of the time patience, explanation and palliative sedation will do very well. (…) The child is given more time to die now, and I think that is fine. To make it a process the parents can even enjoy, holding their child that is finally without all the wires and tubes.' (R7)

Furthermore, several participants expressed the view that the exact medication at the very end of life was subordinate to the earlier decision to withdraw further treatment. That is the reason some would find it disappointing that the Dutch debate about end-of-life decisions for neonates seems to

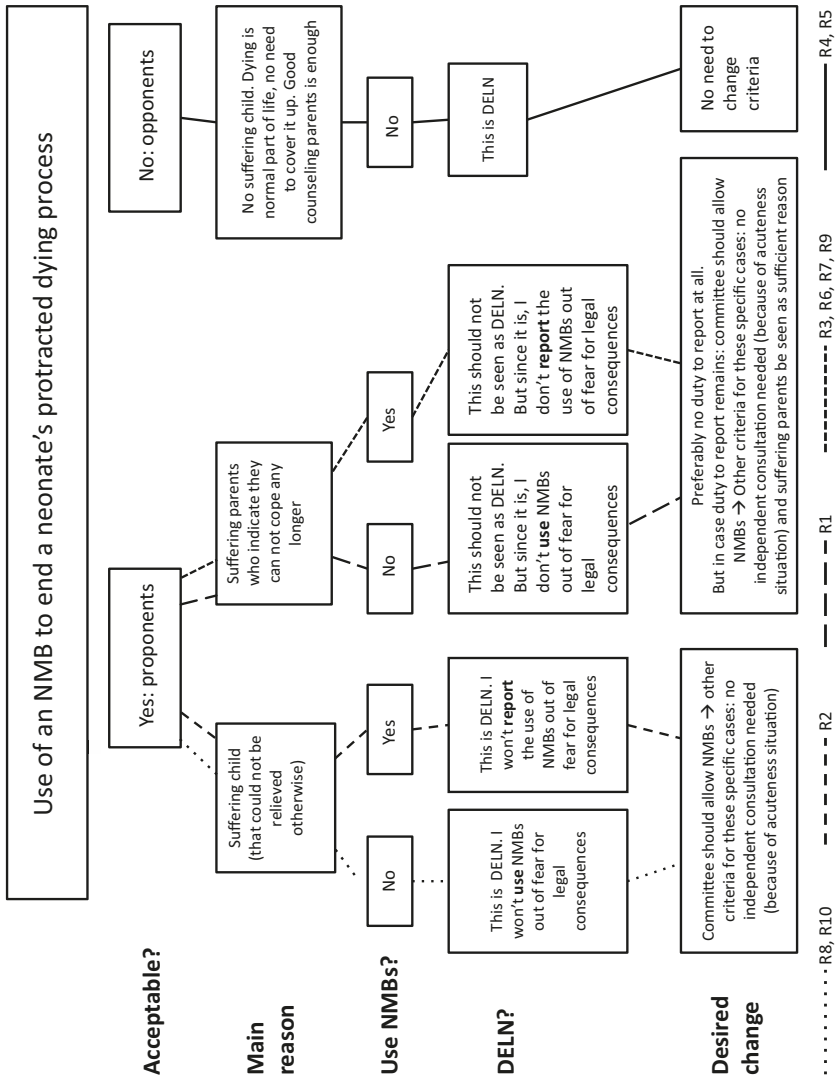

Figure 3.1 Opinions on the use of NMBs for dying neonates encountered in interviews with Dutch paediatricians.

focus on the use of NMBs to end a protracted dying process, while they believe the debate should be about when to start treatment, and if started, when to stop. Most participants expressed a great need for clear criteria and guidance on this matter and would not mind more debate about, and even (judicial) review of, these treatment decisions. The current focus on the use of NMBs has led to discontent for some participants; they do not

feel acknowledged for the work they do, the difficult decisions they have to make and the good intentions they have.

> 'It should not be about those last five minutes. The focus on that is severely detrimental to all the effort that paediatricians put into those difficult decisions about when to treat and when to stop.' (R1)

Discussion

The results of our study show that paediatricians think differently about the use of NMBs to end a protracted dying process of a child who persistently gasps. They differ in their view on the (lack of) suffering of the child and the role that the suffering of the parents should have. There is also no consensus about how the use of NMBs should relate to the current DELN legislation. These points of disagreement can also be found in literature on this topic. (17-21) Despite their disagreements, however, paediatricians perceive the use of NMBs in the dying phase as clearly distinct from DELN on a stable child. In the first situation the central questions are what 'dying well' looks like and how this should be realized. Although this question is answered differently (some believe NMBs can be an answer, while others favour a more natural course towards death), the fact that the doctor has a role to play in the care for the dying child and its parents is not disputed. This contrasts with the situation of the stable child who will not be dying soon, but whose life is ended deliberately because its (future) quality of life is deemed to be very poor.

The DELN legislation was created with the latter cases in mind. (10) However, the expert committee has made clear that the use of NMBs should be reported as DELN, and then, most likely, a negative judgment would be sent to the public prosecutor because the criteria of due care are not met. (2) The effect of the current legislation and this interpretation of it by the expert committee on the care paediatricians provide is that they have become reluctant to use NMBs out of fear for legal consequences. What used to be perceived as normal palliative care by many paediatricians is now drawn into the realm of criminal law. On the one hand, this has increased paediatricians' awareness that life-shortening drugs can cause an unnatural and hastened death, and thus should be avoided when not necessary. This is probably beneficial for the parents too, because they are allowed more time with their dying child to make it a meaningful experience. (22,23) On the other hand, there are still cases, although rare, where paediatricians

perceive the use of an NMB to be necessary to provide good care for the child or its parents. Some paediatricians set aside their own convictions about what would be best and do not use NMBs, including paediatricians who believe the child might be suffering. Others let their own convictions prevail and do use NMBs, but will not report this to the expert committee. Fear seems to be a poor basis for decision-making, as both situations are not desirable; the first might amount to more suffering than necessary, the second hinders transparent practice.

Limitations

This qualitative study was small. Figure 3.1 shows all the opinions encountered in the interviews, but one can conceive of other positions as well that were not represented by the interview participants. The findings of this study cannot be generalized to all Dutch paediatricians working with severely ill neonates. Despite the limitations of this study, however, the conclusion that there is no consensus among paediatricians about the use of NMBs in the dying phase seems very plausible. Furthermore, our interviews have provided more insight into what points of disagreement there are. The interviews also suggest that the current DELN legislation has an effect on the care paediatricians provide to dying neonates and their parents.

Conclusions

We conclude that this study signals friction between legislation and the ethical convictions of a part of Dutch paediatricians. This is problematic, especially for legislation, which relies on physicians' willingness to report. Without the support of those whose practice it is about to regulate, legislation will not serve its purpose. (24) The findings of our study give rise to the question how to let legislation and practice be better aligned. The finding that there is no consensus among paediatricians makes it harder to adjust legislation to fit practice, as practice has a heterogeneous character. More consensus among paediatricians about what would be acceptable ways to deal with a dying neonate and its parents seems needed to bring practice and legislation closer. More debate on this topic might be a step to reach more consensus. We suggest that this debate should be initiated soon. Important ethical questions that need to be reflected upon in this debate are: what comprises 'dying well' for a neonate and should the parents' perspective on that be allowed to have a role? In addition to that, as proponents, as well as opponents of the use of NMBs use the parents' grieving process, among other reasons, as a justification for their actions, more insight into what is beneficial for parents' grieving process seems needed.

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Katja ten Cate designed the topic list, recruited respondents, conducted interviews, analysed the data and wrote the first draft of this article. Suzanne van de Vathorst was her supervisor; she made a substantial contribution to the conception and design of the article and revised it critically.

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Part 2

Chapter 4
General practitioners' considerations on requests for euthanasia and assisted suicide

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Abstract

Background In the Netherlands, euthanasia or assisted suicide (EAS) is neither a right of the patient nor a duty of the physician. Beside the legal requirements, physicians can weigh their own considerations when they decide on a request for EAS.

Objective We aim at a better understanding of the considerations that play a role when physicians decide on a request for EAS.

Methods This was a qualitative study. We analysed 33 interviews held with general practitioners (GPs) from various regions in the Netherlands.

Results The considerations found can be divided in three main types. (i) Perceived legal criteria, (ii) individual interpretations of the legal criteria and (iii) considerations unrelated to the legal criteria. Considerations of this third type have not been mentioned so far in the literature and the debate on EAS. Examples are: the family should agree to EAS, the patient's attitude must reflect resignation, or conflicts must be resolved.

Conclusions Our study feeds the ethical discussion on the tension that can arise between a physician's own views on death and dying, and the views and preferences of his patients. When considerations like 'no unresolved conflicts' or 'enough resignation' influence the decision to grant a request for EAS this poses questions from an ethical and professional point of view. We hypothesise that these considerations reflect GPs' views on what 'good dying' entails and we advocate further research on this topic.

Introduction

In the Netherlands, euthanasia or assisted suicide (EAS) largely takes place within general practice; in 2014, 88% of the EAS cases were performed by a GP. (1) Patients who have a wish to die can request their treating physician, mostly a GP, to perform either euthanasia (in which the physician administers a lethal dose of a suitable drug to a patient) or assisted suicide (where the physician supplies the drug but the patient administers it himself). The same regulations apply to both options. (2) When Dutch physicians perform EAS, they need to comply with the legal criteria of due care, laid down in the Termination of Life on Request and Assisted Suicide (Review procedures) Act. (2) These legal criteria of due care are listed in text box below.

1. *The physician must be satisfied that the patient has made a voluntary and carefully considered request;*
2. *The physician must be satisfied that the patient's suffering is unbearable, and that there is no prospect of improvement;*
3. *The physician must have informed the patient about his situation and his prospects;*
4. *The physician must have come to the conclusion, together with the patient, that there is no reasonable alternative in the light of the patient's situation;*
5. *The physician must have consulted at least one other, independent physician, who must have seen the patient and given a written opinion on the due care criteria referred to above;*
6. *And the physician must terminate the patient's life or provide assistance with suicide with due medical care and attention.*

The Act is designed to shield physicians against criminal liability, not to empower patients. Compassion of the physician with his suffering patient is the key rationale of the Act, not the autonomy of the patient; although a voluntary and careful considered request is a necessary prerequisite, it is not a sufficient one. (3,4)

The due care criteria are adopted from Dutch case law on EAS (in particular, the Postma case (1973) and the Schoonheim case (1984))(3,4). The Chabot case (1994) and the Brongersma case (2002) are two other influential cases from Dutch case law. In both these cases, the criterion of unbearable suffering, that was already developed in earlier cases, was refined. (3,4) In

1994, the Supreme Court ruled in the Chabot case that it is the severity of the suffering (in combination with the lack of prospect of improvement) that counts, not the cause of the suffering. (5) This vision of the Supreme Court found support in the parliamentary debates on the Act before it came into force in 2002 and is one of the foremost reasons the Act does not discriminate between physical and psychiatric suffering. (5) This does not mean though, that any perceived suffering is allowed to be a ground for a physician to perform EAS. In 2002, the Supreme Court ruled in the Brongersma case that the suffering of the patient needs to originate mainly in a medically classified condition for a physician to escape criminal liability when he performs EAS. Suffering caused by other than medical conditions was thought to lie outside the domain of medical expertise. (6) This is still the current judicial norm.

The Dutch legislator has purposefully formulated the due care criteria in an open and abstract manner. (3,4) According to Griffiths and Pans, the legislator has done so with the intention to do justice to the specificity of individual cases and to allow for the interpretation of the criteria to shift in accordance with changes in public and professional opinion. (3,4) The Regional Review Committees have recently published a 'Code of practice' in which physicians are given guidance on how the due care criteria can be interpreted in practice. (7) Nevertheless, the open and abstract formulation of the criteria implies that physicians are to apply and interpret the criteria themselves when they receive a concrete request for EAS. Furthermore, there is, in Dutch practice, room for physicians' own considerations that may not be related to the legal criteria or the interpretation of those criteria. Because EAS is thought of as an extraordinary action, not belonging to normal medical practice, physicians are, at least where the Dutch Act on EAS is concerned, free to make their own considerations and to refuse a request at any time and for whatever reason. (3,4)

To get a better picture of the considerations that play a role when physicians decide on a request for EAS, we analysed 33 in-depth interviews held with general practitioners (GPs) from various regions in the Netherlands. Since EAS in the Netherlands largely takes place within general practice, this is the place to look for physicians' considerations regarding EAS requests. We had the following research question: what considerations play a role in practice when Dutch GPs have to decide on an EAS request?

Methods

The 33 qualitative interviews with Dutch GPs, that we report on here, were conducted earlier (in 2010) as part of a large nationwide study into the knowledge and opinions of the general public and professionals on decision-making and treatment at the end of life: the KOPPEL study. (8,9)

We used two different sets of interviews from the KOPPEL study; one set of 18 interviews with Dutch GPs about their experiences, knowledge and opinions regarding EAS, and another set of 15 interviews with Dutch GPs that were more specifically about reasons for granting an EAS request or not. Although the two sets of interviews had a different aim and topic-list, both sets of interviews proved to be a rich source of considerations that play a role in deciding on EAS. That is the reason we combined both sets of interviews, and did a secondary analysis on them with our own research question.

