End-of-Life Decisions for Children

Empirical Studies on Physicians' Practices and Attitudes

Astrid M. Vrakking

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Contents

Part I

Introduction

1

Introduction

Background of the study

In the Netherlands, end-of-life decision-making has been under debate for several decades. Medical end-of-life decisions are defined as medical decisions that intentionally hasten death or decisions where the probability of hastening death has been taken into account. Such decisions can involve the withholding or withdrawing of possible life-sustaining treatment, or the alleviation of pain or other symptoms, thereby taking into account the fact that by doing so, death might be hastened, or possibly even doing so partly with the aim of hastening death, or the use of drugs to end life.
Special attention has been given to end-of-life decision-making for children. Children are only starting out in life and in most cases are not competent to take part in the discussion about the decision. Both factors raise a great responsibility for the decision-makers.

In 1992, the Dutch Paediatric Association published a guideline about end-of-life decision-making for neonates and infants.[1] However, nothing was known about the frequency with which end-of-life decisions were made in this age group in the Netherlands. In 1995, the first nationwide study was conducted on end-of-life decision-making for neonates and infants.[2-5] This study found that an end-of-life decision preceded the majority of these deaths (62%). Decision-making seemed to be done with care, and decisions were mostly in close consultation with colleague-physicians and with the parents. A European study among neonatologists also found that a substantial number of neonatologists made end-of-life decisions[6], although these neonatologists varied in the degree to which they reported ever having made the decision to administer drugs with the aim of hastening death. In France and the Netherlands, the proportions of physicians who had ever done so were substantial (73% and 43% respectively), but in the other countries, the proportions were smaller (2 to 4%). The Dutch 1995 study showed that in 8% of all deaths, decisions were made to forgo life-sustaining treatment, followed by the administration of drugs aimed at hastening death, and in 1%, drugs were administered to hasten death, not preceded by the forgoing of a life-sustaining treatment.[2,3]
Hastening death without an explicit request of a patient is legally prohibited in the Netherlands. However, two physicians who reported having hastened the death of a severely ill neonate to the Public Prosecutor were dismissed from prosecution.[7-10] The

Court analysed the cases along the line of euthanasia jurisprudence. They concentrated on the futility of treatment, the acceptability in these circumstances of the active ending of life, and the applicability of *force majeure* - in the sense of a moral conflict of duties. Currently, the Public Prosecutor receives reports in about three cases every year in which the life of a severely ill neonate is ended, whereas it is estimated that the total number of cases is at least 15 to 20.[2,3,11,12] In the reported cases, it was concluded that conditions of prudent practice were met, i.e., that 1) the suffering of the child was unbearable without any prospect of improvement; 2) independent physicians were consulted; 3) the parents were in agreement with the decision; and 4) physician assistance in dying was provided with care.[12] The Dutch 1995 study showed that the majority of neonatologists and paediatricians were in favour of having cases in which drugs are administered to end life reviewed not only by the public prosecutor or only by the health care providers themselves, but also by independent medical professionals and by a committee consisting of medical and other professionals.[2,3] In 1997, a conference group that was initiated by the Dutch Ministry of Health recommended that the Minister established a special review committee, composed of a lawyer, a paediatrician and an ethicist. One of the reasons for installing such a committee was to stimulate physicians to report cases, and to encourage an open and transparent practice.[9]

The guideline on end-of-life decision-making of the Dutch Paediatric Association focused on neonates and infants.[1] The guideline paid no attention to older children, who may or may not be competent to make such decisions or involved in making decisions of this kind, that can have such far-reaching and irreversible consequences. The rules in the 'Ending of Life on Request and Assisted Suicide Review Procedures Act' (Euthanasia Act), state that physicians are allowed to hasten the death of children who are capable of a reasonable judgment of their interests, that is, of children aged 12 years or above, provided that physicians apply the conditions for prudent practice.[13] For children between the ages of 12 and 16 years old, the agreement of the parents must be obtained, while the parents of 16 and 17 year old children are required to be involved in the decision-making. The Euthanasia Act was passed in April 2001 and came into effect in April 2002.

Objective and research questions

Previous studies proved that insight into the practice of end-of-life decision-making in children and a knowledge of the views of physicians on this topic contribute to the debate and can have an effect on health policy.[14] The objective of this thesis is to describe the practice of end-of-life decision-making for neonates and infants and for

children beyond the neonatal period in the Netherlands, and to describe the attitudes of physicians on assistance in dying in children and opinions on the euthanasia act.

Research questions were:

1. How often are end-of-life decisions made and what are the characteristics of end-of-life decision-making in neonates and infants?
2. How did the Dutch practice develop over time, and is it different from Belgium?
3. How often are end-of-life decisions made in older children and what are the characteristics of the decision-making process?
4. What are the attitudes of paediatricians and other physicians towards assisted death in children and what are their opinions about the Euthanasia Act?

Methods

The first study we used was a death certificate study from 1995 that was repeated in 2001. Throughout a four-month period in both years, any physician reporting the death of a child younger than one year of age to the Central Death Registry was sent an anonymous mail questionnaire. The questionnaire contained questions on the frequencies of end-of-life decisions, and on the decision-making process. Terms like euthanasia or physician-assisted death were avoided because they have many different connotations to physicians. In 2001, the study comprised 347 out of a total 1088 of certified deaths in that year. These figures were comparable to those of the 1995 study. We also compared the Dutch end-of-life practice with that of Belgium, with the help of data from a comparable Belgian study. This study included all neonates and infants who died under the age of one (n=292) in Flanders, during a 12-month period (August 1999 – July 2000). In all these studies, the response was 84% or higher.

A second death certificate study, which examined the deaths of children between the ages of one and 17, was conducted during the same four-month period in 2001. In that year, 619 children in this age group died in the Netherlands, of whom 188 in the study period. The study focused on the 158 reported deaths for which the addresses of the reporting physicians were available. The response was 75%. Again, the physicians in question received an anonymous mail questionnaire. The questionnaire was similar to that sent in the neonates and infants death certificate study, but included additional questions about the child's ability to assess the situation and make decisions.

Thirdly, interviews were conducted with physicians who were specialized in paediatric oncology, paediatric intensive care, and paediatric neurology, as these specialties cover most deaths of children in the Netherlands. In total, 63 physicians were

interviewed (27 paediatrician-oncologists, 18 paediatrician-intensivists, and 18 paediatric neurologists), representative for the total of 98 eligible physicians in these specialties.
Trained physicians conducted the interview, which had an average duration of 1.45 hours (minimum 30 minutes; maximum 5 hours). The questionnaire was divided into different parts. First, respondents were asked about their experiences with different end-of-life decisions. Subsequently, questions were asked about the patient characteristics and the decision-making process in the most recent case in their practice, if any. In addition, 10 hypothetical cases were presented to study the willingness of Dutch physicians to use potentially life-shortening drugs or lethal drugs. The age of the child (15, 11, or 6 years), the child's (explicit) request, and the opinion of the parents varied. Finally, questions were asked on the Euthanasia Act and assistance in dying in general. Two hypothetical cases and questions on the effect of the Euthanasia Act were also presented to 125 general practitioners and 208 clinical specialists.

Contents of this thesis

This thesis consists of five parts, the first one being this introduction (**chapter one**). Part two contains two chapters. In **chapter two**, end-of-life decision-making for neonates and infants in 2001 is described and compared with 1995, and in **chapter three**, a comparison of end-of-life decision-making in neonates and infants between the Netherlands and Belgium (Flanders) is made. Part three contains chapters on end-of-life decision-making in children beyond the neonatal period. In **chapter four**, nation-wide frequencies of end-of-life decisions, paediatricians' experiences and characteristics of the decision-making process are described. In **chapter five**, the decision-making process in cases of physician-assisted dying is compared with cases in which potentially life-sustaining treatment was withheld or withdrawn. Part four contains views of paediatricians on assistance in dying in children and on the Euthanasia Act. In **chapter six**, the hypothetical case study is described, and in chapter seven, views of paediatricians on the effects of the Euthanasia Act and the rules on children in the Act are described. Finally, part five contains the general discussion (**chapter eight**), in which the main research questions are discussed and recommendations for health policy and further research are made.

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Part II

Practice of end-of-life decision-making for neonates and infants

2

Medical end-of-life decisions made for neonates and infants in the Netherlands, 1995–2001

Abstract

End-of-life decision-making for severely affected infants might be influenced by technical advances and societal debates. In 2001, we assessed the proportion of deaths of infants younger than 1 year that were preceded by end-of-life decisions, by replicating a questionnaire study from 1995. This proportion increased from 62% to 68% (weighted percentages), but the difference was not significant. Most of these decisions were to forgo life-sustaining treatment. Decisions to actively end the lives of infants not dependent on life-sustaining treatment remained stable at 1%. The practice of end-of-life decision-making in neonatology of 2001 has changed little since 1995.

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Introduction

Many deaths of neonates and infants in the developed world are preceded by end-of-life decisions.[1-3] Neonatologists (46–90%) in different European countries sometimes set limits to intensive care.[1] In an intensive care nursery in the USA, 74% of all deaths were preceded by end-of-life decisions.[2] In the Netherlands, we recorded 62% of all deaths of infants younger than 1 year in 1995.[3] Most of these decisions related to the withdrawing or withholding of a potentially life-sustaining treatment.

Practices might change as a result of advances in medical technology to sustain life in severely ill infants. The societal debate about the acceptability of euthanasia and its legal regulation in the Netherlands might also change attitudes towards end-of-life decision-making of health-care professionals and parents. In 2001, we replicated our 1995 survey in physicians to investigate whether the occurrence and characteristics of end-of-life decisions for neonates and infants had changed.[3]

Methods

In 2001, 1088 live born infants died under 1 year of age in the Netherlands (1041 corresponding deaths in 1995). We studied 347 cases that took place between August and November (338 in 1995). For 23 cases, the reported cause of death precluded an end-of-life decision (26 in 1995)— eg, sudden infant death; these cases were included in our study, but no questionnaire was sent. We were not able to contact the physicians who reported 75 deaths that occurred in the study period; therefore, these were not included in our study (all addresses obtained in 1995). For the remaining 249 cases, questionnaires were sent to the physicians who reported these deaths to the Central Death Registry (312 in 1995); 210 questionnaires (84%) were returned (299 [96%] in 1995).

Our four-page questionnaire included structured questions about the decision-making process and about whether death had (intentionally or unintentionally) been hastened by decisions to forgo potentially life-sustaining treatment or by the use of (potentially) life shortening drugs. All results were weighted for non-response for sex and place of death. Statistical comparison with the results of the 1995 study was done by calculating odds ratios and 95% CIs of end-of-life decisions. We used Pearson $\chi 2$ test for differences in characteristics of end-of-life decisions.

Results

In 2001, 20% of neonates and infants died suddenly and unexpectedly (table 2.1). Of all deaths, just under 70% were preceded by an end-of-life decision. Almost all these decisions withdrew or withheld potentially life-sustaining treatments (63%). In 29% of all deaths, the decision to forgo life-sustaining treatment was followed by the use of possible life-shortening drugs to alleviate pain or symptoms (or both), and decisions in

Table 2.1 End-of-life decisions for children aged younger than 1 year

	2001 (n=233*)			1995 (n=299*)			2001 vs 1995 (OR†)	
	N	(%)	95%CI	N	(%)	95%CI	OR	95%CI
Sudden and unexpected death	52	(20)	15-26	74	(24)	19-29	0.80	0.53-1.22
Expected death, no end-of-life decision	27	(12)	9-17	41	(14)	10-18	0.89	0.53-1.48
Total end-of-life decisions	154	(68)	61-73	184	(62)	57-68	1.25	0.87-1.80
- Life-sustaining treatment withheld, withdrawn, or both								
- No drugs given	60	(26)	21-32	76	(26)	21-31	1.02	0.69-1.51
- Use of drug with possible life-shortening effect	65	(29)	24-35	68	(23)	19-28	1.38	0.93-2.03
- Use of drug with the explicit intention to hasten death	18	(8)	5-12	24	(8)	5-12	0.96	0.51-1.81
- No life-sustaining treatment withheld, withdrawn, or both								
- Use of drug with possible life-shortening effect	7	(3)	1-6	12	(4)	2-7	0.70	0.27-1.83
- Use of drug with the explicit intention to hasten death	4	(1)	0.5-4	4	(1)	0.5-4	1.04	0.25-4.34

* Actual numbers; weighted percentage of all deaths of children aged younger than 1 year in the Netherlands between Aug 1, and Dec 1, 2001 (n=347), and 1995 (n=338).
† OR=Odds ratio

Table 2.2 Characteristics of end-of-life decisions for children aged younger than 1 year

	2001* (n=154)			1995* (n=184)			
	N	(%)	95%CI	N	(%)	95%CI	P
Place of death							0·25
- Neonatal intensive care unit	84	(56)	48-64	91	(50)	43-57	
- Hospital, not neonatal intensive care unit	58	(37)	30-45	85	(45)	38-53	
- Not hospital	11	(7)	4-12	8	(5)	2-9	
Diagnosis							0·79
- Congenital abnormality	33	(20)	15-27	40	(22)	16-28	
- Other diagnosis	120	(80)	73-85	138	(78)	72-84	
Reason end-of-life decision							0·53
- No chance of survival	110	(72)	64-78	139	(76)	69-81	
- Extremely poor prognosis for later life	36	(23)	17-30	34	(18)	13-25	
- Other	8	(5)	3-10	11	(6)	3-10	
Use of drugs with possible life-shortening effect							0·25
- Morphine or other narcotic analgesics (except neuromuscular relaxants)†	79	(52)	44-59	84	(46)	38-53	
- Only sedatives	2	(2)	0·4-5	3	(2)	0.6-5	
- Neuromuscular relaxants†	6	(4)	2-9	17	(9)	6-14	
Estimated shortening of life							0·85
- Less than 1 month	130	(85)	78-89	151	(82)	76-87	
- More than 1 month	19	(12)	8-18	25	(13)	9-19	
- Not known	5	(3)	1-8	8	(4)	2-9	
Discussion							
- With parents	147	(97)	93-99	163	(91)	86-94	0·01
- Decision made at the explicit request of parents	44	(29)	23-37	50	(28)	22-34	0·94
- With others‡							
- Colleague-physicians	144	(97)	93-99	149	(91)	86-94	0·04
- Nurses or other caregivers	39	(28)	21-35	66	(40)	34-48	0·02
- No discussion	5	(3)	1-7	12	(7)	4-12	0·12

* Actual numbers; weighted percentage of all end-of-life decisions that preceded death of children aged younger than 1 year in the Netherlands between Aug 1, and Dec 1, 2001, and 1995
† Possibly in combination with other drugs
‡ One or more answers possible

8% were followed by the use of drugs with the explicit intention to hasten death. The decision to give a possible life-shortening drug to alleviate pain or symptoms (or both) to infants who were not dependent on life-sustaining treatment preceded 3% of deaths (table 2.1). In 1% of all deaths, a drug was given with the explicit intention to hasten death to infants who were not dependent on life-sustaining treatment. Compared with 1995, the number of end-of-life decisions in 2001 had risen by 6%, mainly because of an increase in decisions that withdrew or withheld life-sustaining treatment followed by the use of possible life-shortening drugs to alleviate pain or symptoms (or both), but this difference was not significant.

More than 70% of decisions were made because infants had no chance of survival (table 2.2). 23% of decisions were made because of the extremely poor prognosis for later life, which was a small increase from the 18% recorded in 1995 (table 2.2). About half of end-of-life decisions were associated with the use of morphine or other narcotic analgesics, slightly higher than those in 1995. Neuromuscular relaxants were used in a very small proportion of decisions, which was less than half of that in 1995. The estimated time by which life was shortened because of an end-of-life decision was less than 1 month in most cases, similar to that in 1995. Decisions that had been discussed with parents increased by 6% in 2001; these percentages were similar to decisions discussed with other physicians. The proportion of decisions made at the explicit request of parents remained unchanged. Compared with the 1995 survey, the proportion of cases in which end-of-life decisions had been discussed with the nursing staff fell by 12% in 2001.

Discussion

During the past decade, continuous advances in neonatal intensive care have further increased the possibilities to treat severely ill newborn infants. This potential benefit exists for extremely small or premature infants, for congenital abnormalities and severe perinatally acquired syndromes, and for obstetrical and neonatal management. However, the number of decisions to forgo potentially life-sustaining treatments, which was already noted to be substantial for this age group in 1995, had only slightly increased from 1995 to 2001. A small rise in the use of drugs with possible life-shortening effect during this period might have been due to a growing attention for alleviation of pain or other symptoms in newborn children.[4]

The neonatal mortality rate in the Netherlands has been suggested to be higher than in some European countries.[5] Whether the number of end-of-life decisions contributed to such differences cannot be concluded from our study. The number of decisions to forgo potentially life-sustaining treatments has also been shown to be high in other

countries.[1,2] Varying percentages of neonatologists in different European countries reported that they occasionally gave drugs with the purpose of ending life.[1] In France and the Netherlands, proportions were substantial (73% and 43%, respectively), but were much reduced in other countries (2-4%). However, in our study, the frequency of drug treatment with the intention to hasten death to infants who were not dependent on life-sustaining treatment remained stable.

In about three-quarters of cases the most important reason for an end-of-life-decision was that the infant had no chance of survival, and in a quarter of cases an extremely poor prognosis for later life. These rates were very similar to those recorded in a review of medical records in a neonatal intensive care unit (NICU) in the USA.[2] In neonatology, end-of-life decision-making is usually discussed between parents and physicians, more so in 2001 than in 1995, which could be because of increased parental awareness or the social debate about the new law on euthanasia in the Netherlands. A high degree of parental participation was also noted in other studies.[1,2] Unexpectedly, nurses were involved in decisions less frequently in 2001 than in 1995. Nurses' low involvement might be partly due to the fact that they are often not consulted in medical decision-making directly after birth, but it is unclear whether this involvement has changed between 1995 and 2001.