Data collection (*KOPPEL study*)
The first set of interviews (18) was about GPs' experiences, knowledge and opinions regarding EAS. For this set of interviews, the KOPPEL researchers made a list of 25 GPs who had been taking part in the quantitative survey of the KOPPEL study and had indicated that they were willing to take part in a follow-up interview study. This list of 25 potential interviewees came about through purposive case selection. Two factors played an important role in this selection: experience with and attitude towards EAS. Attitude towards EAS was categorized as liberal, neutral or conservative, based on respondents' answers to five statements about autonomy and EAS from the KOPPEL's quantitative survey. The statements had a five point likert scale from totally agree to totally disagree and were:

- 'I believe everyone has the right to get EAS if so desired';
- 'I believe EAS should be allowed for people who have a wish to die but do not suffer from a severe disease';
- 'I believe everyone has the right to decide about his own life and death';
- 'I believe a physician should stop medical treatment if the patient requests that';
- 'I believe elderly people who wish to die should get lethal drugs to end their own lives if they wish'.

On the basis of the answers to these five statements, an additive 'right to die'-index was built by the KOPPEL researchers. The items used to build the index show a high internal consistency (Cronbach alpha: 0.81). The minimum score on this index was 5, the maximum was 25. A score between

5 and 14 was categorized as conservative, a score of 15–19 as neutral and a score of more than 19 was categorized as liberal. Age and gender were no selection criterion in the purposive case selection but these characteristics were post hoc checked for to make sure distribution was balanced. From this list of 25 selected cases, 18 were eventually interviewed, because at that point data saturation was reached. Every time a next respondent from the list was invited to give an interview, the KOPPEL interviewers tried to keep the distribution balanced. Eventually, 8 GPs with a liberal attitude, 8 with a conservative and 2 with a neutral attitude were interviewed. 15 GPs with experience with EAS were interviewed and 3 without. 12 respondents were male, 6 were female. Respondents' age ranged from 35 to 61 years, with a mean age of 49.4 years. Table 4.1 shows the characteristics of these 18 respondents.

Three separate interviewers (BV, PK and DT) conducted these 18 interviews. The interviews were conducted at the GPs' working place and lasted about an hour. Before the start of the interview, the voluntary character and confidentiality of participation were emphasised. Respondents agreed to the interviews being recorded with an audio recording device. The interviews were semi-structured with the use of an interview guideline with open questions and topics. First, the respondents were asked about their thoughts regarding euthanasia. To explore opinions about EAS further, participants were asked what they would tell a foreign colleague about Dutch EAS practice and how it is regulated. The GPs were asked to reflect on vignettes that were also used in the quantitative questionnaires. Finally, personal experiences (if any) with (requests for) EAS were discussed. The interview guideline was tested in a pilot study for length and comprehensibility by all three interviewers. This led to some minor adjustments. Because several researchers performed the interviews, the use of the interview guideline was discussed and practised intensively during an interview-training weekend set up for this purpose. One of the interviewers (BV) monitored the degree of saturation by reading all the interviews to see whether any new opinions, thoughts and patterns of reasoning were brought up.

The second set of interviews (15) with other GPs was more specifically about reasons for granting an EAS request or not. These respondents were selected via snowball sampling; after an interview respondents were asked if they would know of other eligible interview candidates, preferably people they thought would have a different opinion on EAS. After 15 interviews, no more new considerations came up; data saturation was reached. Gender and age were distributed as follows: 9 respondents were male, 6 were female, age ranged from 37 to 63 years, with a mean age of 51.2 years. 3 GPs worked in a large city, 6 in a smaller city, 1 in a large village and 5 in a rural area. All had

Table 4.1 Characteristics of respondents interview set 1 (18 Dutch GPs interviewed in 2010)

Gender	*Age*	*Attitude on EAS according to 'right to die index' KOPPEL survey*	*Number of EAS performed*
M	44	liberal	1-2
M	61	liberal	1-2
M	54	liberal	>2
M	58	liberal	>2
M	47	liberal	>2
F	51	liberal	>2
F	44	liberal	>2
M	52	liberal	>2
F	35	conservative	none
F	56	conservative	none
M	51	conservative	none
M	58	conservative	1-2
F	38	conservative	1-2
M	45	conservative	1-2
M	52	conservative	>2
F	45	conservative	>2
M	unknown	neutral	1-2
M	unknown	neutral	1-2

experience with rejecting EAS requests. Table 4.2 shows the characteristics of these 15 respondents.

These interviews were all done by SV. First, respondents were asked about the most recent case in which a patient requested them to perform EAS but they refused the request. They were also asked about the case they remembered best. By 'a refused request' situations were meant where the patient requested EAS but the GP refused the request or postponed the decision until it was too late to perform EAS. The reasons for refusing the request were further explored, with the following aspects in mind: knowledge on the legal regulations, interpretation of the situation, prior experiences with EAS (positive or negative), behaviour and attitude of family and patient, and the respondent's opinions regarding EAS.

As tables 4.1 and 4.2 show, a heterogeneous group of GPs is interviewed. The purposive sampling of the first set of interviews, as well as the snowball sampling in the way it was done in the second set of interviews, contribute to finding a wide range of different opinions, thereby increasing the validity of the study. (10)

Table 4.2 Characteristics of respondents interview set 2 (15 Dutch GPs interviewed in 2010)

Gender	*Age*	*Years of experience as GP*	*Geographical area*	*Population*
M	47	15	Rural area	No specific features
F	49	18	City	Many young people
M	56	26	City	Many elderly
M	53	23	City	No specific features
M	43	11	City	No specific features
F	57	11	Rural area	No specific features
F	63	35	Large city	Many young people, immigrants and drug addicts
M	52	20	Rural area	Many people with high level of education
F	56	20	City	No specific features
M	57	28	City	No specific features
M	49	15	Large village	Many elderly
M	37	6	Rural area	Many elderly
M	38	6	Rural area	Many elderly and people with low education and SES
F	55	23	Large city	Many young people, many people with psychiatric problems
F	56	22	Large city	No specific features

Data analysis

For our analysis, we combined both set of interviews, so we reanalysed 33 interviews in total. This analysis was done by KC and SV, with help of MaxQDA, software for the analysis of qualitative data. All interviews were read several times. Fragments in which respondents talked about their considerations for granting or refusing a request for EAS were given one or more codes (open coding). KC and SV compared and discussed the differences and similarities in their coding, which led to a refinement of the code tree. The coded fragments where further analysed by KC during several phases of coding (axial and selective coding); codes were refined, sub codes and overarching codes were assigned and relationships between codes were explored. Interviews were also analysed as a whole, to look for patterns and inconsistencies in reasoning.

Results

By analysing the interviews, we found that quite a number of different considerations come into play when Dutch GPs have to decide upon a request for EAS. We have divided these considerations in three main types: (i) perceived legal criteria, (ii) individual interpretation of the legal criteria and (iii) considerations unrelated to the legal criteria.

Perceived legal criteria

Respondents obviously take into account the legal criteria (see text box) when they have to decide on a request for EAS. However, in the interviews we found that several respondents perceive some things to be legally required while these are not.

This respondent, for example, answers that he thinks a life expectancy of less than 2 weeks is legally required when he is asked in which case EAS would be allowed.

> R: 'The disease must lead to death within the foreseeable future, right? But I thought there was also case law saying that this life expectancy of two weeks mentioned in the law can be longer, but I'm not totally sure about that.' (R10)

Another respondent answers he thinks unbearable pain is a legal requirement, in reaction to questions about a vignette of a cancer patient whose suffering is mainly psychological and existential in nature.

> R: 'She doesn't have physical complaints, like pain. I think unbearable pain is a condition to legally perform euthanasia.' (R14)

In reaction to the same vignette of the cancer patient whose suffering is mainly psychological and existential, the following respondent combines the two misunderstandings and says he thinks physical suffering as well as a disease in a terminal stage are legally required.

> R: 'No, this is not legally allowed, because this physician is not cornered. It is only allowed when one is on the horns of a dilemma; I mean when the suffering is so severe there is no other solution.'
> I: 'and if this same woman would also get physical complaints that cannot be controlled adequately with medication?'
> R: 'Then it would be allowed, but only if she would be in a terminal stage of disease.' (R16)

Another common misunderstanding is the need for a written request; this is not legally required while several respondents think it is.

Individual interpretations of the legal criteria

When GPs receive a concrete request for EAS, they have to apply the law's rather abstract and openly formulated criteria to a real life case. Respondents differed in how they apply the legal criteria. For example, they differed in what they understand and recognise as 'unbearable suffering with no prospect of improvement'. This type of considerations does not stem from incorrect knowledge of the legal criteria like the type of considerations described above, but rather from respondents' individual interpretation of these legal criteria.

This respondent for example says he would find it very hard to perform EAS with a patient who can still walk, talk and eat; apparently the suffering of a patient in such a situation would not (yet) classify as unbearable in this GP's view.

> R: 'Some patients who have been told they can't be cured anymore say after a couple of weeks: 'I feel I'm getting more tired, my condition declines, this last phase of life, I just don't want it'. It would be very hard for me to perform EAS in such situations, when the patient can still move around in his home. Performing EAS on a patient who is still able to talk, to eat, no, it would be a bridge too far in my opinion. (…) Look, if someone isn't able to eat anymore, to drink anymore, feels terrible, is nauseated, vomits a lot of the time, is extremely weakened or has a lot of pain, okay. But without that, I think of someone still walking around. No I won't do that [perform EAS], that would be too hard for me.' (R14)

Many other respondents also mention that psychiatric, psychological and/or existential suffering alone would make it very hard for them to empathise with a patient's unbearable suffering.

> R: 'This request was from a woman with oesophagus cancer, with liver metastasis. So of course, her condition declined slowly, but so far there were no real physical complaints. But she lived alone and didn't accept any help, like home care. She had always been very independent and active. And actually, she wanted to die before she became dependent. Here, we differed of opinion. She suffered from loss of autonomy and a fear of dependency. And she thought her life was meaningless. But I couldn't empathise with that; I thought her condition was still too good to perform EAS.' (R13)

Others state it a bit differently and speak of their feeling they could only perform EAS on patients who have a life-threatening disease, or who are in the final stage of life. For example, this respondent who explains that in his view EAS might only be a solution for people in the last weeks of their lives.

> R: 'A colleague of mine, who works in the same building, recently got an EAS request from a patient with MS. This patient might have lived for another year or two, but didn't want to experience that process of decline. My colleague granted the request. For me that would be very hard. I don't think I would have done that. As a doctor, I don't want to help such patients to step out of life early. My view on EAS is that it is only a solution in the terminal stage, the very last weeks.' (R2)

Another respondent seems to have just the opposite viewpoint. For him, EAS might be a solution for those patients whose suffering will not be ended by a natural death in the near future.

> R: 'I tell patients who want EAS that they need to have a life expectancy of more than two weeks, otherwise I'm not even considering it. Otherwise we will just wait for death to come naturally and use palliative sedation if necessary. (…) For me, EAS is really for those cases where the suffering will last so long, and where death will not save the patient at short notice, because in those cases there are no other solutions and you have to act.' (R30)

Respondents also differ in their interpretation of the 'voluntary and carefully considered request' criterion. Many mention, for example, that they want their patients to write their requests down. Only then they are satisfied that the patient has carefully considered his request. The following respondent mentions a patient with a request for EAS, whom he visited very frequently during several weeks because he wanted to be sure her request was consistent. For this physician 'carefully considered' means 'repeatedly done over a longer period of time'.

> R: 'A case in which I had a lot of doubts whether to grant the request was a case of a paraplegic woman in her early fifties with two amputated legs. Her condition rapidly declined, she was malnourished and had very severe pressure ulcers. She had spent a year in a rehab clinic just to attain some improvement on those pressure ulcers, but that didn't help. Her plastic surgeon told her there was nothing else that could be done to improve

> her wounds and that, at a certain moment, these wounds would cause multiple organ failure and she would die. At that point she asked me to perform EAS. I found that very difficult, because she didn't have a fatal disease like cancer – although she had a very poor prognosis, of course. I took a lot of time to talk to her, because her request was not consistent to me, or at least: she had never spoken to me before about EAS. I wanted to be sure her request was consistent. First I tried to have her admitted to a nursing home or a hospice, with the idea that if she was pampered her request might disappear. But everything was full so we arranged a lot of home care. But she stayed in severe pain because of those wounds. I visited her very frequently during some weeks. Sometimes I saw her every day, just to talk to her about her request. But every time she ensured me her wish wasn't going to change. So eventually, I felt I had no other option than to help her die.' (R20)

Another respondent wants to have deep conversations on life and death with a patient before he can be satisfied a request is carefully considered.

> R: 'It is not totally up to me and what I think about it or just about the type of disease, it also has to do with what kind of person is asking me. If I think about EAS, this implies, for me, a lot of talk, talk about death and dying, talk about life, about saying goodbye, really seeing and feeling what is happening in this last phase of life and reflect on that. But not everybody is capable of talking and reflecting this way, while everybody is going to die. So that's my problem. For me talking about and reflecting on life and death is a necessary condition to perform EAS. But you can't reasonably expect that from certain people, that they are able to do that. Perhaps I should recognise that earlier and say to those people: 'sorry I won't be able to perform EAS on you because I can't have a deep enough conversation with you about it and then it doesn't feel right.' And I learned not to do these things when it doesn't feel 100% right, otherwise I can't sleep at night. But the thing is, I do treat people unequally this way.' (R33)

Considerations unrelated to the legal criteria

Apart from the legal criteria that were sometimes incorrectly understood and differently applied by our respondents, we also found that considerations play a role that have little or nothing to do with the legal criteria.

The Dutch Act on EAS, for example, does not require a (treatment) relationship between physician and patient, but many respondents mention

that for them it is important to have a good relationship with the patient in order to be able to perform EAS. This respondent, for example, says he wants to know a patient well before the patient becomes ill.