Although the response was high and the privacy procedure was extensive, our results could have been biased because of non-response or sampling errors. Furthermore, because of the few infant deaths in the Netherlands, the power of our study to detect significant differences between 1995 and 2001 was restricted. However, a study longer than 4 months was not possible because of practical and financial restraints, and would probably have reduced the response rate.

Conclusion

Our study suggests that the practice of end-of-life decision-making in neonatology was stable between 1995 and 2001. The frequency of the active ending of life has not risen despite the new, more liberal, regulatory system of such actions in the Netherlands.

Acknowledgments

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had full access to all the data in the study and had final responsibility for the decision to submit for publication.

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3

End-of-life decision-making in neonates and infants: Comparison of the Netherlands and Belgium (Flanders)

Abstract

Objective. Recently, in both Belgium (Flanders) and the Netherlands, studies have been done to get insight in the practice of end-of-life decisions with a possible or certain life-shortening effect (ELDs) for neonates and infants. We compared the results to gain insight in similarities and differences between these countries.

Methods. Questionnaires were sent to physicians who reported the death of a child who died under the age of one (Belgium: n=292, response 87%; Netherlands: n=249, response 84%). The questionnaires included structured questions about whether death had been preceded by ELDs, and about the decision-making process.

Results. In both countries, in about 25% of all deaths a life-sustaining treatment was withheld, and in about 40% pain or other symptoms were alleviated taking into account that death might be hastened. In Belgium a life-sustaining treatment was less often withdrawn than in the Netherlands (32% vs 50% respectively). Drugs were administered with the explicit intention of hastening death in similar percentages of all deaths (Belgium: 7%; Netherlands: 9%), but Dutch physicians more often estimated the shortening of life more than one week than Belgian physicians. In the Netherlands, the decision was more often than in Belgium discussed with parents (96% vs 81% respectively), and with colleague-physicians (94% vs 80% respectively).

Conclusion. End-of-life decision-making in severely ill neonates and infants seems to be rather similar in Belgium and the Netherlands. Differences are that Dutch physicians more often withdraw life-sustaining treatment and decide to administer drugs with the intention of hastening death in an earlier stage. Further, parents and colleague-physicians are more often involved in the decision-making in the Netherlands.

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Introduction

Medical end-of-life care is aimed at improving the quality of the last stage in life, and may, as such, involve consideration of medical practices that, intentionally or otherwise, hasten death. Such end-of-life decisions include decisions about whether or not to withhold or withdraw possible life-sustaining treatment, decisions about the alleviation of pain or other symptoms with drugs that possibly hasten death, and decisions to administer drugs with the explicit intention of hastening death.

In both Belgium and the Netherlands, nationwide studies have been done on end-of-life decision-making.[1-6] In 2001, of all deaths of persons aged one year or older, 38% in Belgium, and 44% in the Netherlands were preceded by an end-of-life decision.[3] In both countries, the large majority of such decisions involved the forgoing of potentially life-sustaining treatment, or alleviation of pain or others symptoms taking into account that death might be hastened. A small percentage involved the use of drugs with the explicit intention of hastening death (1.8% of all deaths in Belgium, 3.4% of all deaths in the Netherlands).

End-of-life decision-making practices for neonates and infants have been studied as well.[7-11] End-of-life decision-making for this age group differs from other age groups for several reasons. Firstly, most often the underlying diseases are severe congenital abnormalities or perinatally acquired diseases, which involve no chance of survival or an extremely poor expected future health status. And secondly, children under the age of one cannot decide for themselves; parents have to decide for the child together with physicians in his or her best interest. Cuttini at al showed that many neonatologists (from 46 to 90%) in different European countries sometimes set limits to intensive care.[7] In the Netherlands, in 1995, 62% and in 2001, 68% of all deaths of children under the age of one were preceded by an end-of-life decision.[8,10] In Belgium, in 2000, 57% of all deaths of children under the age of one were preceded by an end-of-life decision.[11] In both countries, the majority of end-of-life decisions involved withdrawing or withholding potentially life-sustaining treatment.

Both in Belgium and the Netherlands, the administration of drugs to end life without an explicit request of the patient is legally forbidden. However, in the Netherlands, physicians are rarely prosecuted when they end the life of a severely ill infant when they have applied the following requirements for prudent practice: 1) the child suffers hopelessly and unbearably; 2) parents approve of the decision; 3) independent physicians are consulted; and 4) the physician performs the ending of life carefully. These requirements are described by professional groups and have been recorded in jurisprudence.[12-18]

End-of-life decision-making is likely to be influenced by medical, societal or cultural factors. Thus far, it was unknown whether differences between Belgium and the Netherlands in end-of-life decision-making in the general population are also found in neonates and infants. Hence, the aims of this study are to gain insight in similarities and differences between Belgium and the Netherlands concerning the frequencies and characteristics of end-of-life decisions in neonates and infants.

Methods

We conducted comparative analyses, using data on end-of-life decision-making practices in neonates and infants that were collected separately in the Netherlands[10] and in Belgium[11].

Sample

In both countries, a survey was done among all physicians who reported the death of an infant under the age of one during a certain period.

Belgium (Flanders)

All neonates and infants who died under the age of one (n=292) in Flanders, during a 12-month period (August 1999 – July 2000) were included. For each case, the attending physician received an anonymous mail questionnaire. The response rate was 87% (254 questionnaires, with one excluded because of incomplete answers).

The Netherlands

A survey was conducted for all deaths of life-born infants under the age (n=347) that occurred during a four-month period (August – November 2001). For 23 cases, the reported cause of death precluded an end-of-life decision (e.g. sudden infant death): these cases were included in the study, but no questionnaire was sent. We were not able to contact the physicians who reported 75 death cases that occurred in the study period: these were not included in the study. For the remaining 249 cases, the physician who reported the death to the Central Death Registry received an anonymous mail questionnaire. The response rate was 84% (210 questionnaires).

Questionnaire

In both countries, the questionnaire contained structured questions about the end-of-life decision-making process. The questionnaires were virtually identical to the ones used in previous studies.[1,4,5,8] Terms such as physician-assisted death and active life ending were avoided in the questionnaire because they have many different connotations to physicians.

The key questions were:
- Did you withhold or withdraw medical treatment
  - while taking into account the possibility or certainty that this would hasten the patient's death,
  - partly with the intention of hastening the patient's death (only in Belgium) or
  - with the explicit intention of hastening the patient's death?
- Did you intensify the alleviation of pain and suffering
  - while taking into account the possibility or certainty that this would hasten the patient's death or
  - partly with the intention of hastening the patient's death?
- Was death the result of the use of a drug that was prescribed, supplied, or administered by you with the explicit intention of hastening the patient's death?

Physicians could answer yes for more than one end-of-life decision. Additionally, for the decision with the most explicit intention, physicians were asked to answer questions about the characteristics of the decision-making process. In case of the same intention, withdrawing treatment prevailed over withholding treatment, and the administration of drugs prevailed over the forgoing of treatment.

Anonymity procedures

A complex mailing procedure, involving a notary, was developed to ensure the anonymity of patients and the participating physicians. The Belgian Medical Disciplinary Board approved the Belgian procedure. The Royal Dutch Medical Association and the Inspector-General of Health Care supported the Dutch procedure. Responding physicians sent their questionnaire to the notary in a prepaid envelope. No Institutional Review Board approval was necessary, because patient data were anonymous.

Analysis

Observed numbers, and percentages with 95% confidence intervals are presented. All Dutch percentages were weighted for non-response by sex and place of death. Each case could involve one or more end-of-life decisions. For the presentation of decisions to withhold as well as decisions to withdraw treatment, we did not take into account the intention, because intention was differently measured in both countries.

Statistical comparison was done with the statistical program StatXact version 6.0. We mainly used the Fisher Exact test (two-tailed) to compare the results of both studies, and to compare cases of administering drugs with the explicit intention to hasten death with other end-of-life decisions. The Kruskal Wallis test was used to compare the estimated degree to which life was shortened by an end-of-life decision.

Role of the funding sources

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Table 3.1 End-of-life decisions in Belgium and the Netherlands for children aged younger than 1 year

	Belgium (Flanders)* N=253			Netherlands* N=233			
	N	(%)	95%CI	N	(%)†	95%CI	P‡
Sudden and unexpected death	59	(23)	19-29	52	(20)	16-26	0.44
Non-sudden death, no end-of-life decision	51	(20)	16-26	27	(12)	9-17	0.03
Non-sudden deaths with at least one end-of-life decision made	143	(57)	50-63	154	(68)	61-73	0.02
End-of-life decisions§							
- Life-sustaining treatment withheld	65	(26)	21-31	54	(23)	18-29	0.53
- Life-sustaining treatment withdrawn	80	(32)	26-38	112	(50)	44-57	<0.01
- Alleviation of pain or other symptoms taking into account the possibility or certainty that this would hasten death	97	(38)	33-44	91	(40)	34-47	0.71
- Alleviation of pain or other symptoms partly with the intention of hastening death	48	(19)	15-24	37	(16)	12-21	0.40
- Administration of drug with the explicit intention of hastening death	17	(7)	4-11	22	(9)	6-14	0.32

* In Belgium, data were collected from August 1, 1999 to July 31, 2000; In the Netherlands, data were collected from August 1 to December 1, 2001

† Dutch percentages are weighted for non-response by sex and place of death for all deaths of children aged younger than 1 year in the Netherlands in the study period (n=347)

‡ Fisher's Exact test, significance of difference between Belgium and the Netherlands for cases of a given category versus the remaining cases (Sudden and unexpected death included)

§ More than one decision could be made

Results

The frequencies of end-of-life decisions are shown in table 3.1. There was no significant difference between Belgium and the Netherlands in the incidence of sudden and unexpected deaths (23% and 20%, respectively). The total number of end-of-life decisions was lower in Belgium than in the Netherlands. In both countries, in about a quarter of all deaths a life-sustaining treatment was withheld, while such treatment was less often withdrawn in Belgium than in the Netherlands (32% versus 50%). The frequencies of the alleviation of pain or other symptoms were similar; in about 40% pain was alleviated with the possibility or certainty that this would hasten death; in about 20% hastening death had been partly intended. Drugs were administered with the explicit intention of hastening death in similar percentages of all deaths in both countries (Belgium: 7%; Netherlands: 9%).

Table 3.2 Characteristics of cases in which an end-of-life decision was made

	Belgium (Flanders) N=143			Netherlands N=154			
	N	(%)	95%CI	N	(%)*	95%CI	P
Place of death							
- Hospital	139	(97)	93-99	142	(93)	88-96	0.11†
- Not in hospital	4	(3)	1-7	12	(7)	4-12	
Reason end-of-life decision							0.29†
- No chance of survival	94	(66)	58-73	110	(72)	64-79	
- Extremely poor quality of life in future life	41	(29)	22-37	36	(23)	17-31	
- Other or unknown	8	(6)	3-11	8	(5)	3-10	
Estimated shortening of life							0.87‡
- More than 1 week	26	(18)	13-25	31	(20)	15-27	
- 1-7 days	31	(22)	16-29	31	(20)	15-27	
- Less than 24 hours	81	(57)	48-65	87	(56)	49-64	
- Not known	5	(3)	1-8	5	(3)	1-8	

* Dutch percentages are weighted for non-response by sex and place of death for all end-of-life decisions of children aged younger than 1 year in the Netherlands between August 1 and December 1, 2001

† Fisher's Exact test, significance of difference between Belgium and the Netherlands in the distribution of characteristics; missing information and 'other or unknown' not included in analysis

‡ Kruskal Wallis test: significance of difference between Belgium and the Netherlands ('Not known' not included in analysis)

Characteristics of cases in which an end-of-life decision was made are shown in table 3.2. There was no significant difference in these characteristics between Belgium and the Netherlands: almost all infants died within the hospital; the most often mentioned reason for an end-of-life decision was that there was no chance of survival and in about a quarter an extremely poor quality of life in future life; and the estimated shortening of life was in somewhat more than half of the cases less than 24 hours.
The end-of-life decision was discussed with colleague-physicians and the parents in the large majority of the cases in both countries, but in the Netherlands more often than in Belgium (table 3.3). The reason not to discuss the decision with parents was most often that the situation was clear and discussion was not necessary. Nurses or other caregivers were consulted in less than one-third of the cases in both countries. In Belgium and the Netherlands, the physician mostly initiated the discussion with the parents, although in Belgium in a higher percentage of the discussed cases. Further, Belgian nurses more often initiated discussion with parents than Dutch nurses. Dutch respondents judged parents to be fully capable to assess the situation and take an adequate decision more often than Belgian respondents did.

Characteristics of the 17 Belgian cases and 22 Dutch cases in which drugs were administered with the explicit intention of hastening death are shown in table 3.4. In both countries in the majority of cases, a physician, sometimes together with a nurse, administered the drugs, mostly morphine or other opioids. In two Belgian cases, a nurse administered the drugs alone, which was never the case in the Netherlands. Neither in Belgium nor in the Netherlands, the parents ever administered the drug. In Belgium, physicians estimated the shortening of life by the administration of drugs to have been less than 24 hours in most cases, while in the Netherlands they estimated shortening of life mostly to have been more than one week.
Comparing cases in which drugs were administered with the explicit intention of hastening death with other end-of-life decisions showed that in the Netherlands, the reason for administering these drugs was more often that the infant would have an extremely poor quality of life than for the other end-of-life decisions, while in Belgium this was not the case (Belgium: $p=0.40$; Netherlands: $p<0.01$). (Not in table)
Further, the decision to administer the drugs was requested by parents in the majority of cases in both countries, whereas only about a quarter of all other end-of-life decisions was requested by parents (Belgium: $p=0.01$; Netherlands: $p<0.01$).

Table 3.3 Consultation with parents and other caregivers

	Belgium (Flanders) N=143			Netherlands N=154			
	N	(%)	95%CI	N	(%)*	95%CI	P†
Discussion with professionals‡							
- Colleague-physicians	114	(80)	72-86	144	(94)	89-97	<0.01
- Nurses or other caregivers	49	(34)	27-42	39	(27)	20-34	0.17
- No discussion	10	(7)	4-13	5	(3)	1-8	0.19
Discussion with parent(s) §	116	(81)	74-87	147	(96)	91-98	<0.01
Reasons for not discussing with parents**							
- No need to discuss because situation was clear	17	(12)	8-18	4	(3)	1-7	0.56
- No time to discuss	1	(1)	0-5	0	(0)	-	1.00
- Other	3	(2)	1-6	0	(0)	-	1.00
Initiator discussion with parents							
- Physician	115	(80)	73-86	137	(89)	83-93	0.03
- Parents	26	(18)	13-25	24	(15)	10-21	0.20
- Nurse	10	(7)	4-13	3	(2)	1-6	0.02
- Other	1	(1)	0-5	0	(0)	-	0.44
- Not known	0	(0)	-	4	(3)	1-7	0.13
Decision made at the explicit request of parents††	35	(24)	18-32	44	(28)	21-36	0.89
Agreement with parents‡‡							0.56
- With both parents	111	(78)	70-84	143	(93)	88-96	
- With one parent	2	(1)	0-5	1	(1)	0-4	
- No	2	(1)	0-5	1	(1)	0-4	
Capability of parents to assess the situation and take an adequate decision at the time of discussion or request§§							0.06
- Fully	103	(72)	64-79	141	(91)	86-95	
- Partly	12	(8)	5-14	3	(2)	1-6	

* Dutch percentages are weighted for non-response by sex and place of death for all end-of-life decisions of children aged younger than 1 year in the Netherlands between August 1 and December 1, 2001

† Fisher's Exact Test, significance of difference between Belgium and the Netherlands in distribution of characteristics for cases of a given category; missing information not included in analysis; Denominator of 'Initiator discussion parents', 'Explicit request parents', 'Agreement parents', and 'Capability parents to assess the situation' was 116 for Belgium and 147 for the Netherlands; Denominator 'Reasons not discussing with parents' was 22 for Belgium, and 4 for the Netherlands

‡ In Belgium in 16 cases, and in the Netherlands in 5 cases, information on discussion with professionals was missing

§ In Belgium in 5 cases, and in the Netherlands in 3 cases, information on discussion with parents was missing
** In Belgium in 1 case, information on reasons for not discussing with parents was missing
††In Belgium in 2 cases, and in the Netherlands in 3 cases, information on the explicit request of parents was missing
‡‡In Belgium in 1 case, and in the Netherlands in 2 cases, information on the agreement of parents was missing
§§ In Belgium in 1 case, and in the Netherlands in 3 cases, information on capability of parents to assess the situation and take an adequate decision at the time of discussion or request was missing

Discussion

End-of-life decisions are known to precede the majority of deaths of neonates and infants in Belgium and the Netherlands.[8,10,11] Decisions to administer drugs taking into account that death might be hastened, and decisions to administer drugs with the explicit intention of hastening death were made in Belgium as often as in the Netherlands, but Dutch physicians somewhat more often withdrew life-sustaining treatment. The parents and colleague-physicians were usually involved in the decision-making in both countries; in the Netherlands even more often than in Belgium. Nurses were involved in the minority of cases in both countries.

The study design was similar in Belgium and the Netherlands and the questions asked were virtually identical, and based on validated questionnaires.[2-5,8] It was therefore possible to make a valid comparison. However, the study had also several limitations. Firstly, although the response rates were high and the privacy procedures were extensive, it cannot be precluded that the results are biased due to non-response or sampling errors. Secondly, the study year of the countries differed from each other: in the Netherlands, the study was carried out a year later. Whereas in Belgium the debate about end-of-life decision-making has more recently started, it is possible that practices have changed during this year.