> R: 'I once got a request for EAS from a terminally ill patient while I was standing in for a colleague who was on a holiday for a couple of weeks. I said to this patient: 'Listen, I work here temporarily, I am prepared to do a lot for you, but one thing must be absolutely clear: I won't perform EAS on you.' That is a line I won't cross, because I hardly knew him. (...) I believe you should know a patient and his family well if you want to perform EAS. You should have a close relationship. That doesn't mean you have to go back for years, but I do believe you should know somebody before he became ill, so you know how he is, how he thinks about life et cetera and that you had the opportunity to monitor the course of illness.' (R19)

The Dutch Act also does not mention the role of family members. In practice, however, for many respondents family members play an important role in the decision-making process. This is the case, for example, for the following two respondents who seem to believe that it is important for a 'good death' that there are no unresolved conflicts in the family.

> R: 'If the family doesn't agree with the EAS there are probably some unresolved issues in the family, you get the feeling some things aren't completed yet. And in case of real family conflicts, performing EAS would be very hard for me. I think I would not do it then, no. And I think I would discuss this with the patient too: 'don't you agree that this is a very harsh time to perform EAS while there are conflicts in your family? Shouldn't those be resolved first?'' (R4)

> R: 'I always ask patients, in private, if there are things from the past that haven't found closure yet, conflicts and that kind of things. I think that is important when I help someone die, that there are no unresolved issues or unfinished business.' (R8)

Also other respondents mention that it is important for them that family members agree with the EAS.

> R: 'Family is essential. I would never perform EAS if the family does not agree, that is asking for trouble.' (R18)

Some respondents seem to be reluctant to perform EAS when their patient's attitude to life differs from their own. This respondent, for example, expects his patients to fight for their life and not give up 'too easily'.

> R: 'This case concerned a man with lung cancer who didn't want palliative chemotherapy anymore. But I managed to convince him to take palliative chemo for a second and even a third time..well, he did die during that last chemo. But the thing was, he had been very sick from the first palliative chemo and didn't want to experience that another time, so he came to me for EAS. And I had a lot of problems with that. I also told him this, that I couldn't perform EAS on him. Because it clashed so fundamentally with my view: fighting for your life, doing everything possible. Okay, he couldn't be cured anymore, but his situation wasn't unbearable yet, he just didn't want to go on anymore. His attitude, that was my problem with it.' (R23)

Another respondent says it is important for him that patients have found acceptation and be at peace with their situation, in order for him to be able to perform EAS.

> R: 'He told me he wanted to walk normally, to function normally, he didn't want home care; he just didn't want Parkinson's disease, that was it. And perhaps, just looking at the law, you could write up his story in such a way that the review committees would condone it. But it felt so wrong. This man, he was just so defiant and sad that he lost his mobility. I thought let's see if he is able to accept his situation and then we can talk from there. (…) Such an opposing attitude, I see that more often from people requesting EAS. And it gives me the feeling it is not the right time yet, that EAS would come too early. [It is the right time for EAS] Only if someone is totally at peace with himself, his life and his death, and if I see and feel that too.' (R27)

Conclusions

For Dutch GPs, different considerations play a role when they have to decide upon a request for EAS. These considerations can be divided in three main types: (i) perceived legal criteria, (ii) individual interpretations of the legal criteria and (iii) considerations that are unrelated to the legal criteria.

GPs obviously consider the legal criteria, but are not always correct in what they think these legal criteria are. For example, a life threatening

disease, severe physical suffering, a disease in a terminal stage or a written request are incorrectly thought of as legally required.

But even if GPs are correct about the legal criteria, they have to interpret these criteria to apply them to concrete cases. In practice, we see quite a bit of variation in this interpretation. GPs differ mainly in what they would classify as unbearable suffering. The stage of the disease the patient has reached, his degree of decline or the nature of his suffering are factors that influence GPs' assessment of the patient's unbearable suffering. This variation in the interpretation and application of the unbearable suffering criterion is also described in earlier research. Quantitative studies on the Dutch EAS practice show that while most physicians will classify severe physical suffering as pain, vomiting, fatigue and dyspnoea in a patient in a terminal stage of disease as unbearable, suffering in an earlier stage of the disease or suffering which is more psychological or existential in nature is less often recognized as unbearable and is a reason to reject a request for EAS. (11–14) Pasman et al. conducted qualitative research with Dutch GPs and relatives of patients about EAS and concluded too that there was often no agreement between physicians and patients about what constitutes unbearable suffering; patients put more emphasis on psychosocial suffering, such as dependence and deterioration, whereas physicians referred more often to physical suffering. In some cases, the physician thought that the suffering was not unbearable because the patient's behaviour seemed incompatible with unbearable suffering – for instance, because the patient was still reading books. (15) Van Tol et al. also found a lot of variation in the application of the unbearable suffering criterion in their qualitative research with Dutch GPs. (16) They offer two explanations for this variation. They show that GPs follow different cognitive routes when assessing a patient's suffering in the context of an EAS request; by imagining how it would be to experience the situation of the patient himself ('imagine self') or by imagining what the situation must be like for this particular patient ('imagine other'). But they also show that most GPs associate the classification of suffering as 'unbearable' directly with granting the patient's request and thus with actually performing EAS. They write: 'this brings in personal values and believes about euthanasia in general and the actual act of terminating this individual's life in particular. It means that the process of assessing a patient's suffering and the decision to grant a request or not, will often be influenced by a doctor's personal normative believes about euthanasia; the kind of suffering she thinks may justify it.' (16) In a quantitative survey on the application of the unbearable suffering criterion, Van Tol et al. found no relation with physicians' gender, age or training on the one hand, and

the judgment of a patient's suffering as unbearable or the willingness to grant the request on the other hand (in hypothetical vignettes). They did find a relationship with experience with EAS; physicians who performed EAS at least once during the past 5 years more often considered the patient's suffering as unbearable and were more often willing to grant the request. (17)

What our study adds to this knowledge is that it is not only a GP's personal interpretation of the legal criteria (notably the unbearable suffering criterion) that influences the decision on an EAS request; we found that GPs also have considerations that have nothing to do with the legal requirements (type 3). Examples are: the family must agree, unresolved family issues need to be addressed first, or the patient's attitude must reflect resignation.

Considerations of this 3rd type have not been mentioned this explicitly in the literature on EAS so far, probably because physicians are not very aware they have these considerations. Such considerations might only come to the surface when physicians are asked to explain thoroughly why they struggled with particular requests for EAS, as was done in the in-depth interviews of our study.

We hypothesise that these type of considerations stem from GPs' underlying views on what 'good dying' entails. For GPs in whose opinion 'good dying' entails that there are no unresolved issues and that the patient dies harmoniously and with resignation, (family) conflicts or a patient still angry and combative might form a problem for granting the EAS request.

When a physician's considerations stay implicit and are not openly discussed between physician and patient this can lead to miscommunication and diverging mutual expectations. That may harm the quality of the last phase of the patient's life, as well as the bereavement process of relatives. To minimise such situations we would like to encourage physicians to reflect on their own interpretation of the legal criteria and additional aspects they may value beside the legal criteria, and to discuss their considerations openly and timely with their patients. This will also enable patients to search for another physician if so desired.

We also think that it is important that in GPs' training more attention is paid to the (correct) legal criteria; it should be avoided that a request for EAS gets refused because a physician mistakenly thinks EAS would not be legally allowed in a certain case while he would be willing to perform it otherwise.

Apart from pointing to these practical recommendations our study can also feed the ethical discussion on the tension that can arise between a physician's own views on death and dying, and the views and preferences of his patients. Next to the abovementioned miscommunication and diverging

mutual expectations owing to considerations that remain implicit, there are other aspects to physicians' considerations that can be problematic for patients and could raise ethical concerns. For example, to find peace and acceptance with the situation, to restore contact with family members or to solve conflicts, can be extra burdensome for patients who are already in a situation they experience as unbearable. Moreover, one could question whether GPs impose their views on what 'good dying' looks like on their patients when considerations like 'no unresolved conflicts' or 'enough resignation' influence the decision to grant a request or not, and whether this is problematic from a moral and professional viewpoint.

These interviews were not conducted with our exact research question in mind. Although the data revealed many examples of the considerations that play a role in practice, the interviews were not specifically about unravelling the views behind them. Especially our new finding that in practice considerations play a role that have little to do with the legal requirements but, as we hypothesise, reflect GPs' views on what 'good dying' entails (type 3), should be studied more in-depth in future research. Furthermore, since this was a qualitative study it is not possible to link characteristics of the respondents such as gender, age, training or experience to our findings. It would be interesting to conduct quantitative research too to see whether there might be a relationship between such characteristics and the degree in which GPs let their own ideas on death and (assisted) dying influence their decisions on an EAS request.

The findings of this future research into GPs' views on death and dying are not only relevant for the Dutch EAS debate, but can also be informative for (research into) other end-of-life practices, in the Netherlands as well as abroad, because having a 'good death' and having a caregiver that can attribute to that is of importance to everyone, not only for those requesting EAS.

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Chapter 5
General practitioners' views on good dying

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Abstract

Objective to gain more insights into the views of Dutch general practitioners (GPs) on good dying and the way these views influence care they provide at the end of life.

Methodology 20 in-depth interviews with GPs from various regions in the Netherlands.

Findings elements of good dying mentioned were: minimal physical suffering, acceptance and resignation, being supported by loved ones, harmony, being at home and in accordance with a patient's personality and preferences. GPs disagreed whether euthanasia or assisted suicide (EAS) can be good deaths. GPs had difficulties dealing with patients who approach death in a way that does not match their view on good dying. GPs differed in how they deal with these mismatch situations.

Discussion and conclusion We used the four models of the physician-patient relationship described by Emanuel and Emanuel to interpret the ways GPs deal with the mismatch between their own views on good dying and those of the patient. Emanuel and Emanuel favour the deliberative model. We argue that their description of this model is too much a one-way-street of the physician telling the patient what to do, and that this is not appropriate in end-of-life care. Instead, we advocate a hermeneutic dialogue about death and dying in which ideas, values and patient's coping strategies are explored in an open and non-judgmental way, in order to support patients in dying 'their own way' as much as possible.

Introduction

In the Netherlands health care is characterised by an emphasis on primary care. Almost all citizens have their own general practitioner (GP) who plays a central role in coordinating care. In the Netherlands many people have a wish to die at home, and there is a general consensus that end-of-life care is indeed best provided in a home setting, if possible. (1) This makes that the majority of Dutch patients with a non-acute illness die at home, with their GP as a central figure providing and coordinating care. (1)

In this home setting patients sometimes request their GP for euthanasia or assisted suicide (EAS), which a physician in the Netherlands can perform without having to face criminal charges (i.e. in case the criteria of due care – laid down in the Termination of life on request and assisted suicide act – are met). (2) Ten Cate et al. did a study to get a better understanding of the considerations that play a role when Dutch GPs are to decide on such a request for EAS, and found that (implicit) norms on 'good dying' possibly influence this decision. (3) For example some GPs indicated that unfinished businesses, conflicts in the family or a patient who has not (yet) reached a certain level of resignation, could be a barrier for them to perform EAS. (3)

This was the direct cause for wanting to know more about GPs' views on good dying and how such views may influence their handling of EAS requests. However, more insight into GPs' views on good dying is not only relevant in the context of EAS requests alone. Since in the Netherlands the GP is the physician who deals with death and dying most often and is the one who has a key role in end-of-life care, it is important to have insights into their views and the (implicit) norms that guide them when they provide care for their dying patients in general.

Background

In 2002 Clarks mentioned the following elements of a good death in modern Western culture: a pain-free death, open acknowledgement of the imminence of death, at home surrounded by friends and family, an aware death in which personal conflicts and unfinished business are resolved, death as personal growth, and a death in accordance with personal preference and in a manner that resonates with a persons' individuality. (4) Other authors come up with similar lists. (5-10) As Goldsteen et al state: 'with regard to a good death authors on terminal care are remarkably consistent in describing the general features of an ideal dying trajectory'. (6) Awareness, acceptance, harmony, growth, open and honest communication, autonomy

and authenticity seem to characterise the modern western paradigm when it concerns good dying. Palliative care is supposed to contribute to arriving at such a good death. (4-9,11)

The question 'what is a good death' is of all times, and has been subject many times in the work of artists, writers, poets, and philosophers, but the attention for death and dying within Western health care is of more recent times. (6,12) Death and dying are medicalised; today hardly anybody dies without physicians and other professional caregivers being involved. In contrast to earlier times, death and dying are now clearly seen as matters medicine in general, and palliative care in particular, has an important role to play in. (12,13) Only some decades ago physicians would not confront terminally ill patients openly with their coming death because shattering their hope for recovery was deemed to be too burdensome. (14) In the sixties and seventies of the twentieth century several developments changed the way medicine dealt with death and dying. (5-6) In Britain for example Cicely Saunders laid the foundation for the hospice movement, which enabled patients to prepare for their coming death. (6,12,15) Also Weisman, who wrote the book 'On dying and denying', and psychiatrist Kubler-Ross who studied the experiences of the terminally ill, emphasized the importance of awareness and acceptance of death and gave professional caregivers a prominent role in helping the patient to achieve these. (6, 16-19) Palliative care was also a reaction to medicine's expanding possibilities to prolong life, sometimes practiced even if it seemed futile with regard to quality of life. (12) Another development that took place at about the same time was the patients' rights movement; medical power and paternalism were challenged and had to make room for informed consent. (14)

These developments, amongst others, have contributed to the current normative ideas of awareness, acceptance, harmony, growth, open and honest communication, autonomy and authenticity that prevail in the modern western perception of good dying, and the idea that medicine, in the form of palliative care, has a prominent role in achieving such a good death.

In the Netherlands the GP is a key figure in palliative care. We wanted to know how individual GPs perceive good dying and how this view influences the way they provide care for their patients at the end of life.

We conducted in-depth interviews with 20 Dutch GPs to answer the following research question: 'What are GPs' views on good dying and how do these views influence the way GPs deal with patients at the end of life?'

Methodology

For this study 20 GPs from various regions in the Netherlands were interviewed in-depth. To recruit respondents an email was sent to the General Practice department of a large academic hospital in the Netherlands with information on the study and its aims, and an invitation to take part in an interview. 10 GPs replied they were willing to give an interview. The other 10 respondents were recruited through snowball sampling. (20) The interviews were conducted between January 2016 and May 2017. The interviews took place at the GPs' working place or their home and each lasted about one and a half hour. Before the start of the interview, the voluntary character and confidentiality of participation were emphasised. Respondents agreed to the interviews being recorded with an audio recording device.

During the interviews respondents were invited to elaborate on their view on dying and their own role as GP in the last phase of their patients' life. Respondents were, for example, asked to describe, from their experience as a GP, examples of 'good dying' and 'bad dying'. They were also asked about their view on EAS and whether they considered EAS a good death. Another topic of the topic list was respondent's dealing with patients who had other ideas on dying, or approached death in a way that didn't match their ideal of good dying (for example patients who would stay in denial until the end). The interviews had an open character, and left respondents much room to speak about their views, feelings and experiences. The topic list was used only to check from time to time whether all relevant themes had been discussed.

After 20 interviews no new themes came up, and data saturation was reached.

As can be seen in table 5.1 a heterogeneous group of GPs was interviewed. 12 respondents were male, 8 were female. Respondents' years of experience as a GP ranged from 5 to 40 years, with a mean of 22 years. The respondents worked in different areas of the Netherlands, from rural areas to large cities and everything in between. The respondents' patient population varied correspondingly. Some respondents had a specialisation in end-of-life care, but the majority did not. The heterogeneity of the group respondents promotes finding a wide range of different views, which increases the validity of the study. (20)

Data analysis

The interviews were analysed with help of MaxQDA, software for the analysis of qualitative data. All interviews were read several times. Relevant fragments were given one or more codes (open coding). A second researcher

Table 5.1 Characteristics of the respondents

	Gender	*Years experience as GP*	*Location*	*Patient Population*	*Specialisation*
1	M	30	City		
2	F	5	Small village		
3	M	20	Small village		
4	M	34	Large city	Youth, immigrants	
5	M	30	Small village	Many elderly	
6	M	34	Large village	Not many elderly	
7	M	15	Small village	Many religious people	
8	F	21	Small village	Many religious people	Palliative care, SCEN physician*
9	F	17	Large city	Immigrants	
10	M	8	Small village	Many elderly	
11	F	20	Small village		
12	M	18	Large village		
13	F	28	City		Palliative care, SCEN physician
14	F	35	City	Immigrants, low SES, many elderly	
15	F	27	Small village	High SES	
16	M	40	Large village	Many elderly, many religious people	
17	M	31	Small village	High SES	SCEN physician
18	M	5	City	High SES	
19	M	8	City		
20	F	11	City	High SES	

* SCEN stands for Support and Consultation Euthanasia in the Netherlands. These are physicians who did a training about euthanasia practice and law. They are consulted as independent physician in the context of a euthanasia procedure.

read and coded some of the interviews. The two researchers compared and discussed the differences and similarities in their coding, which led to a refinement of the code tree. The coded fragments where further analysed during several phases of coding (axial and selective coding); codes were refined, sub codes and overarching codes were assigned and relationships between codes were explored. (20) Interviews were also analysed as a whole, to look for patterns and (in)consistencies in reasoning.

Findings

Our research question was: 'What are GPs' views on good dying and how do these views influence the way GPs deal with patients at the end of life?'

Views on good dying
When asked about their view on good dying many respondents mention that they hope patients have little physical suffering when they die and they stress their role as GP in minimizing such suffering.

> 1. 'Preferably someone dies with as little physical suffering as possible. Suffering like dyspnoea, pain, nausea, vomiting, et cetera. And as a doctor your hope is that you can minimize this suffering in such a way that it stays bearable for the patient.' (R1)

Another aspect of good dying that many respondents mention, is that a patient has come to accept the fact that he is dying and has found a kind of resignation in his situation.

With this resignation respondents seem to point to the absence of fear, anger or mental struggle as well as the acceptance of the inevitability of death.

> 2.'You hope that people are not afraid, that they are not fighting anymore, but have found a kind of resignation.' (R9)

> 3.'I mean a kind of mental acceptance, that people are not struggling with themselves, but surrender to their tragic fate.' (R1)

This respondent adds to that the acceptance that things will be left unfinished:

> 4. 'People have to acknowledge that death is the logical and inevitable next step. That they accept that there is nothing that can be done to stop it. And that people are okay with that, despite all the unfinished things they may leave behind.' (R13)

That a patient's loved ones are present, and that there is a kind of harmony is also mentioned often as an aspect of good dying. Acceptance is an important element here too. For example this respondent says it is nice if the family is also able to accept the fact that their loved one is dying:

5. 'It is very special and nice to see that family members, who have been very involved in caring for their loved one these last weeks or days, have reconciled themselves to the fact that their loved one is going to die. And then when you enter such a home, you see a bed in the middle of the living room and people are walking around a bit, but everyone is very calm and everything goes harmoniously.' (R11)

Although most respondents mention the elements of a good death described above, many add that good dying is also dying in line with a patient's personality and preferences:

6. 'I used to think good dying meant being at peace with your situation, accepting your death and having completed your life. But now I believe people die in the same way they've lived. So that's different for every person. Some people won't go harmoniously. No, they'll go angry while still fighting their situation. But those are people who had this attitude all their lives. It doesn't suit them to go peacefully, but that's okay too.' (R8)

7. 'I had a patient once, a very young woman with cancer. And I could not talk to her about her going to die. She didn't let me. She really didn't want to talk about it. Eventually, when her condition became very bad and death was near, she insisted on going to the hospital per ambulance. In the hospital she died within ten minutes. The physician from the emergency room was not amused, he didn't understand why I chose to send a cancer patient that was obviously dying to the hospital. But the reaction of her husband was a real treat for me, he said 'this was exactly how she had wanted it. Dying at home would not have been an option for her; she would not have been able to handle that. This was the best thing that you could have done for her, I'm sure'.' (R2)

Good dying and EAS

That respondents believe good dying is also dying according to a patient's personality and preferences does not automatically imply that they consider a self-chosen death (EAS) as a good death, as one might assume. The same respondents who were just quoted (quote 6 and 7) say about EAS:

8. 'Humans are actually just animals. And animals, at least in nature, do not die with EAS do they? Nature takes care of that her own way. That doesn't mean I believe dying will be fun or easy, but I do believe we just have to face the fact that it's part of life. Dying is a natural thing, and not

a medical one in my view. I hope for patients they will have a natural death with not too much assistance from the doctor. Of course as a doctor you can provide palliative care, but preferably you should not intervene with the moment or the pace of dying.[...] I have difficulties with EAS, especially for people that still have some time left. I always think: it is the emergency exit you take; you can't handle life so you take this escape. I don't know, it feels a bit cowardly. I think the possibility of EAS hinders people in their personal growth. People can still learn a lot in the last phase of life. They can grow, in their relationships, in the way they view life. EAS takes that opportunity away from them.' (R8)

9. 'This patient had Parkinson's disease and then suffered a CVA. He wasn't able to do very much anymore, but he was not in severe pain. He asked me to perform EAS. But I rejected his request. [...] Life is not always fun, but I believe you just have to wait until the end is there. I would be happy for him if he died though. I did understand his wish; I guess for him this life was really unbearable. But for me EAS would not be the appropriate answer in cases like this. It is such a drastic measure. I don't know, it feels kind of disrespectful towards death. I think one should have respect for life, and for death, that it will come when the time is right. You cannot be in control of everything. This is something that is up to nature.' (R2)

For other respondents EAS does match their ideal of good dying. In sharp contrast with the former two respondents, this respondent for example describes EAS as something beautiful:

10. 'Yes, an arranged death can be good too, sometimes even better than a natural death. I once had a patient with ALS and at a certain moment she decided it was enough. She had talked about it with her husband and her children a lot and they were fully supporting her. So in harmony with her family she chose the moment, the place, the time and the way she wanted to die. And that matched very well with who she was and how she had lived. I thought it was a brave decision. I admire people that choose EAS, it is a tough decision that requires courage and strength. Another aspect that makes EAS a good death in my opinion is that in most cases it takes a while, it is a trajectory. Sometimes it takes weeks or months to reach that decision. So by that time patients are really 'ready to die'. And everyone has gotten the time to get used to the idea, to prepare, to find closure, to say goodbye etcetera. It enables a very conscious way of dealing with death.' (R3)

Mismatch

The abovementioned quotes show that there can be a mismatch between the GP's and the patient's ideas on EAS. However, EAS aside, in cases of a 'normal death' too there can be a mismatch between GP's own ideas on good dying and patient's preferences or the way a patient deals with the situation. Two situations in particular respondents have difficulties dealing with; patients who are in denial and patients who are in a 'fighting mode'.

11. 'Of course I have my own ideas about elements that contribute to a good death, so it isn't easy if patients want or do it differently. I once had a patient, an old farmer, who lived on his farm, all by himself, somewhere in a remote area. He did everything his own way and showed a lot of resistance. Resistance against his disease, but also resistance against the care we wanted to arrange for him. I think he was very afraid for what might come, but he didn't want to talk to me about that. In fact, he didn't wanted to talk at all about his disease and the fact that he was going to die. He could not accept that. That was very hard for me, very frustrating.' (R10)

12. 'Patients who are dying while still trying to fight their disease, I find that very difficult. I once had a patient with cancer who was born in Ghana. And his family took him to Ghana to undergo all kinds of alternative medicine there and to visit all kinds of places of pilgrimage. While he was very very sick they moved him around in an old shabby car. Eventually he died in some church while his family was busy paying the priest to do another ritual. That makes me very sad [...]. However, in the Netherlands you see this type of patients too. Patients who are already very ill, but still want to undergo all kinds of aggressive or experimental treatments. Sometimes I do not understand that.' (R9)

Different ways to deal with the mismatch

In the interviews we encountered different ways GPs deal with a mismatch between their own ideas on good dying and the patient's ideas. Some respondents mention that they accept a patient's preference or a patient's way to deal with his coming death (although some admit that this can be very difficult).

13. 'I need to hold myself back because normally I tend to talk a lot about death and dying with patients. And most of them want that too, but if they don't, I need to remind myself: this is about them, not me. Dying should really happen in the patient's own way, not in mine [...] So I try to comply with their wishes as much as possible.' (R2)

Others try to change the view or behaviour of the patient, but without being judgemental.

> 14. 'I try to talk to people about what they want and why they want it. And of course I have my own ideas on good dying, but I try to keep those aside, because those won't help the patient. [...] Actually, sometimes I do try to change the way people look at things. But that is not because I have a judgment about them, but because I think it will be pleasant for them if they could enjoy the time they have left more, instead of being angry all the time or fighting till the end. So yes, when I think a patient is open to it I'll try to talk about those things. But I don't want to give the patient the impression I'm judging him. I believe that when you are judging people you'll lose your ability to help and really be there for them. So I'll try to avoid that. I do tell patients I find things difficult, for example when they stay in denial, I'll say to them: 'I find it very hard to help you if I can't talk to you about your condition and the care you want'. And then I just ask them for advice. 'What do you need from me? What do you expect from me? Is there something I cán do for you?'' (R15)

Other respondents seem to have a more directive attitude. For example this respondent who tried to mediate in a family conflict.

> 15. 'Maybe I should have asked him first whether it was okay to call his daughter. But I guessed he would have said his children didn't need to know he was about to die. In that case I think I would have tried really hard to persuade him to inform his children.' (R11)

Or this respondent who tells his patients they need to come to terms with their death.

> 16. R: 'I think it is very important that people accept their death, that they don't fight their situation or stay in denial. I try to convince patients they need to come to terms with their death. I see that as an important task. If I don't succeed in that, I feel I have failed.'
> I: 'You don't say, this is the way this person has always dealt with difficult things in his life...?'
> R: 'Oh please no. That is so banal. People can still learn things on their deathbed you know. And yes perhaps this patient has always dealt with difficult things like this before, but I doubt that was a rational choice. Our 'choices' are not that rational most of the time.' (R6)

Discussion and conclusion

Our research question was: 'What are GPs' views on good dying and how do these views influence the way GPs deal with patients at the end of life?'.

Our interviews show that GPs in general have rather similar views on good dying. Elements often mentioned are: little physical suffering, acceptance and resignation, being supported by loved ones, harmony, and being at home. Many add that good dying is also dying according to a patient's personality and preferences. These elements were also described in previous literature. (4-11) We found that although GPs' ideals of good dying seem to be rather similar to each other, their views on how EAS fits this ideal differ greatly. For some, EAS fits the ideal perfectly, while for others the opposite is true.

Surprisingly, the respondents who put most emphasis on dying according to patients' personality and preferences are also the ones who had the most difficulties with EAS. Their difficulties seem to arise from the perceived unnatural character of EAS. They have difficulties with the idea that people want to be in control of everything, while they believe it is an illusion to think that is possible. They also have difficulties with the time EAS 'takes away'; time that could have been spent meaningfully if life was not ended actively. These GPs seem to regard EAS and 'good dying' as two completely separate issues. The sharp line these GPs draw between EAS that they perceive as unnatural, and other deaths that they – in contrast – perceive as natural is striking, since prior to most deaths medical treatment and non-treatment decisions have been made that had an influence on the time of death. In the Netherlands 58% of all deaths (in 2015) were preceded by some kind of end-of-life decision. (21) One might wonder to what degree deaths are ever 'natural' in a highly medicalised country as the Netherlands of today.