No difference was found between the countries in the frequency of alleviation of pain and symptoms, and in the administration of drugs with the intention of hastening death. In a study in six European countries of end-of-life decision-making of all deaths of patients aged one year or over, alleviation of pain or other symptoms also occurred at similar rates in different countries.[3] However, there were differences in frequencies of the use of drugs with the explicit intention of hastening death without a request of the patient in these countries, a practice that varied from 0.06% of all deaths in Italy to 1.5% of all deaths in Belgium.[3] It seems that using drugs to alleviate pain or other symptoms, that are typically made to end the suffering of a severely ill patient, are part of medical care anywhere, sometimes even with the explicit intention of hastening death.[3,7,8]

Table 3.4 Characteristics of cases where drugs were administered with the explicit intention of hastening death

	Belgium (Flanders) N=17			Netherlands N=22			
	N	(%)	95%CI	N	(%*)	95%CI	P†
Administered drugs‡							0.19
- Morphine or other opiates (except neuromuscular relaxants)§	9	(53)	36-69	17	(78)	68-85	
- Only sedatives	1	(6)	1-31	1	(4)	1-25	
- Neuromuscular relaxants§	5	(29)	15-50	2	(11)	3-30	
Who administered the drugs?							0.11
- Only physician	9	(53)	36-69	17	(79)	69-86	
- Physician and nurse	6	(35)	19-55	5	(22)	10-41	
- Only nurse	2	(12)	3-35	0	(0)	-	
Estimated shortening of life							0.02
- More than 1 week	3	(18)	6-40	11	(49)	34-64	
- 1-7 days	3	(18)	6-40	5	(23)	11-42	
- Less than 24 hours	11	(65)	50-77	6	(29)	16-47	
Reason end-of-life decision							0.52
- No chance of survival	10	(59)	43-73	10	(47)	32-63	
- Extremely poor quality of life in future life	7	(41)	25-60	12	(54)	39-68	
Discussion with professionals**							
- Colleague-physicians	14	(82)	73-89	21	(97)	95-98	0.42
- Nurses or other caregivers	9	(53)	36-69	7	(34)	20-52	0.18
- No discussion	0	(0)		0	(0)		-
Discussion with parents	14	(82)	73-89	22	(100)	-	0.07
Decision made at the explicit request of parents††	9	(53)	36-69	15	(69)	56-79	0.32

* Dutch percentages are weighted for non-response by sex and place of death for all end-of-life decisions of children aged younger than 1 year in the Netherlands between August 1 and December 1, 2001

† Fisher's Exact Test, significance of difference between Belgium and the Netherlands for distribution of characteristics; Kruskal Wallis Test for estimation of shortening life; missing information not included in analysis; Denominator of 'Explicit request parents' was 14 for Belgium and 22 for the Netherlands

‡ Information on the use of drugs was missing for 2 Belgian and 2 Dutch cases

§ Possibly in combination with other drugs

** Information on discussion with professionals was missing for 2 Belgian cases and 1 Dutch case

††Information on request of parents was missing for 1 Dutch case

Secondly, although in general, in only about one quarter of cases parents request the end-of-life decision, this is the case in more than half of the cases where a drug is administered with the aim of hastening death. Whereas the administration of drugs

seems to be a medical answer to suffering of the child, when drugs are administered with the explicit intention of hastening death, it appears to be determined by other factors as well. Physicians might feel that deciding about forgoing of treatment or alleviation of pain or symptoms belongs to their medical-professional domain, while the administration of drugs to hasten death comprises more than solely that domain. Preserving life can be very important for either physicians or parents, for example because of religious arguments.[19,20] Besides that, the administration of drugs aimed at hastening death without a patient's request, is legally prohibited in both countries. Physicians therefore probably often do not suggest administering such drugs to the child as an option, but parents request it themselves.
Thirdly, in both countries, most other characteristics of all end-of-life decisions in neonates are also similar. Most children died in hospital and physicians estimated life to be shortened less than 24 hours in about half of all cases. Most children had no chance of survival, and in a part of the cases, the decision was made because of the expected poor quality of life. Although some claim that physicians should not make a decision on the base of expected quality of life, it is apparently a consideration for physicians in different countries.[8,10,21]

We also found some differences between the studied countries. Firstly, in the Netherlands life-sustaining treatment is more often withdrawn than in Belgium. The difference is in accordance with findings from the European study for patients aged one year or over.[3] In this study, deaths were more often preceded by decisions to forgo treatment in the Netherlands, while alleviation of pain or other symptoms and the use of life-shortening drugs without the patient's request was practiced about as often as in Belgium. It is not clear what the cause of this difference is. It could be explained by different ideas of medical futility. In the Netherlands, physicians may be more inclined to start with treatment of severely ill newborns, which in a later stage proves to be medically futile, while in Belgium the treatment may not even be seen as an option to start with. Another possible explanation is a different opinion of whether or when to withdraw life-sustaining treatment. It is known that by some withdrawing treatment appears to be experienced as more difficult to do than withholding treatment.[22-24]
Secondly, although end-of-life decisions seem to be made carefully in both countries, whereas discussion mostly took place with both colleagues and parents, Dutch physicians almost never make a decision without consultation of the parents or another professional. In the Netherlands, there has been an increase in the percentage of cases that were discussed with both colleagues as parents in 2001 compared to 1995.[10] This finding can be confirmed by the study of Van der Heide et al,[3] in which it was found that in the Netherlands end-of-life decisions are much more often discussed with colleague-physicians, the patient, and the patient's family than in Belgium. Belgian

physicians might more often have a 'paternalistic' attitude, where they decide what is best for the patient, while Dutch physicians consider the autonomy of the patient or the involvement of parents more important.[25] The difference in consultation can also be explained by the societal debate about end-of-life decision-making in severely ill neonates and infants during the last decades in the Netherlands. The debate especially focused on the introduction of requirements for prudent practice and about the preference of some to install a multidisciplinary committee to review cases of active ending of life.[8,9,14,16-18,26] This debate might have influenced attitudes and practices and might have increased the awareness of the importance of communication.

Thirdly, bearing in mind the small numbers, characteristics of cases of administering drugs with the explicit intention to hasten death differed. Dutch physicians more often estimated life to have been shortened more than a week than Belgian physicians. Moreover, although both Belgian and Dutch physicians administered drugs to hasten death in a substantial number of cases because of the expected poor quality of life of the child, Dutch physicians administered drugs to hasten death more often for that reason than they did in case of other end-of-life decisions. In the Netherlands, there is an ongoing debate about ending life in neonates with congenital abnormalities who suffer hopelessly and unbearably. In 1995 and 1996 two physicians who ended life of such a child were dismissed of legal prosecution, because they applied rules for prudent practice.[12,13,15] Further, physicians who reported 22 cases in which the life of severely ill neonates was ended to the public prosecutor were also dismissed, because the rules for prudent practice were applied.[17,18] This background could imply that Dutch physicians and parents already in an earlier stage of the disease decide to administer drugs to end life, where Belgian physicians wait longer to take such decision.

Conclusion

Our study shows that in Belgium and the Netherlands, the practice of end-of-life decision-making in severely ill neonates and infants is rather similar. The Dutch social debate about administering drugs aimed at hastening death in severely ill newborns does not seem to have resulted in more cases compared to Belgium, but it seems to have resulted in more openness towards the parents and colleague-physicians.

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Part III

Practice of end-of-life decision-making for children after the neonatal period

4

Medical end-of-life decisions for children in the Netherlands

Abstract

Objective. Most end-of-life decision-making studies have, until now, involved either the general population or newborn infants. The objective was to assess the frequency of end-of-life decisions preceding child death and the characteristics of the decision-making process in the Netherlands.

Methods. Two studies were performed. The first was a death certificate study in which all 129 physicians reporting the death of a child aged between 1 and 17 years in the period August to December 2001 received a written questionnaire; the second was an interview study in which face-to-face interviews were held with 63 physicians working in pediatric hospital departments.

Results. Some 36% of all deaths of children between the ages of 1 and 17 years during the relevant period were preceded by an end-of-life decision: 12% by a decision to refrain from potentially life-prolonging treatment; 21% by the alleviation of pain or symptoms with a possible life-shortening effect; and 2.7% by the use of drugs with the explicit intention of hastening death. The latter decision was made at the child's request in 0.7% and at the request of the family in 2% of cases. The interview study examined 76 cases of end-of-life decision-making. End-of-life decisions were discussed with all 9 competent and 3 partly competent children, with the parents in all cases, with other physicians in 75 cases, and with nurses in 66 cases.

Conclusion. While not inconsiderable, the percentage of end-of-life decisions was lower for children than for adults and newborn infants. Most children are not considered to be able to participate in the decision-making process. Decisions are generally discussed with parents and other caregivers and, if possible, with the child.

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Introduction

Until now, studies on end-of-life decision-making have mainly focused on adults and newborn infants. In these patient groups, end-of-life care frequently involves end-of-life decisions (ELDs), that is, decisions that, whether intentionally or otherwise, hasten death.[1-7] A recent study in 6 European countries showed that ELDs played a role in 23% to 51% of all deaths.[3] In the Netherlands, about two thirds of the deaths of children younger than 1 year are preceded by an ELD.[8,9] Studies from other countries have shown comparably high incidences in newborns and infants.[10-12] Earlier studies about ELDs in older children have concentrated on specific subgroups, such as children cared for in pediatric intensive care units, or specific types of ELDs, such as forgoing life-sustaining treatments or physician-assisted dying.[13-19]

End-of-life decisions range from decisions to forgo potentially life-sustaining treatments and decisions to alleviate pain or other symptoms by using drugs with a possible life-shortening effect, to decisions to give physician assistance in dying, that is, the use of drugs with the aim of ending life. End-of-life care can also involve the use of deep sedation while withholding artificial administration of food or fluids.[20] In the Netherlands, the use of lethal drugs with the explicit intention of hastening death is defined as euthanasia if someone other than the patient administers the drugs at the explicit request of the patient and as physician-assisted suicide if the patient takes these drugs himself or herself. Before April 2002, physicians who observed the established rules for careful decision-making could perform euthanasia or physician-assisted suicide for persons who made a well-considered and voluntary request. More formal procedures were laid down in the new Euthanasia Act[21] that was introduced in April 2002. The new law allows physicians to grant requests for euthanasia or physician-assisted suicide from minors aged 12 to 16 years if parents agree and from minors aged 16 or 17 years if parents are informed. Neither euthanasia nor physician-assisted suicide is permitted in children younger than 12 years.

However, very little is known about the practice of end-of-life decision-making for children in the Netherlands. We performed 2 retrospective, descriptive studies in an attempt to gain insight into this practice. The major objective of the studies was to quantify the practice of end-of-life decision-making in children in the Netherlands.

Methods

Data are presented from 2 studies: the death certificate study and the interview study.

Study 1: death certificate study

All deaths in the Netherlands are reported to the central registry of Statistics Netherlands, Voorburg/Heerlen. In 2001, 619 children between the ages of 1 and 17 years died in the Netherlands, of whom 188 died in the 4-month period of our study. Our study focused on the 158 reported deaths occurring in the 4-month period between August 1 to December 1, 2001, for which the addresses of the reporting physicians were available. The identified physicians were sent a written questionnaire as to whether, and if so what type of, end-of-life decision making preceded death; 119 questionnaires were sent out and 90 (75%) were returned. In 39 cases, no questionnaires were sent because the children died suddenly and unexpectedly, which precluded any end-of-life decision-making. Nonetheless, these cases were included in the analyses, bringing the total number of cases used for analysis to 129. Key questions in the questionnaire were (1) Did you withhold or withdraw medical treatment while taking into account the possibility or certainty that this would hasten the patient's death or with the explicit intention of hastening the patient's death? (2) Did you intensify the alleviation of pain and suffering while taking into account the possibility or certainty that this would hasten the patient's death or partly with the intention of hastening the patient's death? (3) Was death the result of the administration, supply, or prescription of drugs with the explicit intention of hastening the patient's death? If the answer to the third question was yes and the drugs had been administered by someone other than the patient at the patient's explicit request (written or otherwise), the case was classified as euthanasia. If the drug was self-administered, it became a case of physician-assisted suicide. If more than 1 question was answered in the affirmative, the decision with the most explicit intention prevailed. In the case of similar intentions, question 3 prevailed over question 2 and question 2 over question 1. Anonymity requirements precluded the collection of further details about patient characteristics in this study. Details about the design of this study have been published elsewhere.[3,20,22]

Study 2: interview study

From June to December 2002, face-to-face interviews were held with physicians of specialties covering the majority of all deaths in children in the Netherlands: pediatric oncologists and hematologists, pediatric intensivists, and pediatric neurologists. Respondents had to have had at least 2 years' work experience, in addition to spending more than 50% of their time in their current practice. Pediatrician-oncologists and -hematologists and pediatrician-intensivists are exclusively found at departments within the 8 university hospitals in the Netherlands. A random sample was taken of half, or if only 1 or 2 physicians were working at the relevant department, all, of the physicians at each department. The sample of pediatric neurologists who also work in

hospitals other than university hospitals was drawn from their professional registry. Half of the pediatric neurologists working at each hospital were randomly selected, except hospitals at which only 1 or 2 pediatric neurologists were employed, in which case all were selected. Most Dutch pediatric neurologists are neurologists with a special training in pediatric neurology according to the criteria of the International Child Neurology Association. In this article, however, the term *pediatricians* should also be taken to refer to pediatric neurologists. Of the 98 total eligible pediatricians, 69 were approached for interviews, of whom 63 (91%) (27 pediatrician-oncologists and -hematologists, 18 pediatrician-intensivists, and 18 pediatric neurologists) consented to participate. Experienced physicians who had been trained in using the structured questionnaire conducted the interviews. In the interview study, all questions concerned end-of-life decision making for children between the ages of 3 months and 18 years. Decision making for neonates was not the subject of our study, and therefore, neonates younger than 3 months were excluded. [9,23] First, the physicians were asked whether they ever had performed any of 6 different ELDs and, if yes, how often.

We defined these ELDs as:

1. Physician-assisted dying by the use (administration, supply, or prescription) of drugs with the explicit intention of hastening death at the explicit request of the child (that is, euthanasia or physician-assisted suicide);
2. Physician-assisted dying by the use of drugs with the explicit intention of hastening death at the explicit request of parents;
3. Physician-assisted dying by the use of drugs with the explicit intention of hastening death without the explicit request of the child or parents;
4. Deep sedation of a child with drugs such as benzodiazepines or barbiturates while forgoing artificial nutrition or hydration (that is terminal sedation);
5. Withholding or withdrawal of potentially life-sustaining treatments (that is non-treatment decisions);
6. The use of drugs to alleviate pain or other symptoms with a possible life-shortening effect.

Subsequently, questions were asked about the patient characteristics and the decision-making process in the most recent case in their practice, if any, for each of the first 5 ELDs listed. The questionnaire was based on similar studies about ELDs for adults.[8,20,22] Respondents were asked to describe only cases in which they acted as the primary responsible physician. In cases involving more than 1 responsible physician, respondents were asked to describe only those cases in which they had personally communicated with the parents or, if more than 1 physician had communicated with the parents, only the cases in which they had communicated with the parents after the child had died. If they never performed physician-assisted dying at the request of the child or the parents themselves, respondents were asked to describe

patients for whom they had been the primary responsible physician but for whom they knew that the family doctor carried out physician-assisted dying at the request of the child or the parents. We compared all cases described by physicians working in the same department, to avoid inclusion of the same case twice. One euthanasia case appeared to have been discussed with 2 physicians; in that case, the information provided by the physician most closely involved was used. In cases concerning more than 1 ELD, the use of drugs with the explicit intention of hastening death was considered to prevail over other decisions, and terminal sedation prevailed over non-treatment decisions. The average duration of the interviews was 1.45 hours (minimum 30 minutes; maximum 5 hours). Where time constraints were an issue, discussion of cases of active ending of life prevailed over discussion of other cases.

Validity

Our questionnaire was based on the validated questionnaire that was used for physicians who treat adult patients.[1,2,8,22,24,25] The questionnaire of study 2 was adapted for pediatric use in close cooperation with physicians (W.F.M.A, R.P., and E.V.D.V.) from the 3 specialties we interviewed. We then tested the questionnaire on 3 caregivers from the specialties involved.

Analyses

Percentages derived from the death certificate study were weighted for non-response by sex and place of death to render them representative for all deaths of persons aged 1 to 17 years in the study period. To ensure that the percentages derived from the interview study were representative for all 98 eligible pediatricians, these were weighted for non-response by specialty of the respondents.[1,9,22] The statistical package SPSS 11.0 (SPSS Inc, Chicago, Ill) was used for the calculations in both studies, while the confidence intervals were based on the binomial errors.

The Minister of Justice ensured all physicians immunity against prosecution. Additionally, a complex mailing procedure involving a notary was developed to ensure absolute anonymity for both physicians and patients in the death certificate study. The physicians in the interview study were ensured that all information would be handled with the utmost confidentiality. The Inspector General for Health Care and the chairman of the Royal Dutch Medical Association informed all physicians in writing about the purpose of the study and its privacy procedures.

Table 4.1 Frequencies of end-of-life decisions for children aged 1 to 17 years (death certificate study)*

	Observed	(%)	95%CI	Annual
Sudden and unexpected death†	65	(42)	35-49	245
Non-sudden death, no end-of-life decision	22	(23)	17-29	135
Total end-of-life decisions	42	(36)	29-43	230
- Non-treatment decisions	17	(12)	7.8-17	70
- Administering drugs to alleviate pain or symptoms with possible life-shortening effect	21	(21)	16-28	125
- Physician-assisted dying	4	(2.7)	1.2-6.1	15
- Euthanasia‡	1	(0.7)	0.1-3.6	5
- Physician-assisted suicide‡	0	(0)		0
- Administering drugs with the explicit intention of hastening death without explicit request of the patient§	3	(2.0)	0.8-5.2	15
Total	129	(100)		610

* Observed numbers, weighted percentages for non-response by sex and place of death, and estimated annual numbers of all deaths for children aged 1 to 17 years between August 1 and December 1, 2001, in the Netherlands. Values are expressed as number of deaths unless otherwise indicated.
† Including all death cases in which the reporting physicians had their first contact after the person had died.
‡ Euthanasia and physician-assisted suicide are defined as the use (administration, supply, or prescription) of drugs with the explicit intention of hastening death at the patient's explicit request.
§These were all performed at the explicit request of the family.