The perceived difference between EAS and a 'normal death' aside, what holds for both situations is that a mismatch may arise between a physician's view on death and dying and a patient's preferences or way to deal with his coming death. Even though most GPs acknowledged that good dying is also dying in a way that reflects a patient's preferences and personality, they struggle with this in practice. The interviewed GPs have difficulties dealing with two situations in particular; patients who are in denial and patients who are in a 'fighting mode'. The GPs differ in how they approach such a situation. Some (try to) accept a patient's way to handle his coming death, others try to make a patient change his views or behaviour, with some GPs being more directive or judgmental in this than others.

In their classic essay 'Four models of the physician – patient relationship' Emanuel and Emanuel distinguish four different models of the relationship between a physician and his patient; the paternalistic, informative, interpretative and deliberative model. (22) The different ways in which our interviewed GPs deal with a mismatch between theirs and a patient's approach to death reflect all four models. For example, the GP who calls a patient's daughter without his permission to tell her that her father is about to die (quotation 15), acts in a paternalistic way. The GP in quotation 13, for example, seems to view the patient's values as 'defined, fixed, and known to the patient' as Emanuel and Emanuel put it, and does not make the values of his patient topic of further exploration. The physician in quotation 14 does seem to explore (together with the patient) the patient's ideas. His approach is an example of an interpretative approach. He also explicitly stresses the importance of not being judgmental about the patient's choices and behaviour. Quotation 16 is an example of a deliberative approach. This physician questions his patients' attitudes towards death and tries to persuade them to adopt a more accepting attitude. He tries to teach his patients something, and wants to foster growth and moral learning.

Which model would be best? Emanuel and Emanuel favour the deliberative model. (22) Goldsteen et al, who studied terminally ill patients' dealing with normative expectations around death and dying, are also in favour of the deliberative model when it comes to palliative care. (6) Goldsteen et al. conclude that professionals should refer to the 'normative framework of palliative care' (i.e. awareness, acceptance, harmony, growth, open and honest communication, autonomy and authenticity) and invite patients to take this into consideration because it has 'normative force'. According to Goldsteen et al. professionals should be open to the fact that individual patients may take different attitudes to these norms, but they add that 'this is not to say that all reactions of patients should be taken for granted'. A patient's values should be challenged according to Goldsteen et al. (6)

We do not think that the deliberative model as described by Emanuel and Emanuel is the most desirable approach for end-of-life care. In this deliberative model the physician has the role of a teacher who tries to 'persuade the patient of the worthiness of certain values', through discussion. (22) They write: 'not only does the physician indicate what the patient could do, but, knowing the patient, and wishing what is best, the physician indicates what the patient *should* do.' (22) But since a physician is no expert in existential matters – nor has he more experience in dying than his patient has – telling a patient how he should deal best with his

coming death is in our view best qualified as 'patronizing'. We rather agree with Widdershoven who warned that the deliberative model as described by Emanuel and Emanuel easily slides off to the paternalistic model, because it is portrayed as a one-way street. (23) With Gadamer he argues for a hermeneutic dialogue between physician and patient in which both can bring in their perspective and try to understand each other and learn from each other. (23)

Such a dialogue on life and death between a physician and a patient can be very valuable in our view, i.e. in case the patient is open to that. In such a dialogue the physician and the patient together can explore their ideas on life, death and dying and the values behind them. It might help the patient to gain a better understanding of himself and what is really important to him, and this may enable him to make choices that fit him, for example regarding the care he wants to receive in this last phase of life. As a side effect it might even broaden a patient's horizon or help him to come to terms with his death. Such a dialogue might also enable the physician to learn something from the patient, instead of only the other way around. In such a dialogue there can be room for a GP to explain why he might have difficulties with the way a patient deals with death and dying, including explaining a possible reluctance towards granting a request for EAS. However, we think in this dialogue there is certainly no place for moral judgement from the physician. In our view, a physician should not try to persuade his terminal patients to adopt the, in his eyes, right way to deal with death, because this can give the patient the feeling he 'does it wrong'. Feeling morally judged is likely to worsen death instead of making it 'better'.

There are settings where it can be appropriate for a physician to argue for the view that certain ways of dealing with death and dying are morally superior to other ways (for example by writing an essay for a newspaper) but caring for a patient in the last phase of life is not one of those settings. Instead, this is a delicate setting in which the patient and his relatives are in a vulnerable and dependent position, and in which the actions and attitude of the GP can have a great impact on how relatives will remember the last phase of their loved one's life. We think this delicate situation demands a serving and supportive attitude from the GP. Therefore we advocate the GP engages in a dialogue about death and dying in which ideas, values and coping strategies – even if those do not match with the GP's ideal of good dying – are explored in an open and non-judgmental way, in order to support patients in dying 'their own way' as much as possible.

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Part 3

Chapter 6
General discussion

The proper place for physicians' personal viewpoints in end-of-life care

Introduction

In the beginning of 2018 my grandfather died, at the age of 90. During his working years he had been working for a multinational in the fishing industry. He had been traveling all over the world and spent a lot of time abroad. He was an intelligent and independent man. The last couple of years he and my grandmother (91) lived in their own home, but at my mother's property somewhere at the Dutch countryside.

Ten years before he died my grandfather suffered a heart attack and was given 4 bypasses. This event made him give up the daily glass of jenever he always drank around noon, the cognac he drank around 4 o'clock and the red wine he drank at dinner, and his daily cigars. Five years before he died he suffered from a tumour in his throat. With radiotherapy the tumour was destroyed, but unfortunately his salivary glands were destroyed too. He also lost his taste. Without saliva eating was not easy; he was only able to eat juicy fruits and yoghurt and therefore needed a couple of nutritional drinks a day to complement his diet. Until then he had always very much enjoyed eating good food. In the last months before he died his vision declined to a level at which he was not able to read anymore, while this was the main activity of his days until then.

Two weeks before he died he got severe pain in his abdomen and heavy diarrhoea with blood in it. He was admitted to the hospital. The gastro-enterologist suspected an 'innocent' bleeding diverticulum. Together with my grandfather the physician decided to wait a couple of days to see if the bleeding would stop by itself, which it did. Diagnostics did not show any abnormalities, and my grandfather was sent home again. When he came home he was weakened, he had lost a lot of weight, and still suffered from diarrhoea he had no control over. My mother had to shower him every time he defecated himself. That was horrific for him.

He told us he did not want to go on living anymore. He did not want to experience further decline. He did not want any more hospitals, doctors, care or 'hassle'; he had had a good life, but now it was enough, he told us repeatedly. First we tried to persuade him to get better. We bought a blender so we could

make extra nutritional shakes for him to gain weight and get stronger again. But he did not want it. He was very convinced it had been enough.

He requested his general practitioner (GP) to perform euthanasia. His GP was not willing to grant his request because he had difficulties with the fact that my grandfather did not suffer from a terminal condition, and he feared judicial consequences. To explain why he was not willing to perform euthanasia he told us about a bad experience he had with another patient. The GP also told us that euthanasia was not possible within the next couple of days because he had to respect a legally prescribed reflection period of 7 days, after which my grandfather should repeat his request.

After the GP's rejection of his request for euthanasia my grandfather decided he did not want to be dependent on the willingness of some other physician to help him die. He decided to do it himself by stopping with eating and drinking, a decision he effectuated immediately. His GP also had difficulties with this decision, because my grandfather had 'nothing serious' in his eyes. We, his family, on the other hand, saw a man that had to give up a lot of his pleasures the last ten years; drinking, smoking, eating, reading. With this recent episode of illness he experienced what it was like to be cared for and losing his independence. He found it horrific, and although he might fully recuperate from this episode of illness, further decline and dependency were likely to come sooner or later. Although we were very sad to lose him, knowing him and seeing him being so convinced, we were also able to understand his wish to die and to support him in his decision.

Unfortunately, the GP failed to give us information on what to expect and how to care for our grandfather now he had decided to stop eating and drinking. All the relevant information about mouth care et cetera we had to look up and arrange ourselves. He did not visit or call to see how my grandfather and we were doing. We had to urge him to. When he came he seemed annoyed, in a hurry, and still occupied with my grandfather's request for euthanasia and his bad experiences with his former patient, although my grandfather had already switched to plan B and was bringing about his death by himself. In the four days it took my grandfather to die after he stopped eating and drinking the GP did not sit down once. He did not even take off his coat once. He was also reluctant to sedate my grandfather when he began to suffer after three days without any fluid intake (moaning, unrest, moving arms and legs, trying to suck on our hands). We had to ask for sedation multiple times, but the GP struggled with whether it was allowed, since my grandfather was not dying from a terminal disease. He was also questioning the necessity of sedation and said 'isn't it nice that he is still a bit aware of you all being here'. Every family member had had a good talk with grandpa and had said goodbye two days earlier when he was still able to speak, so we did not see anything nice in his

suffering or in him being conscious in this condition. When the GP eventually gave my grandfather midazolam in order to relieve his suffering he told us not to tell anyone, insinuating we were complicit to something illegal.

In the Netherlands physicians can perform EAS (euthanasia or assisted suicide), without having to face criminal charges, i.e. when they comply with the legal criteria of due care, laid down in the Termination of Life on Request and Assisted Suicide (Review procedures) Act. (1) These legal criteria of due care are listed in text box below.

1. *The physician must be satisfied that the patient has made a voluntary and carefully considered request;*
2. *The physician must be satisfied that the patient's suffering is unbearable, and that there is no prospect of improvement;*
3. *The physician must have informed the patient about his situation and his prospects;*
4. *The physician must have come to the conclusion, together with the patient, that there is no reasonable alternative in the lightof the patient's situation;*
5. *The physician must have consulted at least one other, independent physician, who must have seen the patient and given a written opinion on the due care criteria referred to above;*
6. *And the physician must terminate the patient's life or provide assistance with suicide with due medical care and attention.*

It is disputable whether my grandfather's case would meet the above-mentioned legal requirements for EAS. Furthermore, EAS is not a right of the patient or a duty of the physician; a physician is free to make his own considerations and to refuse a request at any time and for whatever reason. (2-4) We would have totally understood the GP's rejection of my grandfather's request to perform euthanasia, if he had just said he found it too hard in a situation like this (without severe disease). We could also imagine that the experience with the former patient he told us about must have been hard for the GP. This former experience, however, had nothing to do with the request of my grandfather. It was a totally different situation, thus as an answer to my grandfather's request we found it not respectful, and also inappropriate that he told our grandfather and us this story extensively and more than once. We, my grandfather included, felt that his request (as an utterance of his suffering and his wish to die) was not taken seriously at all.

The 7 days reflection period the GP spoke of, which does not exist in the law or any other guideline, shows that the GP also lacked the knowledge on the legal and professional rules for euthanasia. He also did not seem to know the professional guidelines for voluntary stopping with eating and drinking (VSED) and palliative sedation (PS) in the Netherlands or at least did not act accordingly. (5,6) VSED is (at least in the Netherlands) regarded as a 'natural death', and providing care for people who VSED is not regarded as assisting in suicide. Also sedating VSED-patients to relieve suffering in de last day(s) is, from a legal as well as a professional perspective, not regarded as problematic in the Netherlands. Nonetheless, the GP was very reluctant to provide care and eventually to sedate my grandfather, he even suggested it was illegal.

That my grandfather's GP lacked essential knowledge on the law and professional guidelines is blameworthy. Apart from his lack of knowledge however, we found some other aspect of his behaviour problematic as well. Let me first of all recognize there is not one right way to look at life, death, suffering, decline and dependency. How one looks at these issues is highly dependent on the values individuals (and society) adhere to. That the GP's views on life, (assisted) death, dying, and dealing with decline, dependency and suffering differed clearly from those of my grandfather (and his family) was not necessarily a problem in itself, but the fact that he made his personal views *leading* in how he provided care for my grandfather and our family was a problem. Because the GP judged my grandfather's decision to bring about his own death while my grandfather 'had nothing serious' he did not provide him with adequate information, care and support, and partly because he viewed being conscious until the very end as something meaningful he was very reluctant to sedate my grandfather on the last day.

I do not share this story to criticize the viewpoints of this GP. As said, there is no right way to look at life, death, decline, dependency and suffering. I share this story because it is an example of a physician who makes his personal viewpoints leading in the care he provides, despite the views, values and preferences of the patient. Especially in end-of-life care this is problematic. The last phase of life is a very delicate setting in which patient and relatives are in a highly vulnerable and dependent position. The actions and attitude of a physician can have a great impact on how relatives will remember their loved one. And off course it is also not favourable for the patient to die without the desired care and support from one's physician.

Figures illustrate that the involvement of physicians with death and dying is increasing: in 1990 39% of all deaths in the Netherlands were preceded by an end-of-life decision, in 2015 this was the case in 58% of all deaths. (7) Death

and dying have become medicalised; today hardly anybody dies without physicians and other professional caregivers being involved. In contrast to earlier times, death and dying are now clearly seen as matters medicine in general, and palliative care in particular, has an important role to play in. (8,9)

This increasing involvement of medicine with death and dying makes it all the more relevant to study the normative viewpoints of physicians and to see how these viewpoints influence the care they provide at the end of life. This is what I did. I analysed 63 in-depth interviews with physicians on care and decisions at the end of life, in particular the decision to deliberately end life. (2,10,11)

I came across many examples of care that was greatly influenced by the physician's personal views on (assisted) death, suffering and dying. To give a few examples: I spoke with paediatricians who did not end a neonate's protracted dying process artificially on request of the parents, because they favoured a 'natural death', while other paediatricians in contrast would weigh relieving the suffering of the parents more important (chapter 3). (10) I spoke with GPs who rejected a request for euthanasia because the patient's attitude did not reflect enough resignation, because there were conflicts in the family that should have been resolved first in their eyes, or because they found the suffering not severe enough if the patient could still walk around (chapter 4). (2) I spoke with GPs who called relatives to tell them their loved one was about to die, against the will of the patient, because they deemed saying good bye to be essential for a good death, or who tried to persuade the patient to deal with death in a certain way they deemed as the only right way (chapter 5). (11)

All these interviews with physicians brought the following question to my mind: **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?** In this chapter I want to formulate an answer to this question. An additional question I want to 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?