Results

Study 1: prevalences

The death certificate study showed that 36% of all deaths of children between the ages of 1 and 17 years in the study period were preceded by an ELD (table 4.1). Of all deaths, 12% concerned a non-treatment decision and 21%, the use of drugs to alleviate pain or other symptoms with a possible life-shortening effect. Some 2.7% of all deaths involved physician-assisted dying, of which 0.7% took place at the request of the patient (euthanasia) and 2.0% did not. The latter cases were all performed at the explicit request of the family. In 50% (n=11) of the cases of the alleviation of pain or other symptoms, the decision concurred with a non-treatment decision. All cases where physician-assisted dying was carried out without the explicit request of the patient were preceded by a non-treatment decision and by alleviation of pain or other symptoms. By contrast, euthanasia was not preceded by a non-treatment decision or alleviation of pain or other symptoms. We found no cases of physician-assisted suicide in this age group. Hence, the estimated absolute number of cases of euthanasia in 2001 in this age group based on the death certificate study is about 5, while the

estimated number of cases of physician-assisted dying at the explicit request of the family is about 15.

Table 4.2 Pediatricians' reports of requests for physician-assisted dying and their practice of end-of-life decisions in children between 3 months and 18 years of age in the Netherlands (interview study)*

	Oncologists/ hematologists	Intensivists	Neurologists	Total†	
	N=27	N=18	N=18	N=63	
	N	N	N	N	(%)
Had ever received an explicit request for physician-assisted dying from child or parents‡	18	7	14	39	(62)
- From parents	12	7	13	32	(50)
- From a child	7	0	2	9	(15)
Had ever performed physician-assisted dying‡	6	1	9	16	(24)
Had ever granted an explicit request for physician-assisted dying from child or parents	5	1	9	15	(23)
- From parents	4	1	9	14	(21)
- From a child	1	0	0	1	(2)
Had ever performed physician-assisted dying without explicit request of child or parents	1	1	0	2	(3)
Had ever made a non-treatment decision	21	15	14	50	(79)
Had ever applied deep sedation while forgoing artificial nutrition or hydration	5	5	5	15	(24)
Had ever administered drugs with a possible life-shortening effect to alleviate pain or other symptoms	19	13	11	43	(71)

* Values expressed as absolute number of physicians or absolute number (percentage) of physicians

† Percentages are weighted for non-response and are representative for all pediatric oncologists and hematologists, pediatric intensivists, and pediatric neurologists in the Netherlands

‡ Physicians could have had a request from parents, a child, or both and could have performed physician-assisted dying at the request of parents, a child, without a request, or all 3

Table 4.3 Characteristics of end-of-life decisions in children between the ages of 3 months and 18 years in the Netherlands (interview study)*

	Physician-assisted dying N=20	Deep sedation while forgoing artificial nutrition or hydration N=12	Non-treatment decision N=44	Total N=76
Child's age				
- 3 mo-5 y	8	5	17	30
- 6-11 y	6	4	18	28
- 12-17 y	6	3	9	18
Diagnosis				
- Cancer	12	5	19	36
- Neurological	4	2	10	16
- Other	4	5	15	24
Length of time in medical care†				
- <1 mo	3	3	15	21
- 1-12 mo	7	3	14	24
- >1 y	10	4	15	29
Place of death‡				
- Hospital	10	6	19	35
- Hospital, intensive care unit	3	5	10	18
- Home	7	1	14	22
Use of drugs§				
- Morphine or other opiates (possibly in combination with other drugs [except neuromuscular relaxants])	8	7	10	25
- Only sedatives	4	5	2	10
- Neuromuscular relaxants (possibly in combination with other drugs)	5	0	0	5
Estimated shortening of life**				
- <1 wk	8	9	14	31
- Between 1 wk and 1 mo	4	1	10	15
- >1 mo	8	2	16	26

* Values are expressed as absolute number of instances. In 2 of the cases of physician-assisted dying, the decision was made at the explicit request of the child; in 1 of these cases, the respondent had solely been involved in a case where a family doctor had performed euthanasia. In 16 cases, the parents had made an explicit request; 2 of these respondents had solely been involved in cases where a family doctor had ended a child's life. In 2 other cases, the decision was made without a request being made by the child or the parents. Furthermore, 3 cases in which the respondent indicated having applied deep sedation and 6 cases in which the respondent indicated having made a non-treatment decision were not discussed because of lack of time of the respondent

† In 2 cases of deep sedation while forgoing artificial nutrition and hydration, information on the length of time in medical care was missing
‡ Information on place of death of 1 case of a non-treatment decision was missing
§ In cases of physician-assisted dying, the drugs refer to the drugs that were used to end the child's life; in cases of deep sedation or a non-treatment decision they refer to drugs that possibly had a life-shortening effect
** In 4 cases of a non-treatment decision, information on the estimated shortening of life was missing

1. Physician-assisted dying at the explicit request of the child (euthanasia)
A 16-year-old child had an autoimmune disease for which no treatment options were left. The child had relapses, infections, cough, fatigue, and loss of appetite and experienced the situation as unbearable. The child was capable of assessing the situation and of making an adequate decision and repeatedly expressed a wish to receive assistance in dying. Parents agreed with the request. Four independent physicians and the medical ethical review board were consulted and also agreed. The pediatrician administered a neuromuscular relaxant after inducing a coma. The parents and a nurse were present at the moment of dying. The physician estimated the shortening of life to be 6 months at maximum. The euthanasia was reported to the Public Prosecutor.

2. Physician-assisted dying at the explicit request of parents
A child 18 months of age had a progressive neurodegenerative disease. There were no treatment options left. The child was very ill. The child was treated for epilepsy and received artificial nutrition. The parents asked for physician-assisted dying because they felt their child suffered unbearably and hopelessly and because they wanted to shorten the dying process. The request was discussed in a multidisciplinary team. The pediatrician also consulted colleague pediatricians, the nursing staff, the family doctor, and an independent pediatrician from another hospital. The discussion partners all agreed to comply with the request. The child received sedatives and opiates and died within a few hours. The parents and a nurse were present at the moment of dying. The physician estimated the shortening of life to be 4 weeks at maximum.

3. Physician-assisted dying without the request of the child or parents
A 13-year-old child had acute myeloid leukemia for which no treatment options were left. The child developed multi-organ failure and a sub-coma. The lack of treatment alternatives and the possibility of ending the child's suffering by ending life were extensively discussed with the parents. The parents agreed with the ending of life. The child received opiates and died within a few days. The parents and a nurse were present at the moment of dying. The physician estimated the shortening of life to be no more than 1 week.

4. Deep sedation
A child 14 years of age had a congenital heart disease. When the child was much younger it was decided that surgery would not be beneficial. The child had developed endocarditis, pulmonary embolisms, and respiratory insufficiency, which required artificial ventilation. The physicians concluded that further treatment and ventilation would be in vain, because the child's recovery was not possible. All treatment, including artificial ventilation and nutrition and hydration, was stopped. To avoid severe shortness of breath and to make the dying process more acceptable for the family, the child, who was already in a subcoma, received opiates and was deeply sedated with barbiturates. The physician estimated the shortening of life to be less than 24 hours.

5. Non-treatment decision
A 5-year-old child had a progressive metabolic encephalopathy, which led to therapy-resistant epilepsy. Different types of drugs, including opiates to induce a coma, were not effective. In the end, it was decided on request of the parents not to start artificial ventilation and to withhold all opiates. One of the attending pediatricians discussed details about prognosis and medical management with the child. The child died shortly afterward. The physician estimated the shortening of life to be about 6 months.

Figure. Case descriptions of 5 end-of-life decisions

Study 2: physicians' experiences

Fifty percent of all the pediatricians taking part in the interview study had at some point received a request from parents to end their child's life, and 15% had ever received such a request from a child (table 4.2). Of the 63 pediatricians, 14 had at some time in the past complied with a request from parents and 1 had granted a request from a child. Of all the pediatricians interviewed, 24% had at some time applied deep sedation while forgoing artificial nutrition and hydration in a dying child. Administering drugs to alleviate pain or symptoms with a possible life-shortening effect and decisions to forgo a potentially life-sustaining treatment (non-treatment decisions) were more common practices among pediatricians (table 4.2).

In the interviews, 76 of the most recent cases in which an ELD had preceded the death of a child were discussed: 20 cases of physician-assisted dying where a drug was used with the explicit intention to hasten death, 12 cases of deep sedation while forgoing artificial nutrition or hydration, and 44 cases of non-treatment decisions (table 4.3) (figure). In 2 of the cases of physician-assisted dying, the decision was made at the explicit request of the child; 1 of these concerned a case of euthanasia performed by a family doctor in which the respondent was involved. Another 16 cases followed an explicit request for physician-assisted death by the parents, of which 2 respondents reported having been involved in cases where a family doctor had ended a child's life. In 2 other cases, the decision was made without an explicit request from either the child or the parents. There were 3 cases in which the respondent indicated having applied deep sedation and 6 cases in which the respondent indicated having made a non-treatment decision. These were unable to be discussed because of lack of time of the respondent; the average duration of these interviews was 1.50 hours. Of the 76 children, 58 children were younger than 12 years. Thirty-six children had cancer, including leukemia and solid malignant tumors; 16 children had neurological diseases such as neurodegenerative diseases and congenital neurological abnormalities; and 24 children had other diagnoses, which included heart diseases, lung diseases, and infections. Most respondents had had the children in their medical care for longer than 1 month; the length of time in treatment was longer for cases of physician-assisted dying than for cases of deep sedation and non-treatment decisions. Fiftythree children died in the hospital, 18 in an intensive care unit. Deeply sedated children more often died in the hospital than did the other groups. Twenty-one of the 53 children who died in the hospital and 14 of the 22 children who died at home had been diagnosed with cancer (data not shown; information for 1 child diagnosed with cancer was missing). The use of (potentially) life-shortening drugs was not limited to physician-assisted dying. Physicians reported that all cases of terminal sedation involved the use of potentially life-shortening drugs, and this holds for 12 cases in which a non-treatment

decision was made. The most frequently used drugs were morphine or other opiates (25 cases) and sedatives (11 cases). Neuromuscular relaxants were used only in 5 of the 20 cases of physician-assisted dying. The pediatricians estimated that life had been shortened by the ELD by less than 1 week in 31 cases and by more than 1 month in 26 cases.

In 9 cases, the respondent considered the child to be fully competent, that is, able to assess his or her own situation and make an adequate decision at the moment of the decision-making (table 4.4). All of these children were 10 years or older. An additional 7 children aged 6 to 18 years were considered to be partly competent. Partly competent could mean that the child was capable of making simple choices and of communicating these or that the child was capable only of understanding simple information. Twelve of 76 children were involved in the decision-making process. The ELD was discussed with all 9 competent children and 3 of the partly or completely incompetent children. All of the children with whom the decision making was discussed were 10 years or older, except for one 5-year-old child for whom a non-treatment decision was made; at an earlier stage of the disease, a colleague of the respondent had talked to the child about his disease and discussed the possibility of forgoing treatment, despite the fact that this child was considered incompetent by the respondent. Of the 20 cases of physician-assisted dying, 4 related to competent patients, of whom 2 had explicitly requested the decision. In the other 2 cases, the request had come from both the parents and the child but that of the child was not explicit (data not shown). In 64 cases, the ELD was not discussed with the child, mainly either because the child was unconscious or, as was the case in most children younger than 12 years, the child was considered too young.

The ELDs were discussed with the parents in all cases; in 34 cases, the ELD had been requested by the parents. In most cases of physician-assisted dying, the request came from the parents, unlike the majority of cases of deep sedation and non-treatment decisions where the parents usually had not requested the decision. In virtually all cases, the respondents had also discussed their decisions with other physicians. Nurses were involved in the decision-making process in 66 cases. In 2 cases, no request was made by either the child or the parents; instead the decision followed from extensive discussion with the team and with the parents. In both cases, all treatment options had been exhausted and the child's suffering was both hopeless and unbearable. The ELD was taken together with the parents because the decision was seen as the only possibility to relieve the child's suffering.

Table 4.4 Discussion of end-of-life decisions for children between the ages of 3 months and 18 years in the Netherlands (interview study)*

	Physician-assisted dying	Deep sedation while forgoing artificial nutrition or hydration	Non-treatment decision	Total
	N=20	N=12	N=44	N=76
Child				
- Child was competent†	4	1	4	9
- Child was (partly or completely) incompetent	16	11	39	66
- Decision was discussed with child	4	1	7	12
- Decision taken at the explicit request of child	2	1	2	5
- Decision was not discussed with child	16	11	37	64
Reasons for not discussing the decision with child‡				
- Child was too young	9	5	16	30
- Child was unconscious	4	5	15	24
- Child was mentally handicapped	1	0	8	9
- Emotional state of the child	2	1	1	4
- Other reason(s)	1	2	2	5
Parents				
- Decision was discussed with the child's parents	20	12	44	76
- Decision made at the request of the parents	16	3	15	34
Other caregivers decision was discussed with‡				
- Other physicians	20	12	43	75
- Nursing staff	18	8	40	66

* Values are expressed as absolute number of instances.
† In 1 case of a non-treatment decision, information on the child's competence was missing.
‡ More than 1 answer was possible.

Discussion

To our knowledge, this study is the first nationwide study on ELDs in Dutch children. In the Netherlands, childhood mortality is very low and mainly concerns children younger than 5 years. The main causes of death in children between the ages of 1 and 17 years in 2001 were accidents (29%), cancer (18%), neurological diseases (11%), congenital abnormalities (8%), and infectious diseases (6%)[26]; causes of death during

the study period were similar. In study 1, we found the proportion of sudden and unexpected deaths among children to be somewhat higher than for all deaths.[3] The proportion of ELDs was lower than in neonates and infants and somewhat lower than in adults.[3,8-12,22] In children, non-treatment decisions occurred less frequently than in other age groups.[3,8,9,22] This can partly be explained by the fact that death in younger age groups occurs more often suddenly and unexpectedly than in older age groups, so that decisions whether to apply potentially life-prolonging treatment are less often required. Furthermore, treatment may more often be continued in non-sudden deaths up to the time the child dies. The proportion of decisions to administer drugs to alleviate pain and symptoms with a possible life-shortening effect was comparable with the proportion in adults.[3] Apparently, the choices made regarding the relief of suffering in the terminal phase are similar for both children and adults. The practice of active life ending occurs as frequently in children as in adults, but a patient request is rare in children.[3,8,9,22] This may be because, predominantly, most deaths in children occur before age 5 years.

The frequency of ELDs in our interview study was higher compared with other studies in Canada and Europe, where percentages of ELDs of between 34% and 41% were reported. However, these studies solely addressed the decision to forgo life-sustaining treatments in pediatric intensive care units.[14,17,19] In the Dutch Medical Treatment Contract Act[27] and the Dutch Euthanasia Act, children 12 years and older are permitted to decide about their medical treatment or to request hastening of their death. Although any legal cut-off point for age seems arbitrary, our study found that pediatricians indeed feel that children from around the ages of 10 or 12 years onward are often able to participate in an important medical decision. Children 10 years or older were often considered to be partly or fully competent and hence were involved in the decision-making process.

A study in the United States, Canada, and the United Kingdom found that of a group of 228 pediatric oncologists, 26% had at some point received a request for euthanasia and 20%, a request for physician-assisted suicide from parents or children, and that 9% and 4%, respectively, had ever granted such a request.[13] In our interview study, the proportion of requests from parents and children for physician-assisted dying and the proportion of requests granted were higher (62% and 24%, respectively). Rarely among these cases did the request come from the child himself or herself, even when only the deaths of children who were old enough to ask for physician-assisted dying were taken into account. The active ending of life at the parents' request is more commonly practiced. Elsewhere, it was shown that more than half of all pediatricians in the Netherlands are willing to perform active ending of life if the child explicitly requests

this and parents agree; when parents do not agree, they are considerably less willing to do so.[28]

Two thirds of all children for whom clinical specialists made an ELD died in the hospital; the remaining one third died at home. Of the children who were diagnosed with cancer, about 60% died in the hospital. In a study of the end of life of children with cancer in the United States, about 50% of the children died in the hospital; nearly half of these deaths occurred in the intensive care unit.[29] The somewhat larger proportion of children with cancer who died in the hospital in our study may be because we only included cases where an ELD had been made. Ending the life of a terminally ill child at home is a rare practice in the Netherlands; this is in accordance with another study in which family doctors reported that they virtually never receive requests for euthanasia or physician-assisted suicide from children younger than 18 years.[8]

Specific problems relate to the medical care and decision making for severely ill children, not in the least because death and dying are usually so far away in this stage of life. Parents are often assigned an important role in the decision making, but there are different opinions on whether parents should make decisions themselves, should be consulted before the physician makes a decision, or should be protected from participating in such emotionally charged decision making.[13,18,29-31]

The parents were involved in the decision making in all cases, and the decision was made at the explicit request in about half of the cases. In the Netherlands, physicians are trained to involve the patient or the patient's relatives in medical decisions, but in the end, it is the physician who is responsible for the decision that is made (Dutch Medical Treatment Contract Act). Because we only interviewed pediatricians, we do not know what the parents themselves thought about their involvement in the decision making. A qualitative study in hospitals showed that physicians and parents did not always agree on the way decisions for children with cancer were made and that parents were often involved only after the physicians had made their decisions.[32] Furthermore, older children may want to participate in the decision process themselves. Their ability to do so, however, is questionable, especially because end-of-life care may involve decisions that have far- reaching and irreversible consequences. It is often difficult to decide whether and when it is possible or desirable to discuss these decisions with the patient and how to address, for example, children's requests to forgo treatment or to receive assistance in dying.[19,30,31,33]

In almost all cases, the physicians involved colleague-physicians and nurses in the decision making. Apparently, a consultative model is dominant in Dutch pediatric practice. This also holds for the Dutch neonatology practice.[9,23]

Our study has a number of limitations. Because of the retrospective design of the study, there is the possibility of recall bias. However, the validity of our death certificate questionnaire has been shown in several studies.[1,3,9,24] It sometimes appeared to be difficult for physicians to distinguish between the different ELDs, even though the interviewers always mentioned the exact definitions and ordering of different types of ELDs. For example, when pain or other symptoms can only be alleviated with drugs that may hasten death, it can be difficult to distinguish whether hastening of death was taken into account or an appreciated goal when using these drugs. Study 2 is not fully representative of the entire population of physicians who may take ELDs for children because physicians who are rarely involved with dying children, such as family doctors, were not interviewed. Furthermore, no firm comparison can be made between pediatrician-oncologists, pediatrician-intensivists, and pediatric neurologists because the numbers were too small.

Conclusion

End-of-life decision-making is an important aspect of end-of-life care for children younger than 18 years. An ELD is made in about one third of the deaths in this age group, although physician-assisted dying is rare in this age group, especially for older children. In most cases, pediatricians consider children unable to participate in the decision-making process because they are unconscious or because they are too young. Communication about end-of-life decision making for children typically involves caregivers, parents, and, if possible, the child. To gain more insight into the end-of-life decision-making process, experiences and opinions of parents and other caregivers, such as nursing staff, should be studied as well.

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5

Making decisions concerning the end of life: Interview study with Dutch paediatricians

Abstract

Objective. We studied the practice of making decisions to forgo potentially life-sustaining treatment or to use drugs aimed at hastening death preceding the death of severely ill children.

Methods. We interviewed 63 paediatricians (response 91%): 54 of them gave details about the decision-making process concerning 44 children in whom treatment had been forgone and 20 children in whom drugs aimed at hastening death had been used.

Results. Paediatricians usually discussed end-of-life decisions with parents, colleague-physicians and nursing staff. They felt that their most important discussion partners were staff members. Topics discussed with other physicians typically included the child's prognosis and the chances of survival, though more frequently in cases where a treatment was forgone than in cases where drugs aimed at hastening death were used; palliative treatment options were more often discussed in cases where drugs were used. Topics discussed with the nursing staff included the child's condition, the parents' emotional capacity and terminal care. The persons involved mostly all agreed with the decision. Most paediatricians evaluated the dying process of their child with the parents, but such evaluation occurred more often when drugs had been used than when treatment had been forgone. Most paediatricians were satisfied about the medical care preceding death, and thought that it had improved the quality of dying.

Conclusion. Paediatricians usually discuss end-of-life decisions with colleagues and other caregivers, and seldomly make such decisions in isolation. The opinion of colleague-physicians is especially important. Paediatricians seem to rarely regret decisions to forgo sustaining life or to hasten death.

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Introduction

End-of-life decisions include decisions to forgo potentially life-sustaining treatments and decisions to alleviate pain or other symptoms by using drugs with a possible life-shortening effect, and decisions to use drugs with the aim of ending life. These often far-reaching and irreversible decisions may non-intentionally or intentionally hasten death. To support the decision-making process near the end of life of children several recommendations have been given and guidelines have been proposed.[1-7] Understanding current practices of medical end-of-life care, which inevitably involve dealing with complex ethical questions, is important for the improvement of the decision-making.

Until now, studies have been mainly focussing on end-of-life decision-making in neonatology.[8-12] A substantial part of deaths of neonates have been shown to involve end-of-life decisions. It has been shown that in the Netherlands, 12% of all deaths of children from one to 17 years in 2001 have been preceded by a decision to forgo a life-sustaining treatment; in 21% of all deaths drugs have been used that possibly hastened death; and in 2.7% drugs have been used with the explicit intention of hastening death, of which 0.7% at the request of the child.[13,14] About 80% of Dutch paediatricians have been involved in end-of-life decision-making. The use of lethal drugs is generally considered to involve a more morally loaded decision than the forgoing of life-sustaining treatment.

The degree to which the parents participate in the decision-making differs between countries.[9,11,15] Garros et al reported in a study on forgoing life-sustaining treatments in a paediatric intensive care unit in Canada, that virtually all families agree with such decision, but in half of the cases more than one formal meeting is required to reach consensus.[16] Not all paediatricians are used to arrange after-death meetings with bereaved parents, although it may support grief response.[9,17,18]

The role of physicians and nursing staff in the decision-making process also seems to vary. It has been shown that physicians initiate the discussion about the end-of-life decision more often than nurses, that their views on whether therapy must be forgone or not may differ, and that nurses are emotionally more involved in care at the bedside near the end of life than physicians.[19-22]

Whether the decision-making concerning the use of drugs aimed at hastening death differs from the forgoing of life-sustaining treatment is unknown.
We studied the practice of making decisions to forgo a life-sustaining treatment or to use of drugs with the explicit intention of hastening death in children older than three

months. The first objective was to find out who the participants are in end-of-life decision-making, what their role is, and what the subjects of discussion are. The second objective was to get insight into how the attending paediatrician and the child's parents look back on the death of the child and the medical decision-making. We compared cases where a life-sustaining treatment was forgone with cases where a drug with the explicit intention of hastening death was used.

Methods

Sample

We interviewed a sample of physicians of specialties that attend the majority of all deaths in children: oncologists-oncologists and haematologists, paediatrician-intensivists, and paediatric neurologists. Paediatrician-oncologists/haematologists and paediatrician-intensivists exclusively work at departments within the eight university hospitals in the Netherlands. From each department, half of the physicians, or all of them in case only one or two physicians worked at the department, were randomly selected. The sample of paediatric neurologists, who may also work in other than university hospitals, was drawn from their professional registry. For each hospital, half of the paediatric neurologists, or all of them in case only one or two paediatric neurologists worked in the hospital, were randomly selected. In the Netherlands, paediatric neurologists have often been trained as neurologists. For readability, we use the term paediatricians also for paediatric neurologists in this paper. Of in total 98 eligible paediatricians, 69 were asked to be interviewed: 63 of them (27 paediatrician-oncologists/haematologists, 18 paediatrician-intensivists, and 18 paediatric neurologists) agreed (response: 91%).

Interviews

Experienced physicians who had been trained in using the structured questionnaire did the interviews. All questions concerned end-of-life decision-making for children between three months and 18 years of age. Because the subject of our study was decision-making for children after the neonatal period, neonates younger than three months old were excluded.[8,10] If applicable, questions were asked about the decision-making process concerning the most recent case in which they decided to:

1. withhold or withdraw potentially life-sustaining or curative treatment (further described as 'forgoing treatment')
2. administer, supply or prescribe a drug with the explicit intention to hasten death (further described as 'use of drugs').

Prior to the interview, we sent the paediatricians definitions of the decisions, and asked them to have the medical record present at the interview. They were asked to only discuss cases in which they acted as the primarily responsible physician. Questions

were asked about who participated in the decision-making process, the issues discussed with colleague-physicians and nursing staff, and the weight of the opinions of both groups. Further, we asked how the parents looked back on the death of their child, and how paediatricians evaluated the dying process. More details of the methods of the study have been described elsewhere.[13,14]

Anonymity procedure

The study design ensured absolute anonymity for the deceased children and their families. The Inspector General for Health Care and the chairman of the Royal Dutch Medical Association supported the study and informed all physicians in writing about the purpose of the study and its privacy procedures.

Statistical analyses

We assessed statistical significance of differences between children for whom a treatment was forgone and children for whom drugs were used. To compare proportions, we used the Chi Square test, and the Fisher Exact test when figures were small. The Mann-Whitney test was used to compare the weights of opinions of different caregivers when forgoing treatment and when using drugs to hasten death, the Wilcoxon Signed Ranks test to compare the weight of opinion of colleague-physicians with the nursing staff, and the Median test to compare median discussed issues.

Results

In total, 64 cases were discussed with 54 respondents: 44 children in whom a treatment was forgone, and 20 children in whom drugs were used.[13,14] On average, the interval between the death of the child and the interview was 13 months (min. 1 month- max. 8 years) for cases in which treatment was forgone, and 20 months (min. 4 months- max. 5 years) for cases in which drugs were used. Half of the children had cancer, and about two-third died in the hospital. The decision was discussed with the child in a minority of cases, mostly because the child was too young, or unconscious. The decision was discussed with the parents in all cases, and was made at the request of the parents in most cases where drugs were used, and in one-third of the cases where a life-sustaining treatment was forgone. In most cases, the decision was discussed with colleague-physicians, and with the nursing staff.[13,14]

Table 5.1 Participants in the discussion about end-of-life decision

Discussion end-of-life decision with colleague-physician(s)	Forgoing treatment N=43		Use of drugs N=20		Total N=63*		
	N	(%)	N	(%)	N	(%)	P§
Within a multi-disciplinary meeting†							0.64
- Yes	34	(79)	14	(70)	48	(76)	
- No	9	(21)	5	(25)	14	(23)	
Present at multi-disciplinary meeting‡							
- Other medical staff member(s) and/or residents	34	(79)	13	(65)	47	(75)	0.37
- Consultant(s)	18	(42)	5	(25)	21	(33)	0.24
- Nursing staff	31	(72)	11	(55)	42	(67)	0.27
- Parents	1	(2)	2	(10)	3	(5)	0.22**
- Others (e.g. social worker, psychologist, pastor/minister)	18	(42)	11	(55)	29	(46)	0.29
Outside multi-disciplinary meeting‡							
- None	17	(40)	4	(20)	21	(33)	0.13
- Staff member and/or resident	11	(26)	3	(15)	14	(22)	0.52**
- Specialist, consultant	9	(21)	7	(35)	16	(25)	0.23
- General practitioner	9	(21)	9	(45)	18	(29)	0.05
- Paediatrician other hospital	8	(19)	4	(20)	12	(19)	1.00**
- Others	4	(9)	3	(15)	7	(11)	1.00
Most important discussion partners‡							
- Staff member or resident	30	(70)	15	(75)	45	(71)	0.67
- Chief of staff	5	(12)	3	(15)	8	(13)	0.70**
- Team	3	(7)	3	(15)	6	(10)	0.37
- Others (e.g. general practitioner, nursing staff, paediatrician other hospital)	10	(23)	7	(35)	17	(27)	0.30

* One of the 64 cases was not discussed with colleague-physicians and was therefore excluded
† In one case of the use of drugs information on discussion within multi-disciplinary meeting was missing
‡ More than one answer possible
§ Chi Square test, except where indicated otherwise
** Fisher Exact test

Participants in discussion about end-of-life decision

Table 5.1 shows that in 76% of 63 cases that were discussed with colleague-physicians the end-of-life decision was discussed within a multi-disciplinary meeting. Staff members and/or residents, and nursing staff often (75%, and 67% respectively) attended these meetings. In a few cases, parents were present, but patients never were. In most cases the decision was also discussed between health care

professionals outside the context of the meeting. General practitioners were more often involved in decisions to use drugs than in decisions to forgo treatment (45% versus 21%). The majority of the paediatricians considered other staff members or residents to be their most important discussion partner.

Table 5.2 Weight of opinions colleague-physicians and issues discussed

Discussion end-of-life decision with colleague-physician(s)*	Forgoing treatment N=43		Use of drugs N=20		Total N=63		
	N	(%)	N	(%)	N	(%)	P†
Colleague(s) agreed with end-of-life decision	39	(91)	20	(100)	59	(94)	0.31‡
Importance of their opinion in the decision-making							1.00§
- Very important	29	(67)	14	(70)	43	(68)	
- Rather important	6	(14)	1	(5)	7	(11)	
- Not important	8	(19)	5	(25)	13	(21)	
Issues discussed, median (min.-max.)	2 (1-7)		3 (1-6)		2 (1-7)		0.01**
- Prognosis concerning quality of life	32	(74)	9	(45)	41	(65)	0.02
- Chance of survival	30	(70)	7	(35)	37	(59)	0.01
- Alternative curative/life-sustaining treatment options	13	(30)	4	(20)	17	(27)	0.39
- Alternative palliative treatment options	4	(9)	7	(35)	11	(17)	0.03‡
- Competence of the patient	3	(7)	2	(10)	5	(8)	0.65‡
- Emotional capacity of the patient	2	(5)	1	(5)	3	(5)	1.00‡
- Emotional capacity of the parents/family	13	(30)	7	(35)	20	(32)	0.71
- Other	7	(16)	2	(10)	9	(14)	0.71‡
- Practical aspects of using drugs to hasten death	-	-	15	(75)	-	-	-
- Whether to use drugs to hasten death	-	-	13	(65)	-	-	-

* 63 of 64 cases were discussed with colleague-physicians[13,14]
† Chi Square test, except where indicated otherwise
‡ Fisher Exact test
§ Mann-Whitney test
** Median test

Table 5.3 Weight of opinions nursing staff and issues discussed

Discussion end-of-life decision with nursing staff*	Forgoing treatment N=40		Use of drugs N=18		Total N=58		
	N	(%)	N	(%)	N	(%)	P†
Nursing staff agreed with end-of-life decision	38	(95)	17	(94)	55	(95)	1.00‡
Importance of the opinion of nursing staff in the decision-making							0.26§
- Very important	8	(20)	6	(33)	14	(24)	
- Rather important	11	(28)	5	(28)	16	(28)	
- Not important	21	(53)	7	(39)	28	(48)	
Issues discussed, median	2		3		2		0.65**
(min.-max.)	(1-5)		(1-5)		(1-5)		
- Condition of the patient	37	(93)	16	(89)	53	(91)	0.61‡
- Terminal care	23	(58)	11	(61)	34	(59)	0.80
- Competence of the patient	3	(8)	3	(17)	6	(10)	0.36‡
- Emotional capacity of the patient	5	(13)	3	(17)	8	(14)	0.69‡
- Emotional capacity of the parents/family	24	(60)	10	(56)	34	(59)	0.75
- Other	7	(18)	2	(11)	9	(16)	0.71‡

* 58 of 64 cases were discussed with nursing staff[13, 14]
† Chi Square test, except where indicated otherwise
‡ Fisher Exact test
§ Mann-Whitney test
** Median test

Weight of opinion and issues discussed with parents

In 98% of the 64 cases, parents agreed with the decision, according to the respondents. In one case, one of the parents did not agree with the decision to forgo treatment. In cases where drugs were used, for all parents who had requested for that decision (n=16), the reason was that they thought their child suffered hopelessly and unbearably. In addition, parents wished to shorten the dying process in 38% of these cases. In 25% the expectation of an extremely poor outcome for their child was a reason for their request.

Weight of opinion and issues discussed with colleague-physicians

Table 5.2 shows that in 94% of the 63 cases that were discussed, the colleague-physicians agreed with the decision, and in 68% their opinion had played an important role in the decision-making of the respondent. Discussions with colleague-physicians

about the use of drugs included a higher median number of issues than discussions about forgoing treatment (3 versus 2). Prognosis concerning quality of life, and the chance of survival were discussed for about two-third of the children in whom a treatment was forgone, and for about one-third of the children in whom drugs were used. For children in whom drugs were used, alternative palliative treatment options, the practical aspects of using drugs, and whether to use drugs were usually discussed too.

Weight of opinion and issues discussed with nursing staff

Table 5.3 shows that in 95% of the 58 cases that were discussed, the nursing staff agreed with the decision, and in 24% their opinion had played an important role in the decision-making. The opinion of nurses had less often been important in the decision-making than the opinion of colleague-physicians (P<0.01). The median number of issues discussed was 2. The condition of the child was the most frequently discussed issue (91%). Terminal care and the emotional capacity of the parents or family were mentioned in about half of the cases.

Table 5.4 Evaluation after the child died

	Forgoing treatment N=44		Use of drugs N=20		Total N=64		
	N	(%)	N	(%)	N	(%)	P
Parents							
- Paediatrician met with parents after the child had died							0.05*
- Once	22	(50)	9	(45)	31	(48)	
- More than once	9	(20)	10	(50)	19	(30)	
- Not	13	(30)	1	(5)	14	(22)	
- Reason for not meeting with parents:							
- It will take place soon	8	(18)	0	(0)	8	(13)	
- Parents did not want it	3	(7)	1	(5)	4	(6)	
- Other reason	2	(5)	1	(5)	3	(5)	
- Time between death and last meeting with parents†							0.01‡
- < 1 month	3	(7)	1	(5)	4	(6)	
- 1 month - 2 months	12	(27)	3	(15)	15	(23)	
- 2 months - 6 months	15	(34)	8	(40)	23	(36)	
- ≥ 6 months	1	(2)	6	(30)	7	(11)	

Table 5.4 continued

	Forgoing treatment N=44		Use of drugs N=20		Total N=64		
	N	(%)	N	(%)	N	(%)	P
- How did parents look back on the death of their child?§							
- They were in peace with their child's death	22	(50)	16	(80)	38	(59)	0.33**
- They had not come to terms with their child's death yet	7	(16)	2	(10)	9	(14)	0.45**
- They had doubts about the end-of-life decision	1	(2)	1	(5)	2	(3)	1.00**
- Other	7	(16)	4	(20)	11	(17)	1.00**
Paediatrician							
- Evaluation of the medical care that had preceded the death of the child††							0.89‡
- (Very) satisfied	36	(82)	15	(75)	51	(80)	
- Moderately/not satisfied	8	(18)	3	(15)	11	(17)	
- Doubts about the end-of-life decision††	5	(11)	0	(0)	5	(8)	0.31**
- Paediatrician felt that the decision had improved the quality of dying‡‡							<0.01§§
- Considerable	22	(50)	16	(80)	38	(59)	
- Somewhat	14	(32)	1	(5)	15	(23)	
- Hardly/ not	6	(14)	0	(0)	6	(9)	
- Do not know	2	(5)	2	(10)	4	(6)	

* Fisher Exact test: meeting with parents once or more than once versus no meeting
† In 1 case in which drugs were used information on time between death and meeting with parents was missing
‡ Mann-Whitney test
§ More than one answer possible
** Fisher Exact test
††In 2 cases in which drugs were used information on satisfaction and doubts with the paediatrician was missing
‡‡In 1 case in which drugs were used information on opinion of the paediatrician on quality of dying was missing
§§Mann-Whitney test: 'do not know' excluded from analysis

Meeting with parents after the child died

Paediatricians reported to have met with the parents after their child's death once in 48%, and more than once in 30% (table 5.4). Such meetings less often took place when a treatment was forgone than when drugs were used (70% versus 95%). The meeting usually took place between 2 and 6 months after the child died, but for children in whom drugs were used it occurred more often after 6 months than for

children in whom treatment was forgone (30% versus 2%). According to the respondents, 59% of the parents were in peace with the death of the child at the time of the last meeting. In 14% they had not come to terms with the death of their child yet, and in 3% of all cases, they had doubts about the decision to forgo treatment or use lethal drugs. Other issues discussed during these meetings were the parents' grief about their child's death, and the timing of the decision-making or the dying process.