The place of physicians' personal viewpoints

With personal viewpoints I mean viewpoints that may differ from individual physician to individual physician, in contrast to professional viewpoints (as brought forward by associations for medical professionals) and legal and societal norms, which *are* expected to guide the care a physician provides.

I fully acknowledge that it is inevitable that a physician 'brings his own person' to his work. Person and professional cannot be totally separated, and that would not be desirable either. A physician is always a human being too, and especially his human capacities, such as empathy, enable him to be a good physician. Although we expect every physician to possess those human capacities (to a certain degree), that does not make a physician easily exchangeable for any other physician; there are personal and relational aspects to care that are not limited to form only but can be substantial to the care provided and the way it is appreciated by patients. (12) Dutch philosopher Medard Hilhorst puts it like this: 'medical care should not be characterized by arbitrariness or (legal) inequality of course, but nevertheless care is and should be always personal too'. (12)

I agree with Hilhorst that more standardization in the way physicians deal with patients is not desirable. Variation between physicians offers – at least in theory – patients the opportunity to choose a physician who matches most with his own viewpoints (i.e. in case physicians' viewpoints would be made public and transparent), which seems to be a positive thing. (12)

American ethicist Robert Veatch has argued for something like this, which he calls 'deep value pairing'. (13) Veatch argues that a physician cannot know what is best for a patient because he is not able to determine what will best serve the patient's health interests, how to make the trade-off between these health interests and other interests and to determine how the patient should relate the pursuit of his best interest with other moral goals and responsibilities. Veatch writes: 'to put it bluntly the only way to know whether an intervention is good medicine is to ask the patient.' (13) Remarkably Veatch dismisses this option (just asking patients about their values) as not realistic, since he writes: 'knowledge on the patient's beliefs and values will be normally unavailable'. (13) Instead he argues for 'value pairing' based on most fundamental worldviews of the patient and the physician, which means that patients should choose their physician on the basis of their religious and political affiliations, philosophical and social inclinations and other deeply penetrated worldviews. 'That way when unconscious bias and distortion occur, as inevitably they must, they will tip the decision in the direction of the patient's own system. (…) There will be biases, but they will be less corrupting of the patient's own perspective.' (13)

A lot of organizational problems with this idea aside, Veatch seems to overlook that most of the time moral viewpoints and underlying values can be subject of conversation between physician and patient. (12) To me, knowledge on patient's beliefs and values are not as unavailable as Veatch

seems to believe. A patient is not a black box; through serious conversations with a patient, physicians most of the time will be able to gain information on and insights in the patient's beliefs and values.

Instead of a unity between physician and patient, as Veatch argues for, it might be even more fruitful when patient and physician do not completely share moral viewpoints but make those topic of conversation, and together search for the best outcome for the patient. This is what philosopher Julian Savulescu argues for in a critique on Veatch's deep value pairing. (14) Savulescu argues that it is not even desirable that physicians always have the same values as their patients, for patients, too, have their biases. Choosing a physician with a similarly biased evaluation of the good is to reinforce one's own biases according to Savulescu. He writes: 'Our own conception of what is in our interests is improved by rational discussion with those who share differing conceptions of the good.' (14) Agreement between patient and physician might be nice but is not the goal of the discussion Savulescu argues for. The goal is a rational discussion on ideas and values (from both physician and patient) that is in the end supposed to enable the patient to make choices regarding his care that fit him best. He calls this 'rational liberalism'. (14) Savulescu makes clear that it is eventually the patient who decides, his suggestion is not a disguised way for physicians to regain their influence on decision-making.

In their famous essay 'Four models of the physician-patient relationship' Emanuel and Emanuel also argue for deliberation between physician and patient as the most desirable mode for medical decision-making (see also chapter 5). (15) In contrast to Savulescu's 'liberal rationalism', however, their description of the deliberative model does seem to be paternalism in disguise. In the deliberative model the physician has the role of a teacher who tries to 'persuade the patient of the worthiness of certain values', through discussion. They write: 'not only does the physician indicate what the patient could do, but, knowing the patient, and wishing what is best, the physician indicates what the patient *should* do.' (15) In contrast to Savulescu they do not mention once the possibility that the physician revises his views in the light of the deliberation with the patient. The deliberative model is in my view too much a one-way street, or at least portrayed as such.

I rather go along with Savulescu's 'liberal rationalism', and also with Dutch ethicist Guy Widdershoven who argues, with reference to philosopher Hans-Georg Gadamer for a rather similar conversation; a dialogue in which physician and patient both can bring in their perspective and try to understand each other and learn from each other (Gadamer calls this

a 'hermeneutic dialogue'). (16,17) In such a dialogue the physician and the patient together can explore their ideas and the values behind them. It might help the patient to gain a better understanding of himself and what is really important to him, and this may enable him to make choices that fit him, for example regarding the care he wants to receive. It might even broaden a patient's horizon. However, such a dialogue might also enable the physician to learn something from the patient, instead of only the other way around.

The place of physicians' personal viewpoints in end-of-life care

In my view the answer to the central question of this thesis – '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?' – is that it would be ethically justifiable and even desirable that a physician brings in his personal viewpoints, but only in a non-judgemental and open dialogue as described above. With regard to end-of-life care, such a dialogue between a physician and a patient on quality of life, suffering, decline, dependency, dying and death can be very valuable. In such a dialogue there can be room for a physician to explain why he might have difficulties with the way a patient deals with death and dying, including explaining a possible reluctance towards granting a request for EAS. As said, this might broader a patient's horizon, which is a good thing either way. At the same time however, the physician should be open to the ideas and values of the patient, should be prepared to learn from those as well and to use this in a critical reflection on his own views and values.

In my view good end-of-life care is about supporting the patient to die in a way that fits him most. An open, non-judgmental and respectful dialogue between physician and patient (or his representatives) on life and death can help achieve that goal. For this purpose it would be ethically justifiable that a physician brings in his personal moral viewpoints. However, caution is required; the setting of a dying patient is a delicate one in which the patient and his relatives are in a very vulnerable and dependent position. Such a delicate situation demands above all a serving and supportive attitude from a physician; there is certainly no place for moral judgement from the physician about the patient, his ideas, values or ways he deals with suffering, decline and dependency, since feeling morally judged is likely to worsen death instead of making it 'better'.

The place of physicians' personal viewpoints in handling EAS requests

EAS is thought of as an extraordinary action, not belonging to normal medical practice. Although I acknowledge that dealing adequately with a request asks a lot from a physician in terms of time, commitment, communication, dealing with heavy emotions (from patients as well as one's own) and (self) reflection, I doubt whether EAS is rightly thought of as extraordinary and very different than other end-of-life decisions that are regarded as normal medical practice.

Ronald Dworkin and other prominent philosophers state in their 'Philosophers' brief' that in the debate on legalizing EAS a 'common-sense' distinction between the moral significance of acts on the one hand, and omissions, on the other is often suggested. (18) This moral distinction would justify a legal distinction between EAS and the removing of life support. They state that it is suggested often that removing life support is only a matter of 'letting nature take its course,' while EAS is an active intervention that 'brings death sooner than natural processes would'.(18) According to Dworkin et al. such suggestions wholly misunderstand the 'common-sense' distinction, which is not between acts and omissions, but between acts or omissions that are designed to cause death and those that are not. They write: 'a patient who insists that life support be disconnected is in fact committing suicide if he aims at death, as most such patients do, just as someone whose wrist is cut in an accident is committing suicide if he refuses to try to stop the bleeding.' (18)

In my view too, the moral distinction between EAS and the withdrawing of life-prolonging treatment is not that self evident, since both aim at bringing about death. The sharp line many draw between EAS that they perceive as 'unnatural', and other deaths that they – in contrast – perceive as 'natural' is striking, since prior to most deaths medical treatment and non-treatment decisions have been made that had a significant influence on the moment of death. One might even wonder to what degree deaths can still be 'natural' in highly medicalised countries.

Although one can philosophize whether the moral distinction between EAS and other end-of-life decisions is so significant that it justifies EAS' extraordinary status, the Dutch law on EAS too reflects this perceived difference; in the Dutch law on EAS, physicians are free to make their own considerations and to refuse a request at any time and for whatever reason. (3,4) This illustrates that the room physicians' personal viewpoints is

granted, is larger than in normal medical care, where physicians do have the obligation to respect a patient's decision to forgo a life-sustaining treatment.

I think this extraordinary status of EAS deserves further debate and re-evaluation. However, since many strongly feel EAS rightly has this extraordinary status, including the Dutch law, the time is not right (yet) to argue for a moral, let alone legal, obligation to perform EAS (i.e. in cases that seem to meet the criteria of due care). Nevertheless, I do want to argue that not every reason to reject a request for EAS is ethically justifiable. Reasons to reject an EAS request that seem to stem from physicians' personal views on good dying like 'the patient's attitude did not reflect enough resignation' or 'there were conflicts in the family that should be resolved first', are problematic in my view. They are especially problematic when the physician lets these personal viewpoints influence his decision on an EAS request *without* making these viewpoints topic of dialogue with the patient. I will explain why.

Patients who request EAS experience their suffering as unbearable. Most of them do not want to die, but their life has become so miserable and their suffering so severe, that being dead seems better than being alive. Patients may have different thresholds for evaluating their suffering as unbearable, but nobody will ask for EAS for trivial reasons. To my opinion the tremendous distress these patients experience obliges every physician who receives an EAS request to take the request very serious and to make a **maximum 'reflective effort'**. With maximum reflective effort I mean that every physician who receives an EAS request should do his utmost to **a)** asses the suffering of the patient by imagining what the situation must be like for this particular patient with this particular history, personality and values and **b)** critically reflect on his own viewpoints and values.

a) is what Van Tol et al. describe as the 'imagine other' route. (19) Van Tol et al. found a lot of variation in the application of the unbearable suffering criterion in their qualitative research with Dutch GPs. They offer an explanation for this variation. They show that GPs follow different cognitive routes when assessing a patient's suffering in the context of an EAS request: by imagining how it would be to experience the situation of the patient themselves ('imagine self') or by imagining what the situation must be like for this particular patient ('imagine other'). The 'imagine other' route is the most desirable route in my view, since suffering is something very personal. Eric Cassell in his influential work on suffering makes clear that 'suffering is experienced by persons, not merely by bodies, and has its source in challenges that threaten the intactness of the person as a complex social and psychological entity'. (20)

With **b)** I mean that physicians must critically examine their own viewpoints, and in doing so must try to get clear which viewpoints stem from values that are so fundamental to them that violating them would mean crossing their moral limits. In the example of the physician who did not want to grant an EAS request because there were unresolved conflicts between the patient and his family (chapter 4), the physician should ask himself the question whether 'leaving life harmoniously' is indeed such a fundamental value to him, it even trumps his moral and professional obligation to relieve the suffering of the patient.

It think the hermeneutic dialogue described above can be very useful to get more insights into **a)** as well as **b)**. This requires physicians to have highly developed communication, interpersonal and reflective skills though – an important assignment for (future) physicians' education and training.

I would like to conclude that in my opinion it is only ethically justifiable to reject a request for EAS (of which one can assume that it meets the criteria of due care, on the basis of previous verdicts from the Regional Review Committees or the EuthanasiaCode 2018 (21,22)) in the case the physician has made a maximum reflective effort (has done a and b) and after that must conclude that performing the EAS is not compatible with values that are fundamental to him. The physician then should communicate this to the patient with reference to his personal views and values that prohibit him to grant the request only; thus without expressing a moral judgement on the patient, and his views on life, death, suffering, dependency and decline.

End-of-life care for children

In the case of a young child who is severely ill the open dialogue about quality of life, death and dying I argued for will not be possible with the patient itself, but must take place with the child's parents. Rare exceptions aside, parents are the ones who know their child best, the ones who love their child most and also the ones who bear the consequences of medical decisions most since they have to live on with or without their child. A young child is so intrinsically connected to its family it can hardly be considered in itself. This makes the parents' ideas and values on life, suffering, dependency and dying very important to get insight into and even to make leading in the care for the child. The acknowledgement of parents as best advocate of their child's interests can be found in the Dutch law too; medical treatment always requires parental consent, only in the rare situation parents do not consent to a treatment that is absolutely necessary to prevent severe harm

to the child's health physicians may (after an intervention of a judge) treat the child without consent of the parents. (23) The other way around, parents cannot demand (continuing) treatment that is or has become medically futile in the eyes of the physician or the medical team.

To my opinion, however, one should be cautious with making an appeal to medical futility. 'Medical futility' is not the objective classification it may seem. The notion incorporates implicit normative ideas on quality of life and the value of life. Those ideas, however, stem from a modern Western and secular worldview and are by no means shared by everyone. As I said earlier I believe there is not one right way to look at (quality of) life, dependency, suffering, death and dying. This is all the more reason to take the ideas and values of the parents with regard to these matters seriously. In case parents have a different view from their child's physician(s) the way to proceed that I would suggest is actually no different than I argued for in case of an adult patient: try to have an open non-judgemental and respectful dialogue with each other on ideas, beliefs and values (here is the room for physicians to modestly bring in their personal moral viewpoints), try to learn from each other and together search for a way of caring for the child that fits this particular family most. This suggestion though, should not be interpreted as a solution to settle all possible conflicts that may arise between physician(s) and parents about the care for severely ill children, but rather as a general norm from which exceptions can be made in case the interest of the child undoubtedly requires this.