Paediatrician's evaluation of the dying process

In 80% of all cases, the paediatricians were (very) satisfied about the medical care that had preceded the death of the child (table 5.4). In 11% of all cases, they had doubts about the decision to forgo treatment, because of its timing, or because the parents may have been insufficiently involved. Paediatricians never doubted the decision to use drugs aimed at hastening death. In 80% of those cases they thought that the quality of dying had improved considerably by the use of these drugs. They less often thought that quality of dying had improved considerably due to the decision to forgo life-sustaining treatment (50%).

Discussion

Dutch paediatricians report to discuss the forgoing of life-sustaining treatments and the use of drugs with the explicit intention of hastening death in severely ill children with all involved parties, and rarely make such decisions in isolation. Colleague-physicians are considered as the most important discussion partners. Further, end-of-life decision-making typically involves discussing the expected quality of life, the chance of survival of the child, and emotional capacity of parents, and alternative treatment options. Using drugs more often followed a request of parents than forgoing treatment, and paediatricians more often met with parents several months after the use of drugs than after forgoing treatment. Parents mostly were in peace with the death of their child at that time.

In interpreting our data some limitations have to be taken into account. Firstly, because we interviewed the paediatricians, we only can draw conclusions about their views on the communication. From other studies, it is known that opinions of physicians do not necessarily reflect the opinions of other professionals or parents.[20,22,23] Besides that, some of the decisions were made several years before the interview. To minimize recall bias, we asked the paediatricians to prepare for the interview and to have the medical record present at the time of the interview. Finally, the Netherlands is known for its liberal view on end-of life decisions and especially concerning euthanasia, which is administering drugs with the explicit intention of hastening death at the request of the patient. Paediatricians in the Netherlands also have a more liberal attitude than

paediatricians in other countries towards using these drugs in children.[11] Therefore, conclusions may not be valid in other countries.

The multidisciplinary meeting seems to be seen as the most appropriate place for professionals to discuss end-of-life decisions.[24] Parents rarely participate in such meetings, which was also reported by others.[11,15,16] With colleague-physicians, paediatricians mostly discuss issues related to prognosis and options for medical treatment. With the nursing staff, they mostly discuss care issues, like the condition of the child and terminal care.[1,20] Paediatricians weigh the opinion of their colleague-physicians more heavily than the opinion of the nursing staff. Further, in case a drug was used the family's general practitioner is more often involved than in cases a treatment was forgone. The use of drugs aimed at hastening death is probably considered to be a more burdensome decision than the forgoing of a life-sustaining treatment,[25] for which involvement of all caregivers is important.

Chance of survival, quality of life, and the possibility of palliative care are usually considered when making the decision to forgo life-sustaining treatment.[10,16,17,19,22,26] In our study, quality of life and chance of survival were more often discussed when a treatment was forgone, while alternative palliative treatment options were more often discussed when drugs were used. The decision to use drugs with the explicit intention of hastening death is possibly discussed in a later stage of the disease of the child, when it is already clear that there is no chance of survival or that the expected outcome is extremely poor.

Paediatricians virtually never make end-of-life decisions when parents do not agree.[9,14,16] However, using drugs aimed at hastening death is more often initiated by parents than forgoing life-sustaining treatment.[14] From a study in six European countries it is known that Dutch physicians more often discuss end-of-life decisions with patients and family as compared to some of the other countries.[27] Cuttini et al concluded in a European study in neonatal intensive care units, that physicians increasingly recognize the importance of participation of parents in end-of-life decision-making.[11] From a study of Garros et al, it is known that often several meetings are required to reach consensus with family.[16] However, parents are not always satisfied with the way difficult news is communicated.[15,28]

Most paediatricians were satisfied when they look back on the decision-making process at the end of the life of the child. They only had doubts about the decision in a small number of cases, because of its timing, or because of insufficient involvement of the parents. Mostly, they felt that the end-of-life decision had improved the quality of

dying, in cases where drugs were used even more often than in cases where a treatment was forgone. Further, paediatricians often regard care for the parents after their child died as part of their responsibility.[9] Adequate palliative care, communication and bereavement management can be helpful in the mourning process of relatives.[17,18]

Conclusion

Forgoing of life-sustaining treatment typically is a physician-initiated decision that is based upon the absence of effective treatment for a lethal disease in its final stage. Using drugs aimed at hastening death more often follows a parental request and seems to be used as the final resort to stop severe suffering. Paediatricians seem to rarely regret decisions to forgo sustaining life or to hasten death. To have a broader insight in the end-of-life decision-making process, experiences and opinions of parents, and other caregivers, such as nursing staff, should be studied too.

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Part IV

Opinions on assistance in dying in children and the Euthanasia Act

6

Physicians' willingness to grant requests for assistance in dying for children: a study of hypothetical cases

Abstract

Objective. The objective was to study the willingness of Dutch physicians to use potentially life-shortening or lethal drugs for severely ill children.

Methods. We asked 63 pediatricians about their approach to 10 hypothetical cases of children with cancer. The age of the child (15, 11, or 6 years), the child's (explicit) request, and the opinion of the parents varied. Two hypothetical cases were also presented to 125 general practitioners and 208 clinical specialists.

Results. Most pediatricians were willing to increase morphine in all cases. A total of 48% to 60% of pediatricians were willing to use lethal drugs in children at the child's request, when the parents agreed; when parents requested ending of life of their unconscious child, 37% to 42% of pediatricians were willing; 13% to 28% of pediatricians were willing when parents did not agree with their child's request. General practitioners and clinical specialists were as willing as pediatricians to use lethal drugs at the child's request, but less willing to grant a request of parents for their unconscious child.

Conclusion. Many Dutch pediatricians are willing to use potentially life-shortening or lethal drugs for children. The legal limit of 12 years, as the age under which voluntary euthanasia is forbidden, is not fully supported by Dutch physicians.

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Introduction

End-of-life decisions, that is, decisions that may intentionally or unintentionally hasten death, include decisions to use drugs with possible life-shortening effects and lethal drugs. In the Netherlands, the use of lethal drugs with the explicit intention to hasten death is defined as euthanasia when someone other than the patient administers the drugs at the explicit request of the patient and as physician-assisted suicide when the patient takes these drugs himself or herself. Before April 2002, Dutch law prohibited euthanasia and physician-assisted suicide. However, physicians who performed euthanasia or physician-assisted suicide were not prosecuted when they applied the established rules for careful decision-making.[1] In recent years, whether euthanasia or physician-assisted suicide should be allowed for children has been debated. The law on euthanasia that came into effect in April 2002 allows physicians to grant requests for euthanasia or physician-assisted suicide to adults aged 18 years or older. Euthanasia, or physician-assisted suicide, for minors aged 16 or 17 years is allowed when parents are informed, and for minors aged 12 to 16 years when parents agree with the request. For children younger than 12 years of age, euthanasia or physician-assisted suicide is not allowed, and the use of lethal drugs without the request of a patient is still legally prohibited for all age groups.

In the Netherlands in 2001, 20% of all deaths were preceded by the use of a drug with a possible life-shortening effect to alleviate pain or other symptoms, whereas approximately 3.5% of deaths were preceded by the use of lethal drugs, mostly at the request of the patient.[1] In 1995, 23% of all deaths of neonates and infants were preceded by the use of a drug with a possible life-shortening effect to alleviate pain or other symptoms, and 9% of deaths were preceded by the use of lethal drugs.[2] No data have been published about end-of-life decision-making in children after the neonatal period.

Dutch physicians are more willing to perform euthanasia in a cancer patient who is in excruciating pain than American physicians from Oregon (59% versus 24%).[3] However, the attitudes of pediatricians or other physicians toward using lethal drugs, or drugs with a possible life-shortening effect (such as morphine) in severely ill children have rarely been studied.[4-6]

End-of-life decision-making in children is complex, because it almost always involves 3 parties: physicians, the child, and the parents.[7-9] Questions arise, such as ‘‘who should have the most important vote in the decision?’’ and ‘‘at what age should children be involved in the decision-making?’’ It is often difficult to decide whether and when it is possible or desirable to discuss end-of-life decisions with the child and how to address,

for example, children's requests to receive assistance in dying.[8-14] Parents are often assigned an important role in the decision-making process. However, there are different opinions about whether parents should make decisions themselves, should be consulted before the physician makes a decision, or should be protected from participating in such emotionally charged issues.[9,12-20]

Therefore, this study was designed to gain insight about the willingness of Dutch pediatricians, other clinical specialists, and general practitioners to use lethal or potentially lifeshortening drugs in children and about the characteristics of cases and physicians that determine such willingness.

Methods

Data are presented from 2 interview studies, one among pediatricians and one among general practitioners and clinical specialists. For both studies, physicians who had worked at least 2 years and for more than 50% of their time in their current practice were sampled. Data were collected between March and December 2002.

Pediatricians

The sample consisted of specialists who attend the majority of all deaths in children in the Netherlands: pediatrician-oncologists and hematologists, pediatrician-intensivists, and pediatric neurologists. Pediatrician-oncologists/hematologists and pediatrician-intensivists work exclusively at departments within the 8 university hospitals in the Netherlands. From each department, half the physicians were randomly selected, or all were selected when only 1 or 2 physicians worked in the department. The sample of pediatric neurologists, who also work in other than university hospitals, was drawn from their professional registry. For each hospital, half the pediatric neurologists were randomly selected, or all were selected when only 1 or 2 pediatric neurologists worked in the hospital. In the Netherlands, pediatric neurologists have often been trained as neurologists. For readability, when we use the term ''pediatricians,'' we include these pediatric neurologists. Of 98 eligible pediatricians, 69 were asked for an interview; 63 agreed (27 pediatrician-oncologists/hematologists, 18 pediatrician-intensivists, and 18 pediatric neurologists; response rate, 91%).

General practitioners and clinical specialists

We also interviewed random samples of general practitioners and clinical specialists (cardiologists, surgeons, and specialists in internal medicine, pulmonology, and neurology) who may also treat children. We selected addresses from the professional registries. Of 403 physicians who were asked for an interview, 333 agreed (125 general practitioners and 208 clinical specialists; response rate 83%).

Hypothetical cases

Pediatricians were presented 10 hypothetical cases of children with cancer and metastases who had pain that could not be controlled with morphine (table 6.1). The age of the child (15, 11, or 6 years), whether the child (explicitly) requested ending of life, and the opinion of the parents varied. An inexplicit request was described as ‘‘the child would like to quietly fall asleep.’’ Eighteen combinations could be made. The age of 6 was not combined with an explicit request of the child, because this combination seemed unrealistic. Further, combinations in which the child and parents did not request ending of life were excluded. The case of a 15-year-old child who explicitly requests ending of life, with parents’ agreement, was the only one for which the use of lethal drugs would be allowed according to the law. General practitioners and clinical specialists were presented a selection of 2 hypothetical cases: a 15-year-old child who explicitly requests ending of life, with parents’ agreement, and a 15-year-old unconscious child for whom the parents requested ending of life. All physicians were asked 2 questions about these hypothetical cases. First, we asked about the willingness to use potentially life-shortening drugs (‘‘Are you willing to increase morphine, taking into account that this may hasten death?’’), and second, we asked about the willingness to use lethal drugs (‘‘Are you willing to administer a drug with the explicit intention to hasten death?’’). They could answer both questions on a 5- point Likert scale (yes; probably; maybe/maybe not; probably not; no).

Statements

Pediatricians, general practitioners and clinical specialists were asked to indicate whether they agreed with 4 statements on the use of lethal drugs in children on a 5-point Likert scale (totally agree; agree; neither agree nor disagree; disagree; totally disagree).

Statistical analyses

All answers were dichotomized; for the hypothetical cases, the answers ‘‘yes’’ and ‘‘probably’’ were considered to be ‘‘willing to increase morphine or use lethal drugs’’; for the statements, the answers ‘‘totally agree’’ and ‘‘agree’’ were considered to be ‘‘agree.’’ Multivariate logistic regression analysis was used to assess the influence of case characteristics on the pediatricians’ willingness. Respondent number was included in this model to correct for repeated measures per pediatrician. In subsequent models, we added factors representing possible interaction between the age and request of the child and between the child’s age and the parents’ opinion. Because the sample of pediatricians contained 64% of all eligible pediatricians (63 of 98), we decided to treat this sample as random and did not choose for multilevel analysis.

Multivariate logistic regression analyses were used to analyze the influence of physician characteristics (sex, age, specialty, years of experience, and religion) on the statements and 2 hypothetical cases that were presented to all physicians. All percentages were weighted for non-response and sampling fraction of the physicians.

Table 6.1 Description of hypothetical cases

Case description

A patient of a certain age has cancer with extensive metastases. The pain is severe and cannot be controlled with morphine.

Case characteristics

		1	**2**	**3**	**4**
A	*Age (Y)*	15	11	6	
B	*Request child*	The child makes an explicit and, to your impression, well-considered request for ending of life	The child is disordered, has reduced consciousness, and is not responsive since last week; the child had earlier said that he/she would like to quietly fall asleep	The child says that he/she would like to quietly fall asleep	The child is disordered, has reduced consciousness and is not responsive since last week; the subject of physician-assisted death is never discussed with the child.
C	*Opinion parents*	Parents agree with this request	Parents make a well-considered and explicit request for ending the life of their child	Parents cannot accept the hopeless situation and ask for the continuation of treatment	

Composition case characteristics

Pediatricians	A1B1C1*; A1B1C3; A1B2C1; A1B4C2; A2B1C1; A2B1C3; A2B2C1; A2B4C2; A3B3C1; A3B4C2
General practitioners and clinical specialists	A1B1C1*; A1B4C2

Questions

1. Are you willing to increase morphine taking into account that this may hasten death?
2. Are you willing to administer a drug with the explicit intention to hasten death?

*This hypothetical case is allowed according to the Dutch law on euthanasia

Table 6.2 Characteristics of pediatricians and other physicians

	Pediatricians* N=63		General practitioners N=125		Clinical specialists N=208		Total N=396		
	%†	95%CI	%†	95%CI	%†	95%CI	%†	95%CI	P‡
Female	38	27-50	21	15-29	15	11-20	22	18-26	0.01
Religious	44	33-57	34	26-43	47	40-54	40	35-45	0.05
Age (y)									0.62
- <40	16	9-27	11	7-18	12	8-17	12	9-15	
- 40-50	51	39-63	46	37-55	50	43-56	48	43-53	
- ≥50	33	23-46	43	35-52	39	32-45	40	36-45	
Years of experience									0.01
- <10	40	29-53	17	11-25	29	23-36	24	20-29	
- 10-20	31	21-43	44	36-53	46	40-53	43	38-48	
- ≥20	29	19-41	39	31-48	25	19-31	33	29-38	

* Including pediatrician-oncologists/hematologists, pediatrician-intensivists, and pediatric neurologists
† Percentages are weighted for non-response and sampling fraction of the physicians
‡ Pearson chi-square test

Results

Physician characteristics

Table 6.2 shows that of all physicians (n=396), 22% were women and 40% considered themselves as belonging to a religious group or adhered to a certain philosophy of life. Most of the physicians were older than 40 years (88%) and had more than 10 years of experience (76%). Pediatricians were more often women and had fewer years of experience than other physicians. General practitioners considered themselves as belonging to a religious group or adhered to a certain philosophy of life less often than pediatricians and other specialists.

Hypothetical cases for pediatricians

In total, 13% to 60% of all pediatricians were willing to use lethal drugs in children (table 6.3); 6% to 35% answered ‘‘yes,’’ and 7% to 33% answered ‘‘probably’’ (not in table). About half the pediatricians were willing to use lethal drugs for children of different ages when the child (explicitly) requested for the ending of life and the parents agreed (48%- 60%). When parents requested ending the life of their unconscious child, 37% to 42% of the pediatricians were willing to grant this request. Pediatricians were least often willing to use lethal drugs when parents did not agree with the explicit request of their child (13% for an 11-year-old child; 28% for a 15-year-old child). In all cases, pediatricians were more often willing to increase morphine (70%-90%) than to

use lethal drugs; 49% to 79% answered ''yes,'' and 8% to 21% answered ''probably'' (not in table).