In the specific situation of a parental request for deliberately ending the life of a neonate (DELN) the room for physicians' personal viewpoints seems even larger than in the case of an EAS request, because DELN has an even more extraordinary status. (10, 24-26) The criminal law is placed closer – all cases are sent to the public prosecutor – and there is no well-considered and voluntary request of the patient itself, which makes the legal category in this respect not 'euthanasia' but 'murder'.

Although one could question again whether the moral differences between DELN and other end-of-life decisions like withdrawing or withholding life-sustaining treatment from the child are indeed so significant they justify DELN's extraordinary status, I do not argue for a moral obligation for a physician to grant a DELN-request (in case it would meet the legal requirements) when this would mean the physician has to violate his own moral limits by doing so. But I do want to recommend that a physician who gets such a DELN request takes the parents' view on the suffering of their child (that they evaluate as unbearable) into account when assessing the suffering of the child, and critically reflects on his own viewpoints.

Unfortunately the current legal regulation on DELN prohibits physicians to end a protracted dying process at the request of desperate parents who, despite a good explanation on what to expect, cannot cope with gasping that holds on for hours. (10) I understand physicians who deny such a request because of the possible legal consequences, but physicians who deny such a request solely because in their view deaths should be 'natural' (chapter 3), are acting harsh to my opinion. (10) For the child it does not matter anymore since it is in an irreversible coma and is not conscious anymore, but for the parents their memories of this event, which is probably the most difficult and traumatic event a person can ever experience – losing one's child –, will stay with them forever. In my view reducing the parents' suffering and facilitating a good death in their eyes should be more important than the physician's viewpoints of a good death. A physician who puts his personal viewpoints on dying well first on such a delicate and tragic moment, does not reflect the serving and supportive attitude I believe every deathbed deserves.

I hope the insights and reflection this thesis offer will be a contribution to better care and assistance for all dying patients and their relatives.

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"Ethical discussion; the proper place for physicians' personal viewpoints in end-of-life care"

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Addenda

Summary

Dutch Doctors & Dying
Do doctors' personal views influence their professional care at the end of life – and should they?

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. The aim of the thesis is to provide more insights into the viewpoints of physicians on death and (assisted) dying, and to provide 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.

This thesis consists of three parts and is a mix of empirical research and ethical reflection and discussion.

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 on end-of-life decisions for neonates in 2010 and elaborates on the decreased frequency of the decision to deliberately end life (DELN). These end-of-life decisions were mainly decisions to withdraw or withhold potentially life-sustaining treatment. The percentage of cases in which drugs were administered with the explicit intention to hasten death was 1% in 2010, while in 1995 and 2001, this was 9% and in 2005, this was 8%. One explanation for this reduction relates to the introduction of legal criteria and a review process for DELN in 2007. This chapter explains why this regulation may have left Dutch paediatricians with less room to hasten death since then. 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. Major themes paediatricians mention were the interpretation of gasping, the role of (the suffering of) the parents, the need for judicial review and legislation's impact on the care participants provide for dying neonates. The interviews show no consensus between paediatricians. 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 (GP) 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). The considerations found can be divided in three main types. (i) Perceived legal criteria, (ii) individual interpretations of the legal criteria and (iii) considerations unrelated to the legal criteria. Examples of this third type are: the family should agree to EAS, the patient's attitude must reflect resignation, or conflicts must be resolved. In this chapter we hypothesize that these considerations reflect GPs' views on what 'good dying' entails. 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. Elements of good dying often mentioned by GPs were: minimal physical suffering, acceptance and resignation, being supported by loved ones, harmony, being at home and dying in accordance with the patient's personality and preferences. GPs disagreed whether EAS can be a good death. GPs had difficulties dealing with patients who approach death in a way that does not match their view on good dying. GPs differed in how they deal with these 'mismatch situations'. We used the four models of the physician-patient relationship described by Emanuel and Emanuel to interpret the ways GPs deal with the mismatch between their own views on good dying and those of the patient. Emanuel and Emanuel favour the deliberative model. In this chapter we argue that their description of this model is too much a one-way-street of the physician telling the patient what to do, and that this is not appropriate in end-of-life care. Instead, we advocate a hermeneutic dialogue about death and dying in which ideas, values and patient's coping strategies are explored in an open and non-judgmental way, in order to support patients in dying 'their own way' as much as possible.

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 formulate 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?

Summarized my answer is that it would be ethically justifiable and even desirable that a physician brings in his personal viewpoints, but only in a non-judgemental and open dialogue. With regard to end-of-life care, such a dialogue between a physician and a patient on quality of life, suffering, decline, dependency, dying and death can be very valuable. However, caution

is required; the setting of a dying patient is a delicate one in which the patient and his relatives are in a very vulnerable and dependent position. Such a delicate situation demands above all a serving and supportive attitude from a physician; there is certainly no place for moral judgement from the physician about the patient, his ideas, values or ways he deals with suffering, decline and dependency.

In the Dutch law on EAS, physicians are free to make their own considerations and to refuse a request at any time and for whatever reason. This illustrates that the room physicians' personal viewpoints is granted, is larger than in normal medical care. In this chapter I argue that this extraordinary status of EAS deserves further debate and re-evaluation. However, I do not argue for a moral, let alone legal, obligation to perform EAS (i.e. in cases that seem to meet the criteria of due care). I do argue that not every reason to reject a request for EAS is ethically justifiable. For patients who request EAS experience their suffering as unbearable. The tremendous distress these patients experience, I argue, obliges every physician who receives an EAS request to take the request very serious and to make a maximum 'reflective effort'. The physician should do his utmost to a) asses the suffering of the patient by imagining what the situation must be like for this particular patient with this particular history, personality and values and b) critically reflect on his own viewpoints and values. I conclude that it is only ethically justifiable to reject a request for EAS (of which one can assume that it meets the criteria of due care, on the basis of previous verdicts from the Regional Review Committees or the EuthanasiaCode 2018) in the case the physician has made this maximum reflective effort, and after that must conclude that performing the EAS is not compatible with values that are fundamental to him. With regard to end-of-life decisions for small children I argue that the ideas and values of the parents should be made leading in the care for the child, exceptions aside.

Samenvatting

Dokters & Doodgaan
Een onderzoek naar de invloed van dokters' persoonlijke opvattingen op hun zorg rond het levenseinde, en de wenselijkheid daarvan.

Dit proefschrift is een weergave van mijn onderzoek naar de persoonlijke visie van artsen op zorg en beslissingen rond het levenseinde in het algemeen en actieve levensbeëindiging in het bijzonder. Het doel van dit proefschrift is meer inzicht verschaffen in de persoonlijke visies van artsen. Daarnaast heeft dit proefschrift tot doel een ethische reflectie te bieden op de invloed die deze visies hebben op de zorg die artsen verlenen rondom het levenseinde. Artsen houden zich tegenwoordig steeds nadrukkelijker bezig met zorg voor stervenden, en ook doen patiënten steeds vaker een beroep op artsen hen te helpen om (goed) te sterven. Dit maakt het des te belangrijker om meer inzicht te hebben in de persoonlijke visie van artsen en te reflecteren op de invloed van hun visie op de zorg die ze bieden.

Dit proefschrift bestaat uit drie delen en is een mix van empirisch onderzoek en ethische reflectie en discussie.

Deel 1 (hoofdstuk 2 en 3) gaat over medische beslissingen rond het levenseinde bij ernstig zieke of aangedane pasgeborenen (kinderen tot 1 jaar) in het algemeen, en in het bijzonder over de beslissing tot actieve levensbeëindiging (LP). Hoofdstuk 2 geeft de resultaten weer van een landelijke studie uit 2010 naar de frequentie en aard van beslissingen rond het levenseinde bij pasgeborenen. Deze beslissingen behelsden voornamelijk de beslissing om geen levensverlengende behandeling in te stellen of deze te staken. Het percentage gevallen waarin een middel was toegediend met het uitdrukkelijke doel het levenseinde te bespoedigen was in 2010 slechts 1%, terwijl dit in 1995 en 2001 nog 9% was en in 2005 8%. Een van de verklaringen voor deze afname is de introductie van een wettelijke regeling voor LP in 2007 en bijbehorende toetsingsprocedure. In dit hoofdstuk wordt uitgelegd waarom deze wettelijke regeling er voor heeft gezorgd dat artsen sindsdien minder ruimte hebben om het leven van een ernstig zieke pasgeborene actief te beëindigen. Hoofdstuk 3 zoomt vervolgens in op dit thema. Het geeft de resultaten weer van een interviewstudie onder kinderartsen naar hun visie op LP – in het bijzonder in het geval het stervensproces van een pasgeborene heel lang duurt en ouders verzoeken daar een eind aan te maken – tegen de achtergrond van de wettelijke regeling voor LP. Belangrijke thema's die

door de kinderartsen genoemd werden waren: de interpretatie van gaspen, de rol van (het lijden van) de ouders, de noodzaak van juridische toetsing en de invloed die de wettelijke regeling heeft op de zorg die kinderartsen deze kinderen bieden. De interviews laten zien dat kinderartsen erg verdeeld zijn. In essentie komen hun verschillen in visie neer op de vraag hoe 'goed sterven' er uit ziet in het geval van een pasgeborene en zijn ouders.

Deel 2 (hoofdstuk 4 en 5) gaat over huisartsen en de zorg rondom het levenseinde die zij bieden. Hoofdstuk 4 geeft de resultaten weer van een interviewstudie onder huisartsen naar hun overwegingen bij de beslissing een verzoek om euthanasie of hulp bij zelfdoding al dan niet in te willigen. De overwegingen die uit de interviews naar voren kwamen kunnen ingedeeld worden in 3 typen. (i) Overwegingen die gerelateerd zijn aan de (door de huisarts veronderstelde) wettelijke zorgvuldigheidseisen, (ii) overwegingen die gerelateerd zijn de huisarts' interpretatie van de wettelijke zorgvuldigheidseisen en (iii) overwegingen die geen relatie hebben met de wettelijke zorgvuldigheidseisen of de interpretatie daarvan. Voorbeelden van die laatste categorie zijn: de familie moet akkoord zijn met de euthanasie, de patiënt moet berusting hebben gevonden in het feit dat hij dood gaat, of conflicten van de patiënt moeten eerst worden opgelost. We vermoeden dat deze overwegingen voortkomen uit onderliggende ideeën van de arts over goed sterven. Hoofdstuk 5 zoomt vervolgens in op de visie van huisartsen op goed sterven. Het geeft de resultaten weer van een interviewstudie naar de visie van huisartsen op goed sterven, en de manier waarop deze visie de zorg rond het levenseinde die de huisarts biedt beïnvloedt. Elementen van goed sterven die de huisartsen vaak noemden waren: zo min mogelijk fysiek lijden, acceptatie en berusting, steun van geliefden, harmonie, thuis sterven, en sterven op een manier die past bij de patiënts persoonlijkheid en wensen. Huisartsen verschilden van mening of euthanasie ook een goede dood kan zijn. Daarnaast hadden huisartsen moeite met het omgaan met patiënten die met hun naderende dood omgingen op een manier die niet in de huisarts' plaatje van goed sterven paste. Zij gingen daar verschillend mee om. Aan de hand van de 4 modellen van de arts-patiënt relatie, beschreven door Emanuel en Emanuel, analyseren we in dit hoofdstuk de verschillende manieren waarop huisartsen omgaan met deze 'mismatch' situaties. Emanuel en Emanuel zelf zijn voorstander van het deliberatieve model. In dit hoofdstuk beargumenteren we waarom wij vinden dat hun beschrijving van dit model te veel eenrichtingsverkeer is van de arts die de patiënt vertelt wat hij zou moeten doen en waarom we dit met name in de zorg rond het levenseinde niet passend vinden. In plaats daarvan stellen we een hermeneutische dialoog voor over leven en dood waarin zowel

de arts' als de patiënts ideeën en waarden en ook de patiënts manier van omgaan met de naderende dood besproken kunnen worden op een open en niet-veroordelende manier, zodat de patiënt het best ondersteund wordt in sterven op een manier die hem past.

Deel 3 (hoofdstuk 6) is een ethische discussie waarin ik reflecteer op de bevindingen uit de voorgaande hoofdstukken. Dit hoofdstuk vormt daarmee de algemene discussie van dit proefschrift. In dit hoofdstuk beantwoord ik de hoofdvraag van dit proefschrift: is het ethisch te rechtvaardigen dat de persoonlijke visie van artsen hun professionele zorg rond het levenseinde beïnvloedt, en zo ja in welke mate? Een subvraag daarbij is of het antwoord op de deze vraag verschilt wanneer het gaat om actieve levensbeëindiging (euthanasie of hulp bij zelfdoding bij volwassenen, of actieve levensbeëindiging bij pasgeborenen) in vergelijking met 'normale' zorg en beslissingen rond het levenseinde, en zo ja waarom dan?

Samengevat komt mijn antwoord hier op neer: het is ethisch gerechtvaardigd en zelfs wenselijk dat artsen hun persoonlijke visie inbrengen, maar dan alleen op een open en niet-veroordelende manier. Ik betoog dat een hermeneutische dialoog tussen arts en patiënt over (kwaliteit) van leven, lijden, aftakeling, afhankelijkheid en sterven heel waardevol kan zijn. Maar wel met het voorbehoud daarbij dat artsen voorzichtig moeten zijn met het inbrengen van hun eigen visie omdat sterven een precaire aangelegenheid is waarbij patiënt en naasten in een hele kwetsbare en afhankelijke positie verkeren. Zo'n setting vraagt vooral om een steunende en dienstbare houding van de arts. Er is in zo'n setting in geen geval plaats voor een moreel oordeel van de arts over de patiënt, zijn ideeën, waarden of de manier waarop hij omgaat met lijden, aftakeling en afhankelijkheid.

Artsen zijn in Nederland vrij om hun eigen afwegingen te maken bij het beslissen over een euthanasieverzoek, en mogen dit te allen tijde en om welke reden dan ook afwijzen. Dit illustreert dat de ruimte voor persoonlijke opvattingen van artsen hier groter is dan bij normaal medisch handelen. In dit hoofdstuk beargumenteer ik dat de buitengewone status die euthanasie toekomt in mijn ogen meer debat en her-evaluatie verdient. Desondanks pleit ik niet voor een morele (of zelf juridische) plicht tot het uitvoeren van euthanasie (in die gevallen die aan de zorgvuldigheidscriteria voldoen). Wat ik wel beargumenteer is dat niet elke reden om een euthanasieverzoek af te wijzen ethisch te rechtvaardigen is. Patiënten die om euthanasie vragen lijden in hun beleving namelijk ondraaglijk. Dit maakt dat artsen die een euthanasieverzoek ontvangen deze naar mijn mening altijd zeer serieus moeten nemen en een uiterste inspanning zouden moeten leveren deze te onderzoeken. Ik beargumenteer dat elke arts die een euthanasieverzoek

ontvangt zijn uiterste best zou moeten doen om a) het lijden van de patiënt te onderzoeken door zich te verplaatsen in de patiënts situatie en zich voor te stellen wat dit voor deze specifieke patiënt met diens specifieke levensgeschiedenis, persoonlijkheid en waarden betekent en b) zijn eigen opvattingen en waarden kritisch tegen het licht te houden. Ik beargumenteer waarom ik vind dat het alleen ethisch gerechtvaardigd is een euthanasieverzoek (waarvan men mag aannemen dat het aan de zorgvuldigheidseisen van de wet voldoet gezien de oordelen van de Regionale Toetsingscommissies Euthanasie en de EuthanasieCode2018) af te wijzen in het geval een arts zowel a) als b) heeft gedaan en vervolgens niet anders kan concluderen dan dat het inwilligen van het verzoek niet verenigbaar is met waarden die fundamenteel zijn voor hem. Met betrekking tot beslissingen rond het levenseinde van kleine kinderen betoog ik in dit hoofdstuk dat de ideeën en waarden van de ouders leidend zouden moeten zijn in de zorg voor het kind, enkele uitzonderingen daargelaten.

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PhD portfolio

Name PhD student: Katja ten Cate
PhD period: 1 October 2013 – 31 December 2018
Name PhD supervisor: Prof. dr. S. van de Vathorst

PhD training

	Year	Workload ECTS
General courses		
– 'Leergang Activerend Onderwijs' BKO-traject AMC (Basic Teaching Qualification)	2018	1 ECTS
– Scientific writing in English – AMC Graduate School	2015	0,5 ECTS
– Qualitative Research – AMC Graduate School	2015	0,5 ECTS
– EndNote – AMC Graduate School	2014	0,1 ECTS
– Pubmed (e-learning) – AMC Graduate School	2014	0,1 ECTS
– Literature search for systematic review – AMC Graduate School	2014	0,1 ECTS
Specific courses		
– Winterschool Ethical Theory and Applied Ethics – Onderzoeksschool Wijsbegeerte (OZSW) Barchem	2014	1,25 ECTS
– Ethiek van Gezondheid en Zorg – Onderzoeksschool Wijsbegeerte (OZSW) Utrecht	2014	0,5 ECTS
Congresses and symposia (visited)		
– KNMG Medisch Contact Live 'De dokter en Ethiek', Nijmegen	2018	0,1 ECTS
– NVBe jaarsymposium 'Ethiek en Praktijk anno 2018', Amsterdam	2018	0,25 ECTS
– 2nd International Conference on End of Life Law, Ethics, Policy and Practice, Halifax, Canada	2017	0,75 ECTS
– KNMG/SCEN-congres 'Voltooid is het nooit', Utrecht	2017	0,25 ECTS
– NVBe jaarsymposium 'de ethiek van One-health', Utrecht	2017	0,1 ECTS
– NVBe Onderwijsmiddag 'Levensbeschouwelijke en culturele diversiteit in ethiekonderwijs', Utrecht	2016	0,1 ECTS
– 4e Els Borst Lezing door Trudy deHue, Den Haag	2016	0,1 ECTS
– 3e Els Borst Lezing door Bert Keizer, Den Haag	2015	0,1 ECTS
– Symposium ErasmusMC 'schriftelijke wilsverklaring bij euthanasie', Rotterdam	2015	0,1 ECTS
– Symposium 'Sharing end-of-life decisions with parents: from limits to possibilities' with Dominic Wilkinson, Amsterdam	2015	0,1 ECTS
– NVVE Symposium 'Voltooid leven', Utrecht	2015	0,25 ECTS
– KNMG Medisch Contact Live 'De dokter en de dood', Utrecht	2015	0,1 ECTS

	Year	Workload ECTS
– KNMG/SCEN-congres 'De puzzel van de SCEN-arts', Utrecht	2015	0,25 ECTS
– Symposium 'Levenseindekliniek wordt centrum voor euthanasie expertise', Utrecht	2014	0,25 ECTS
– NVVE Symposium 'Euthanasie bij dementie, kan dat?', Amersfoort	2014	0,25 ECTS
– Symposium Vereniging voor Gezondheidsrecht 'Ethiek en Gezondheidsrecht', Amsterdam	2014	0,1 ECTS
– Symposium bij oratie 'De goede dood' van Suzanne van de Vathorst, Amsterdam	2014	0,1 ECTS
– NVBe jaarsymposium 'De rol van ethicus bij wetsevaluaties', Utrecht	2013	0,1 ECTS
– NVVE symposium 'Hulp is geen misdaad', Maarssen	2013	0,25 ECTS
– Symposium Vereniging Filosofie en Geneeskunde 'Kwaliteit van leven', Leiden	2013	0,1 ECTS
Workshops and masterclasses (participated)		
– NEON Expertmeeting with Menno de Bree 'Ethiekondersteuning en moreel beraad', Nijmegen	2018	0,1 ECTS
– Workshop with David Velleman 'Euthanasia and assisted suicide', ErasmusMC Rotterdam	2018	0,1 ECTS
– Masterclass 'Ethics in Pediatrics' with John Lantos, Groningen	2015	0,2 ECTS
– AMC Philosophy of Care Lectures (interactive lectures with speakers, every two months)	2014-2016	1 ECTS
Presentations given		
– Public library Eindhoven 'Euthanasie en Voltooid leven'	2018	0,5 ECTS
– KNMG/SCEN-congres 'Voltood is het nooit'. 'KNMG-pilot: steun door coaching', Utrecht	2017	0,5 ECTS
– Afscheidssymposium Petra de Jong NVVE 'Dokters en euthanasie', Laren	2015	0,5 ECTS
– IFMSA-VU symposium Week van de euthanasie 'de rol van de dokter', Amsterdam	2015	0,5 ECTS
– Symposium Medisch begeleid sterven HAGA, 'Waardig sterven en goede palliatieve zorg', Den Haag	2015	0,5 ECTS
– Symposium CTB 'Ethische aspecten van chronische thuisbeademing bij kinderen', Arnhem	2015	0,5 ECTS
Presentations given on international conferences		
– 2nd International Conference on End of Life Law, Ethics, Policy and Practice, Halifax, Canada 'Dutch GPs' Views on Good Dying and Euthanasia'	2017	0,5 ECTS
Other activities		
– Ethicus Regionale Toetsingscommissie Euthanasie (RTE)	2018	1 ECTS
– Projectcoördinator SCEN/KNMG	2017	> 4 ECTS
– Bestuurslid Nederlandse Vereniging voor Bio-ethiek (NVBe)	2015 – 2018	4 ECTS
– Organisator 'Philosophy of Care lectures' AMC	2014 – 2016	0,5 ECTS

Teaching

	Year	Workload ECTS
Lecturing		
– Lecture and interactive learning on Euthanasia for GPs in training, nationwide GP training program Palliative Care (4x 1,5 hour)	2017 – 2018	0,3 ECTS
– Lecture and interactive learning on Euthanasia for GPs in training, 2nd year ErasmusMC Rotterdam (4x 1,5 hours)	2017 – 2018	0,3 ECTS
– Lecture and interactive learning on end-of-life decisions for children on the ICU for Paediatric intensivists (fellows), nationwide training program (1x 4 hours)	2018	0,2 ECTS
– Moral case deliberation with MA students (3rd year) AMC Amsterdam (10x 3,5 hours)	2015 – 2018	1,3 ECTS
– Interactive learning on medical ethics for MA students (1st year) AMC Amsterdam (10x 1,5 hours)	2015 – 2018	0,5 ECTS
– Interactive learning on medical ethics for BA students (3rd year) AMC Amsterdam (16x 1,5 hours)	2015 – 2018	0,8 ECTS
– Lecture and interactive learning on end-of-life decisions for medical specialists in training, ErasmusMC Rotterdam (3 hours)	2017	0,1 ECTS
– Lecture and interactive learning on euthanasia for BA students (2nd year) AMC Amsterdam (2x 1 hour)	2017 -2018	0,1 ECTS
– Lecture on euthanasia for MA students (3rd year) AMC Amsterdam (1,5 hour)	2015	0,1 ECTS
– Interactive learning on ethical aspects premiumdifferentiation for BA students UVA/AMC ('keuzevak Ethiek en recht') (1,5 hours)	2014	0,1 ECTS
– Lecture and interactive learning on end-of-life decisions for children for BA students EUR/ErasmusMC (minor medical ethics) (3 hours)	2014	0,1 ECTS
– Lecture and interactive learning on DELN for neonatologist in training AMC Amsterdam (2 hours)	2014	0,1 ECTS
Supervising		
– Supervision BA thesis on viewpoints of GPs in Europe on euthanasia	2017	1 ECTS

Publications

	Year
Peer reviewed	
– Ten Cate K. Ethical discussion; the proper place for physicians' personal viewpoints in end-of-life care. (submitted to *Medicine Health Care and Philosophy*)	2018
– Ten Cate K, van Tol DG, van de Vathorst S. Dutch doctors and dying; a qualitative stydy on general practitioners' views on good dying. (submitted to *Journal of Medical Ethics*)	2018
– Ten Cate K, van Tol DG, van de Vathorst S. Considerations on requests for euthanasia or assisted suicide; a qualitative study with Dutch general practitioners. *Fam Pract*. 2017;34(6):723-9.	2017
– Ten Cate K, van de Vathorst S, Onwuteaka-Philipsen BP, et al. End-of-life decisions for children under one year of age in the Netherlands: decreased frequency of administration of drugs to deliberately hasten death. *J Med Ethics*. 2015;41(10):795-8.	2015
– Ten Cate K, van de Vathorst S. Dutch paediatricians' views on the use of neuromuscular blockers for dying neonates: a qualitative study. *J Perinatol*. 2015;35(7):497-502.	2015
Other	
– Van der Heide A, Onwuteaka-Philipsen BP, van Thiel G, van de Vathorst S, Weyers H, Busscher R, ten Cate K, Hagens M. *Kennissynthese Ouderen en het zelfgekozen levenseinde*. Den Haag: ZonMw; 2014.	2014
– Van de Vathorst S, ten Cate K. Klaar met leven. In: *De dokter en de dood*. Van Zuylen L, van der Heide A, van de Vathorst S, Geijteman E (red). Diagnosis uitgevers; 2014.	2014
– Ten Cate K. Meer ziektekostenpremie bij ongezond gedrag: geen goed idee. *Tijdschrift voor Gezondheidszorg en Ethiek*. 2014;24(2):34-41.	2014
– Van de Vathorst S, Gevers JKM, van der Heide A, Bolt LLE, ten Cate K. *Evaluatie Regeling centrale deskundigencommissie late zwangerschapsafbreking in een categorie-2 geval en levensbeëindiging bij pasgeborenen*. Den Haag: ZonMw; 2013.	2013

About the author

Katja ten Cate (1986) studied medicine at Leiden University. During this study she realised that she didn't want to become a physician, but rather would like to think about and reflect on medicine and healthcare. For one year she followed philosophy courses at the Leiden University and after obtaining her 'doctorandus-degree' in medicine she went on to do a master in Applied Ethics at Utrecht University. Here she graduated in 2012 with a thesis on ethical concerns regarding premium differentiation on the basis of lifestyle in the basic healthcare insurance. After graduation she worked for one year as a junior researcher at the department of Medical Ethics and Philosophy from the ErasmusMC in Rotterdam on an evaluation of the Dutch legal provision for 'late termination of pregnancy and deliberately ending the life of a neonate'. Here she met Suzanne van de Vathorst, who invited her to come to the Academic Medical Centre in Amsterdam (AMC) to do further research into physicians' views on the end(ing) of life. This thesis is the result of her research activities in Rotterdam and Amsterdam.

In 2017 she worked temporarily at the KNMG (the Royal Dutch Medical Association) on the SCEN-program (Support and Consultation in Euthanasia in the Netherlands). In 2018 she became a member of a regional review committee for euthanasia in the Netherlands. In 2019 she will be appointed as a lecturer at the AMC on (the ethics of) end-of-life decisions.

Katja lives in Oosterbeek, a village near Arnhem, in the Netherlands. She lives together with her husband and their two sons. In February 2019 they are expecting their third child.

This PhD-thesis is a reflection of the research Katja ten Cate has done from 2013 until 2018: studying physicians' experiences with and personal views on end-of-life decisions, in particular physician-assisted dying. The thesis aims at providing more insights into the personal views of physicians on death and (assisted) dying, and also offers an ethical reflection on the influence these views 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 ethical reflection all the more relevant.

Katja ten Cate (1986) works as a researcher and teacher at the Medical Ethics section of the General Practice Department at the Amsterdam UMC-location AMC.