Table 6.3. Percentage of the pediatricians (n = 60*) who would use lethal drugs or increase morphine at different ages of the child

	Use of lethal drugs						Increase morphine					
	15-year old		11-year old		6-year old		15-year old		11-year old		6-year old	
	%†	95%CI	%†	95%CI	%†	95%CI	%†	95%CI	%†	95%CI	%†	95%CI
Request child/ opinion parents												
- Explicit request of child, parents agree	60	47-71	57	45-69	‡		84	72-91	84	73-91	‡	
- Inexplicit request of child, parents agree	52	39-64	48	36-61	49	27-91	90	78-95	90	79-95	85	73-92
- No request of child, request of parents	37	25-49	42	30-54	39	36-61	84	71-90	84	73-91	78	65-86
- Explicit request of child, parents do not agree	28	18-41	13	07-24	‡		73	57-80	73	58-81	‡	

* Three pediatricians did not answer questions about the 10 hypothetical cases; 1 pediatrician answered questions about only 4 of the 10 hypothetical cases
† Percentages are weighted for non-response and sampling fraction of the pediatricians
‡ Not asked

Table 6.4 Influence of case characteristics of 10 hypothetical cases on willingness of pediatricians (n = 60) to use lethal drugs or increase morphine

Case characteristics‡	Categories	N_{cases}=594*	Willingness to use lethal drugs† OR	95%CI	Willingness to increase morphine† OR	95%CI
- Age (y)	15	240	1		1	
	11	236	0.49	0.24-1.01	0.84	0.32-2.20
	6	118	0.57	0.23-1.43	0.16	0.04-0.60
- Child's request	Explicit request	238	1		1	
	Inexplicit request	178	0.23	0.08-0.67	5.92	1.33-26.4
	No request	178	0.05	0.02-0.16	0.85	0.23-3.11
- Parents' opinion	Agreement/ request	475	1		1	
	No agreement/ no request	119	0.01	0.00-0.02	0.04	0.01-0.17

* Total of all hypothetical cases; 3 pediatricians did not answer the questions about the hypothetical cases; 1 pediatrician answered questions about only 4 of the 10 hypothetical cases
† All answers were dichotomized; the answers ''yes'' and ''probably'' were considered to be ''willing to use lethal drugs or increase morphine''
‡ Multivariate logistic regression analysis; respondent number is included in the model to control for repeated measures of the pediatrician; first category of each variable is the reference category. For example, the OR for willingness to use lethal drugs in case of an inexplicit request of a child as compared with an explicit request of a child is 0.23 (95% CI, 0.08-0.67). This means that physicians were significantly less willing to use lethal drugs when the child made an inexplicit request as compared with a case in which the child made an explicit request

Table 6.5 Percentage of pediatricians and other physicians who would use lethal drugs or increase morphine for a 15-year-old child

	Pediatricians N=60*		General practitioners N=120*		Clinical specialists N=198*		Total N=378		
	%†	95%CI	%†	95%CI	%†	95%CI	%†	95%CI	P ‡
Use lethal drugs									
- Request of child, parents agree	60	47-71	58	49-67	54	47-61	57	52-62	0.67
- No request of child, request of parents	37	25-49	23	16-31	27	21-33	26	22-30	0.08
Increase morphine									
- Request of child, parents agree	84	72-91	84	76-90	81	75-86	83	79-87	0.71
- No request of child, request of parents	83	71-90	85	77-90	87	82-91	85	81-89	0.68

* Three pediatricians, 5 general practitioners, and 10 clinical specialists did not answer the questions about hypothetical cases
† Percentages are weighted for non-response and sampling fraction of the physicians
‡ Pearson chi-square test

Table 6.6 Percentage of pediatricians and other physicians who agreed with statements on the use of lethal drugs in children

	Pediatricians N=63		General practitioners N=125		Clinical specialists† N=207		Total N=395		
	%*	95%CI	%*	95%CI	%*	95%CI	%*	95%CI	P ‡
1. Euthanasia is acceptable for children who are able to assess their interests	75	63-84	67	59-75	63	56-69	67	62-71	0.24
2. For a child younger than 12 years, euthanasia is never acceptable	13	6-23	17	11-25	14	10-20	15	12-19	0.63
3. It must be allowed to grant a request for euthanasia of incurably ill children in the age group 12-16 without permission of the parents	40	20-43	28	21-36	28	22-34	30	25-34	0.17
4. If parents of a child who is not able to value his or her interests think their child suffers unbearably and hopelessly, active ending of life is acceptable	68	56-78	45	36-53	43	36-49	47	43-52	<0.01

* Percentages are weighted for non-response and sampling fraction of the physicians
† One clinical specialist did not address the statements
‡ Pearson chi-square test

Differences between physicians

For the hypothetical case of a 15-year-old child who requested ending of life, with which the parents agreed, pediatricians were willing as often as general practitioners and clinical specialists to use lethal drugs (54%-60%; table 6.5). When parents requested ending of life of their 15-year-old unconscious child, pediatricians were somewhat more often (37%) willing to use lethal drugs than general practitioners (23%) and clinical specialists (27%). There was no difference between pediatricians, general practitioners, and clinical specialists in the willingness to increase morphine (81%-87%). Most pediatricians, general practitioners, and clinical specialists thought that euthanasia is acceptable for children who are able to assess their interests (67%; table 6.6). A minority felt that euthanasia is never acceptable for children younger than 12 years (15%). Pediatricians more often (40%) agreed with the statement that children's requests for euthanasia can be granted without permission of the parents than general practitioners (28%) or clinical specialists (28%). Further, pediatricians more often (68%) agreed with the statement that active life-ending can be acceptable when parents think their child suffers unbearably than general practitioners (45%) or clinical specialists (43%). Female physicians were less often willing than male physicians to use lethal drugs at the request of either the child (OR, 0.43; 95% CI, 0.26-0.73) or the parents (OR, 0.58; 95% CI, 0.31-1.10); female physicians also more often agreed with the statement that euthanasia is never acceptable for children aged younger than 12 years (OR, 2.10; 95% CI, 1.10-4.00; not in table). Religious physicians were also less often willing to grant a request for euthanasia of a child than non-religious physicians (OR, 0.46; 95% CI, 0.30-0.70). Further, religious physicians less often agreed with the first and third statement of table 6.6 on acceptability and allowance of euthanasia in children (OR, 0.47; 95% CI, 0.31-0.72; OR, 0.42; 95% CI, 0.26-0.67, respectively) and more often agreed with the second statement on unacceptability of euthanasia for children younger than 12 years (OR, 2.83; 95% CI, 1.61-4.99).

Discussion

A substantial proportion of Dutch pediatricians is willing to use lethal or potentially life-shortening drugs in children, including when legal conditions are not met. Whether parents agree is a more important factor in the decision-making process of pediatricians than whether the child requests ending of life or the age of the child. Pediatricians are more willing than general practitioners and clinical specialists to grant a request from parents for ending of life of their unconscious child. Female pediatricians and religious physicians are less willing to use lethal or potentially life-shortening drugs, as found in other studies.[3,4,21,22]

Some limitations of our study should be kept in mind. Concise information about the hypothetical cases can lead to differences in interpretation of the respondents. End-of-life practice is often more complex than is presented in the hypothetical cases, and there might be barriers to performing intended behavior in practice. Therefore, physicians may act differently in practice. Possible differences in interpretation were minimized by instructing the interviewers not to give additional information and enabling respondents to explain their answers.

In general, there are no indications that the practice of end-of-life decision-making has significantly altered in the last 10 years, during which a regulatory system was developed.[1,3] For children, we do not know whether the new Dutch law on euthanasia is a regulation of existing practice or whether it will expand the practice of euthanasia.

The rules on euthanasia for children 12 years or older imply a legal recognition of the competence of children to form an opinion and make a well-considered request, albeit with the parents' agreement. Our study shows that pediatricians did not distinguish between the explicit request of a 15-year-old child and that of an 11-year-old child, provided that parents agree with the decision. In both cases, more than half the pediatricians were willing to use lethal drugs. However, when parents do not agree with the explicit request of the child, the willingness to use lethal drugs substantially decreases, especially for 11-year-old children. Further, most physicians find euthanasia acceptable for children with decision-making capacity and think that euthanasia can be acceptable for a child younger than 12 years. Thus, although the age of 12 years does not seem to be regarded as a clear cutoff for the capacity of a child to be involved in end-of-life decision-making, physicians tend to weigh the opinion of parents more heavily in children younger than this age. The opinion of the parents in decision-making has also been found to be important elsewhere, but opinions about age cutoffs for capacity of children to participate in the decision-making have not been clearly studied.[7,9,15,19,23]

Ending of life without an explicit request of the child remains legally prohibited in the Netherlands. However, when parents agree with the inexplicit request of their child to be allowed to quietly fall asleep, about half the pediatricians are willing to use lethal drugs, and when parents request ending of life for their unconscious child, more than one third of pediatricians are willing to do so. Apparently, a substantial number of pediatricians is willing to use lethal drugs even when not all legal conditions are met.[15,16] However, general practitioners and clinical specialists are more reluctant than pediatricians to use lethal drugs in an unconscious child when the parents request it. Thus, they seem to attach more importance than pediatricians to the legally required

request of the patient. Pediatricians may feel that relief of suffering also justifies ending the life of children with decision-making incapacity when their suffering is unmitigated.[5] Further, pediatricians may be more familiar than other physicians with discussing important medical decisions with parents who decide for their child.[7,9,18,19] The answers of other physicians are probably based more often on a theoretical perspective or abstract principles.

Remarkably, pediatricians are more often willing to use potentially life-shortening drugs for a child who asks to be allowed to quietly fall asleep than for a child who explicitly requests ending of life. The child's request to quietly fall asleep is apparently more often interpreted as indicating a need to be relieved of pain or other symptoms, for instance by sedation, than as a request for ending of life. Further, most pediatricians and other physicians are willing to increase morphine for all hypothetical cases. Because all case descriptions indicated that the pain was severe and could not be controlled with morphine, the goal of increasing morphine can be questioned. Although some respondents might have thought that increasing morphine (or another narcotic analgesic) could further relieve pain, it is likely that the possible effect of hastening death is appreciated by many of the physicians who are willing to increase morphine. Whether such practices can be justified is doubtful,[24-26] especially when dosages are increased without taking notice of the degree of symptom relief. To what extent the use of potentially life-shortening drugs represents good end-of-life care or should be seen as an option to avoid the illegal practice of the use of lethal drugs remains to be discussed.[6,27]

Conclusion

A substantial proportion of Dutch physicians is willing to use lethal drugs in children at different ages. The finding that general practitioners and clinical specialists are less willing than pediatricians to grant a parental request for ending of a child's life suggests that for them the legally required patient's request is a more important condition than it is for pediatricians. Further, the legal rule in the Dutch law on euthanasia that ending life at the request of a child 12 years or older is allowed when parents agree is more consistent with views of physicians than the rule that it is not allowed for children younger than 12 years.

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7

Regulating physician-assisted dying for minors in the Netherlands: views of paediatricians and other physicians

Abstract

Objective. In 2002, the Dutch Euthanasia Act came into effect, which made euthanasia available to individuals from the age of 12 and up. The objective of our study was to gain insight into how Dutch paediatricians and other physicians treating children feel about the way physician-assisted dying is regulated in the Netherlands.

Methods. We interviewed 63 paediatricians, 125 general practitioners and 208 clinical specialists about their views on physician-assisted dying and the effect of the Euthanasia Act.

Results. Of the paediatricians, 44% agreed with the age limit of 12 years and over, and 52% agreed with the requirement that parents be involved. Somewhat more than half thought the Act could contribute to the disclosure of end-of-life practices (52%), the quality of the review procedure (61%), careful decision-making (54%), and the reporting rate (65%). These percentages were comparable for other physicians. A minority of the physicians in all three groups indicated that, with this Act in place, they would be more willing to report such practices. The most optimistic in this respect were the paediatricians, of whom 39% expected such an effect.

Conclusion. About half of the Dutch paediatricians support the age limits and rules on parental involvement. Furthermore, about half expect the Euthanasia Act to achieve its aims, which is the same percentage as was found for the other two groups of physicians. However, the majority of physicians in all three groups do not foresee any increase in their willingness to report cases of physician-assisted dying.

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Introduction

The Netherlands is the first country to regulate the practice of euthanasia and physician-assisted suicide is regulated. The Euthanasia Act defines euthanasia as the administration of drugs by a physician with the intention of hastening the death of the patient at his or her explicit request. Physician-assisted suicide is defined as the prescription or supply of drugs by a physician with the explicit intention of enabling the patient to end his or her own life.

In 1994, the first review procedure officially came into effect. The goals of this procedure were to stimulate disclosure of cases, verifiability, and adherence to the requirements for prudent practice. These requirements were as follows: the patient must have made a voluntary and well-considered request; the patient is suffering irremediable and unbearable pain; all treatment options have been exhausted; the opinion of a second physician has been sought; and the euthanasia death must be performed in a medically appropriate fashion. Physicians were required to report cases of physician-assisted dying as an unnatural death, and a public prosecutor judged whether the requirements for prudent practice had been met. From 1998, physicians had to report cases of euthanasia or physician-assisted suicide to one of five Regional Review Committees instead of the Public Prosecutor. These committees, consisting of a lawyer, an ethicist and a physician, reviewed reported cases and advised the Assembly of Prosecutors General whether the requirements for prudent practice had been followed carefully. In April 2002, the 'Ending of Life on Request and Assisted Suicide Review Procedures 2001 Act'[1], also called the Euthanasia Act, came into effect. Since that time, euthanasia and physician-assisted suicide have been legally allowed, provided that the requirements for prudent practice, which remained unchanged, are met. Under this Act, Regional Review Committees are entitled to make the final judgment; only cases in which the Committee has judged that the requirements failed to be met are submitted to the Assembly of Prosecutors General.[2]

The Euthanasia Act includes provisions regulating the situation around physician-assisted dying for minors for the first time. Under this Act, a request for euthanasia and physician-assisted suicide of minors aged 16 or 17 years-old may be granted if their parents are involved in the discussion. Minors aged 12 to 16 are able to demand euthanasia or physician-assisted suicide, but this may be performed solely with their parents' consent. Euthanasia and physician-assisted suicide are illegal for children under age twelve. Previously, neither the requirements for prudent practice nor jurisprudence had offered any guidance on possible age limits. These legal age limits are based upon the age limits in the Dutch Medical Treatment Contract Act (WGBO), where 12 to 16-year-old children can make treatment decisions with the parents'

agreement. However, no parental consent or involvement is required for treatment decisions made by children aged 16 or up.

It is a fact that a substantial group of Dutch physicians is willing to end the life of a severely ill child with drugs at his or her the request, especially when the parents agree with the decision.[3] The extent to which paediatricians support the Euthanasia Act is unknown. Furthermore, it is unclear whether paediatricians share the same attitudes towards end-of-life decision-making and the Euthanasia act as their colleagues in other specialties, who may be more familiar with the practice of euthanasia due to their experiences with end-of-life decision-making for adults.

The objective of our study was therefore to gain insight into the views of Dutch paediatricians on physician-assisted dying and on the age limits and effects of Euthanasia Act. We compared these views with those of clinical specialists and general practitioners.

Methods

Data for this study were collected during interviews with paediatricians, clinical specialists, and general practitioners, in which these physicians were questioned about their experiences with and attitudes towards end-of-life decision-making practices. All physicians had worked for at least two years for at least 50% of their time in their current practice. Data were collected between March and December 2002, at the time of introduction of the Euthanasia Act.

Paediatricians

The sample of paediatricians consisted of physicians in specialties involving the majority of deaths in children: paediatrician-oncologists and haematologists, paediatrician-intensivists, and paediatric neurologists. Paediatrician-oncologists/haematologists and paediatrician-intensivists work exclusively at departments within the eight university hospitals in the Netherlands. Half of the physicians were randomly selected from each department. At departments employing only one or two physicians, all were selected. As paediatric neurologists also work in hospitals other than university hospitals, their sample was drawn from their professional registry. Half of the paediatric neurologists at each hospital were randomly selected, unless the hospital employed only one or two paediatric neurologists, in which case, all were selected. In the Netherlands, paediatric neurologists have often trained as neurologists. Throughout this paper, we will refer to paediatric neurologists as paediatricians, for the purpose of better readability. Of in total 98 eligible paediatricians, 69 were asked to be interviewed: 63 agreed (27 paediatric

oncologists/haematologists, 18 paediatric intensivists, and 18 paediatric neurologists; response rate: 91%).

Clinical specialists, and general practitioners

We also interviewed random samples of clinical specialists (cardiologists, surgeons, and specialists in internal medicine, pulmonology, and neurology), and general practitioners. We selected addresses from the professional registries. Of the 403 physicians who were asked to be interviewed, 333 agreed (208 clinical specialists, and 125 general practitioners; response rate: 83%).

Opinions and statements

We started this part of the interview with an explanation about the new Euthanasia Act and it's the specific provisions in the Act pertaining to children. Subsequently, all respondents were asked whether they expected the Act to contribute to the quality of the review procedure and to physicians' willingness in general and their own willingness, in particular, to report cases. Paediatricians were asked specific questions about the rules for minors. Furthermore, they were asked to indicate, on a 5-point Likert scale, whether they agreed with several statements on physician-assisted dying. (totally agree; agree; neither agree nor disagree; disagree; totally disagree).

Analyses

All answers were dichotomized into 'agree' ('totally agree' and 'agree') and 'not agree' (neither agree nor disagree; disagree; totally disagree). The total percentages were weighted for differences in the sampling fractions in the sub-groups of the physicians. We used the Chi-Square test to test the differences between paediatricians, clinical specialists, and general practitioners in sex, religion, age, and years of experience. The Kruskal Wallis test was used for differences in opinions about the effect of the Act according to physician characteristics (specialty, sex, religion, age, and years of experience). Multivariate logistic regression analyses were done to assess the influence of physician characteristics (specialty, sex, religion, age, and years of experience, all included in one model) on their opinions on the statements.

Results

Physician characteristics (Table 7.1)

Of all paediatricians, 38% were female; this percentage was lower for clinical specialists (15%) and general practitioners (21%). Forty-four percent of the paediatricians indicated that they belonged to a religious group or adhered to a certain philosophy of life, which percentage was comparable to the other physicians. Paediatricians (57%) and clinical specialists (63%) were less likely to be over age 45

than general practitioners (73%). In addition, paediatricians (47%) and clinical specialists (49%) less often had over 15 years of experience than general practitioners (58%).

Table 7.1 Characteristics of paediatricians, clinical specialists, and general practitioners

	Paediatricians N=63		Clinical Specialists N=208		General practitioners N=125		
	N	(%*)	N	(%*)	N	(%*)	P†
Female‡	24	(38)	31	(15)	26	(21)	<0.01
Religious§	28	(44)	96	(47)	40	(34)	0.07
Age <45 yr**	27	(43)	76	(37)	32	(27)	0.04
Years of experience <15 yr**	33	(53)	101	(50)	45	(38)	0.04

* Percentages are weighted for non-response and sampling fraction of the physicians
† Pearson Chi Square test
‡ Information on sex was missing for 1 general practitioner
§ Information on religion was missing for 1 paediatrician, 6 clinical specialists, and 8 general practitioners
** Information on age and years of experience was missing for 5 clinical specialists and 7 general practitioners

Opinions about the effect of the Euthanasia Act (Table 7.2)

About half of the paediatricians indicated that the Act might contribute to their willingness to be open about their practices, and to the quality of the review of reported practices. This percentage was similar for clinical specialists and general practitioners. The different opinions of paediatricians may be elucidated by two quotations. One paediatrician who supported the Act said: '*It is better to be open about Euthanasia, and to review these cases than to do it in secret*.' Another paediatrician who did not support the Act indicated: *'When reviewing these cases, it is very difficult to take into account the quality of life of the child, the emotional development of the child, and the opinion of the parents*.' While most paediatricians, clinical specialists and general practitioners thought that the willingness of colleagues to report cases of physician-assisted dying would increase as a result of the Act, this did not apply to their own willingness to be more open. However, paediatricians expressed the opinion that their own willingness to report instances of physician-assisted dying would increase more often (39%) than did the clinical specialists (19%) and the general practitioners (13%).

Table 7.2 Opinions of paediatricians, clinical specialists, and general practitioners about the Euthanasia Act*

	Paediatricians N=62		Clinical specialists N=205		General practitioners N=125		
	N	(%†)	N	(%†)	N	(%†)	P‡
Act contributes to:							
- Physicians' willingness to be open about their practices							0.44
- Yes, considerably	14	(22)	58	(29)	30	(24)	
- Yes, only for >12yrs§	19	(30)	-	-	-	-	
- Yes, somewhat§	-		89	(45)	56	(45)	
- No	17	(26)	41	(20)	27	(22)	
- Do not know	12	(20)	17	(7)	12	(10)	
- Quality of the review of reported practices							0.46
- Yes, considerably	10	(16)	63	(32)	32	(26)	
- Yes, somewhat	29	(45)	68	(33)	50	(40)	
- No	13	(23)	54	(27)	36	(29)	
- Do not know	10	(16)	20	(9)	7	(6)	
- Careful decision-making							0.92
- Yes, considerably	10	(16)	46	(22)	33	(26)	
- Yes, somewhat	24	(38)	47	(23)	28	(22)	
- No	25	(42)	96	(47)	58	(46)	
- Do not know	3	(5)	16	(8)	6	(5)	
- Increasing reporting rate							0.49
- Yes, considerably	12	(19)	46	(23)	27	(22)	
- Yes, somewhat	28	(46)	101	(50)	57	(46)	
- No	13	(22)	40	(19)	30	(24)	
- Do not know	9	(13)	18	(9)	11	(9)	
- Own willingness to report**							<0.01
Increase	24	(39)	38	(19)	15	(13)	
Does not change	35	(57)	162	(80)	103	(87)	
Decrease	1	(2)	2	(1)	1	(1)	

* The answers of 1 paediatrician-oncologist, and 3 clinical specialists are missing
† All percentages are weighted for non-response and sampling fraction
‡ Specialty compared with Kruskal-Wallis test, 'Do not know' not included in analysis
§ 'Above 12 years of age' for paediatricians and 'somewhat' for other physicians
** Own willingness to report of 6 general practitioners missing

Opinions of the paediatricians about the Euthanasia Act

Forty-four percent of the paediatricians agreed, 29% neither agreed nor disagreed, and 27% did not agree with the age limits in the Euthanasia Act. About half of the

paediatricians, whether they agreed or not, thought that the age limits were arbitrary and that all cases needed to be considered individually. In the words of one paediatrician : *'It depends very much on the situation, how 'grown-up' the child is given the situation. A 10-year old child can sometimes make a well-considered decision'*. Fifty-two percent agreed, 22% neither agreed nor disagreed, and 25% did not agree with the rule that parents have to agree with the euthanasia of the child. Nine of the respondents in favour of the age limits felt that that it was important to strive for consensus, four respondents considered it is a right of parents or parents are responsible for their child. Another four held that parents had to be able to live on after the death of their child. On the other hand, nine respondents opposed the age limits on the grounds that children should have the right or be considered capable of deciding for themselves. One paediatrician said: '*15-year olds are in general capable of deciding for themselves, and we discuss the decision with each other to try to come to agreement with all involved'*. Most paediatricians had not changed their opinion about euthanasia in the preceding 5 years, but 21% of the paediatricians had become more permissive with respect to granting a request of a child, and 2% had become more restrictive.

Table 7.3 Paediatricians and other physicians who agree or totally agree with statements concerning physician-assisted dying

	Paediatricians N=63		Clinical specialists* N=206		General practitioners N=125	
	N	(%†)	N	(%†)	N	(%†)
- People have the right to decide about their own life and death.	45	(72)	121	(60)	67	(54)
- An increasing number of people consider assistance in dying as a right.	46	(71)	157	(75)	96	(77)
- Every health care institution has to open about its attitude concerning assistance in dying.	46	(72)	166	(80)	103	(82)
- Substantial economic constraints in health care will increase the pressure on physicians to provide assistance in dying. ‡	5	(7)	22	(11)	20	(16)
- When euthanasia is not legally forbidden anymore, the number of cases of euthanasia will increase.	21	(32)	53	(24)	31	(25)

* Answers of 1 clinical specialist are missing
† All percentages are weighted for sampling fraction
‡ One answer general practitioner is missing

Statements on physician-assisted dying (Table 7.3)

Most paediatricians supported the statement that people have the right to decide about their own life and death (72%), that an increasing number of people consider assistance in dying as a right (71%), and that all health care institutions should be open about their attitudes towards assistance in dying (72%). A small minority of the paediatricians thought that substantial economic constraints in health care would increase the pressure on physicians to provide assistance in dying (7%), and a larger minority felt that the number of cases of euthanasia would rise if euthanasia were no longer illegal (32%). The two other groups, i.e., those of the clinical specialists and the general practitioners, mainly differed from the paediatricians on the statement that people have the right to decide about their own life and death: of the clinical specialists, only 60% and of the general practitioners, a mere 54% agreed with this statement (overall p=0.02).

Differences in opinions by physician characteristics

When we tested difference in opinions on the effects of the Euthanasia Act (see table 7.2) looking at other characteristics than specialty, we found that female physicians were less positive about the effects of the Act, and about their own willingness to report euthanasia cases than male physicians. Further, physicians aged 45 years and up and experienced physicians were more positive about the effect of the Act on the quality of the review of reported cases than were other physicians.

When we tested whether there are predictors of the opinions of physicians about the statements (see table 7.3), we found that female physicians less often felt that all health care institutions needed to be open about their attitudes towards assisted-dying than male physicians, and were less afraid that the number of euthanasia cases would increase as euthanasia was no longer illegal. Furthermore, religious physicians were less likely to agree that people have the right to decide about their own life and death than non-religious physicians. Finally, older physicians agreed less often than younger physicians with the statement that an increasing number of people consider assistance in dying a right. In addition, they more often agreed that the pressure on physicians to provide assistance in dying would increase, in the event of substantial economic constraints in health care.

Discussion

Paediatricians were divided about the rules on minors in the Euthanasia Act and about the effects of the Act. Their opinions on statements on assistance in dying hardly differed from those of the clinical specialists and general practitioners. Female physicians, younger physicians and religious physicians expressed less support for the

Act or assistance in dying, a finding which has also been borne out by other studies in this field.[3-7]

Previously, it has been shown that a minority of paediatricians in the Netherlands have received any request for euthanasia from a child.[8] The finding that not all paediatricians expect the Euthanasia Act to achieve its aims may partly be attributable to their doubt whether it is possible to review cases of euthanasia in children or to the fact that children rarely request for euthanasia. It may also be attributable to the general acceptance of the rules for prudent practice prior to this Act coming into effect. In that case, the Euthanasia Act contributes nothing to prudent practice, as it merely regulates existing practice. The majority of Dutch physicians were quick to recognize the importance of the aims of the review procedure, which are similar to those of the Euthanasia Act.[2] However, the finding that some three-quarters of the paediatricians feel that every health care institution should be required to be open about its attitude towards assistance in dying is an indication that paediatricians consider such openness as valuable, irrespective of their support for the Euthanasia Act.

The age limits in the Euthanasia Act do not seem to be supported by all paediatricians. Some feel that the 12-year age limit is an arbitrary choice. A child's decision-making capacity is also determined by other factors, such as the degree to which a child is cognizant about its disease, the child's intelligence, and how well the child is capable of assessing the situation and making a decision.[8,9] Furthermore, according to the Act, the parents' opinion has to be taken into account. However, some physicians indicate that children can sometimes be capable of deciding themselves. Nevertheless, paediatricians consider the opinion of parents to be very important in the decision-making at the end of the child's life.[3,11]

About 70% of paediatricians thought that people are entitled to decide about their own life and death, but only somewhat more than half of general practitioners and clinical specialists did so. Dutch general practitioners, clinical specialists, and nursing home physicians supported this statement less strongly compared to 1995, when about 65% of the physicians agreed with this standpoint.[10] The introduction of the Euthanasia Act may lead to the idea among the general public that they have a right to assistance in dying, since 55% of the Dutch population agreed with the statement that physicians should no longer be permitted to refuse well-considered requests for euthanasia when carefully performed euthanasia is no longer punishable.[2] There is however no legal right to euthanasia or physician-assisted suicide. Because of the insistence on this supposed right, physicians may well have adopted a more restrictive stance towards requests for euthanasia compared to 1995.[10] Paediatricians, on the other hand, were

by no means more restrictive towards granting requests for euthanasia. On the contrary, 20% of them had become more permissive, probably because children only seldom request euthanasia. Paediatricians are therefore relatively infrequently confronted with this supposed patients' right .[11]

The majority of the physicians did not expect their readiness to report cases to grow, a finding that could be explained by the fact that, in general, the Act is merely an official regulation of the practice. However, at no time did the requirements for prudent practice and jurisprudence provide guidance on the practice of euthanasia on children. The new Act lays down specific provisions for children for the first time. This will probably increase the willingness to report cases of paediatrician-assisted dying.

In general, the Euthanasia Act would appear to be acceptable to paediatricians, clinical specialists and general practitioners. Citing the 'slippery slope argument', some expect this relatively liberal view on euthanasia in the Netherlands, and legislation of euthanasia, to lead to a higher number of euthanasia cases. However, the number of cases of euthanasia has remained more or less stable between 1995 and 2001.[10] Moreover, most of the paediatricians, clinical specialists, and general practitioners do not expect the number of euthanasia cases to rise. Nevertheless, whether or not the enactment of the Euthanasia Act and the formulation of the rules on minors will expand the practice of euthanasia for either adults or children remains to be seen.

Some limitations of our study have to be taken into account. Firstly, in interpreting the results of our study, it should be kept in mind that physicians had no experience with the Act, as we interviewed the physicians in 2002. Whether their opinions reflect how they behave in practice is unknown. Secondly, although the response was high and the privacy procedure was extensive, it cannot be ruled out that our results are biased due to non-response. Thirdly, the views on euthanasia and euthanasia legislation in the Netherlands may be less accepted in other countries.[5,6,12] However, studies on the opinions of Dutch paediatricians and other physicians about euthanasia legislation might contribute to discussions about end-of-life decision-making elsewhere.

Conclusion

About half of Dutch paediatricians support the rules for prudent practice and the Euthanasia Act. The Euthanasia Act seems to be as acceptable for them as for other physicians. The finding that paediatricians, more often than other physicians expected their willingness to report euthanasia cases to increase may be a result of the formulation of the rules on minors. Whether or not the Act has changed clinical practice remains to be evaluated.

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Part V

General discussion

8

General discussion

Introduction

The objective of this thesis was to describe the practice of end-of-life decision-making for neonates and infants and for children beyond the neonatal period in the Netherlands, and to describe the attitudes of physicians on assistance in dying in children and opinions on the euthanasia act. This chapter will examine the main results of the thesis.

First, the strengths and weaknesses of the studies will be mentioned, after which the following research questions will be discussed:

1. How often are end-of-life decisions made and what are the characteristics of end-of-life decision-making in neonates and infants?
2. How did the Dutch practice develop over time, and is it different from Belgium?
3. How often are end-of-life decisions made in older children and what are characteristics of the decision-making process?; and
4. What are the attitudes of paediatricians and other physicians towards assisted death in children and what are their opinions about the Euthanasia Act?

Following, the implications for health policy will be given. Recommendations for further research will be provided in the last paragraph.

Strengths and weaknesses

Strengths

Many efforts were applied to ensure that the studies presented in this thesis yielded valid and reliable data. An extensive privacy procedure was used to rule out any legal consequences for the respondents. In addition, the Dutch Health Care Inspectorate and the Royal Dutch Medical Association supported the study, which was communicated to all physicians in the Netherlands in writing.[1] Further, experienced physicians who were trained in using the structured questionnaire conducted the interviews with the paediatricians and the interviews were evaluated with a researcher to promote unambiguous interpretations. Moreover, the response rates of all studies were high and the data can therefore be considered to be representative for a large part of Dutch neonatal and paediatric care. Finally, it should be noted that the validity of the death certificate questionnaire has been previously shown in several studies.[2-6]

Weaknesses

Because of the small number of infant deaths, the power of the death certificate studies to detect significant differences was restricted (chapter 2 and 3). Further, the interview study was not fully representative for the entire population of physicians who may take end-of-life decisions for children, because physicians who are rarely involved with dying children were not interviewed. In addition, no firm comparisons could be drawn between the different specialties of paediatricians that were interviewed, as the numbers were small. Moreover, paediatricians in the Netherlands have been shown to demonstrate a more liberal attitude towards using lethal drugs in children than paediatricians in other countries.[7-9] Therefore, these results cannot be simply generalized to other countries. Finally, because we studied the practices and attitudes of physicians, this does not imply that conclusions can also be drawn about the attitudes of other health care professionals, parents or children themselves towards end-of-life practices in children. There have been various studies that have shown that the opinions of physicians do not necessarily reflect the opinions of the other parties involved.[8,10-12]

End-of-life decision-making for neonates and infants

The Dutch practice

Our study showed that in 2001, the practice of end-of-life decision-making for neonates and infants had remained stable compared to 1995. (Chapter 2) The total number of end-of-life decisions increased slightly, but not significantly, from 62% of all deaths in 1995 to 68% in 2001. End-of-life decisions were mainly motivated by the absence of any chance of survival, although a slight shift was seen towards an extremely poor prognosis for future life. Decisions were discussed in virtually all cases with the parents and with colleague-physicians, an increase of more than 15% compared to 1995 when such discussions occurred in about 80% of these cases.

Apparently, the number of end-of-life decisions hardly changed between 1995 and 2001. The influence of background developments could have been obscured because of their opposite effects. Several developments could have been expected to result in an increase in end-of-life decisions. Firstly, women tend to get pregnant at an older age, which is associated with more congenital abnormalities.[13,14] Additionally, at a higher age, women more often need assistance to get pregnant, for example by hormone therapy or in vitro fertilisation.[14] These therapies can lead to complications, for instance due to multiple foetuses resulting in premature or immature newborns and an increased risk of multiple morbidities.[14-17] Further, it is sometimes argued that the societal debate about active ending of life can lead to an increase in the number of such cases. Finally, advances in neonatal intensive care have increased the

possibilities to treat severely ill newborn infants,[14,18] which can have a positive or negative effect on morbidity and can therefore lead to an increase, as well as a decrease, in the occurrence of end-of-life decisions.

International perspective

Comparing the Netherlands with other countries shows that end-of-life decision-making practices are not exclusive for the Netherlands. The fact that in several European countries, most neonatologists engage in end-of-life decision-making other than the active ending of life, was already known.[7] Only in France and the Netherlands did a substantial group of neonatologists admit to having been involved at some time in the active ending of life. The present thesis has shown that similar percentages of end-of-life decisions were made in the Netherlands and Belgium, although the number of times possible life-sustaining treatment was withdrawn was slightly higher in the Netherlands.[19, 20] (Chapter 3) Although there was hardly any difference in the number of end-of-life decisions between Belgium and the Netherlands, there were differences in the characteristics of the decision-making. In Belgium, decisions were discussed in about 80% of all cases with the parents and colleague-physicians. This number is lower than the number of the Dutch 2001 study, but comparable with the Dutch number in 1995.[6] (Chapter 2) Moreover, decisions to administer drugs with the explicit intention of hastening death more often seemed to be made at an earlier stage in the Netherlands than in Belgium, as evidenced by the fact that the Dutch physicians more frequently estimated life to have been shortened by more than a week. The Dutch societal debate may have led to more clarity about the decision-making process compared to Belgium, where there was less debate on end-of-life decision-making at the time of the study. This clarity may have resulted in Dutch physicians being less reluctant to make end-of-life decisions.

Opinions on viability and on when to take end-of-life decisions in premature newborns were shown to differ between countries. In the Netherlands, children born at 24 weeks of gestation are usually not treated, whereas in other countries treatment is sometimes started even at younger ages.[21,22] A study among neonatologists from eleven European countries revealed that opinions also varied on whether resuscitation should be started for a baby born after 24 weeks of pregnancy and a birth weight of 560 grams.[8] Except for the Netherlands, physicians in most countries indicated they would, indeed, resuscitate this baby and start intensive care. However, in the case of the subsequent deterioration of the child's clinical condition due to severe intraventricular haemorrhage, attitudes diverged: in some countries, most neonatologists would then favor continuation of intensive care, whereas in other countries some form of limitation

of treatment would be the preferred type of management. However, it can be questioned whether differences in opinions also lead to differences in practice.

It has been suggested that the relatively high neonatal mortality rate in the Netherlands as compared to some other European countries may be explained by the Dutch practice of end-of-life decisions.[23-25] However, differences in the medical management of pregnancy must be taken into account when discussing this issue. Pregnancy termination practices differ between countries, which might result in differences in the number of severely ill newborns. In the Netherlands, prenatal serum screening for Down's syndrome and neural tube defects was only offered routinely to women from 36 years or older, and only on indication or request to other pregnant women.[26] Furthermore, there is no systematic offering of ultrasound with which possible morphologic abnormalities can be found, while in other countries, the standard procedure is to offer prenatal screening to all pregnant women in the first or second trimester of gestation.[24] It may be argued that on the basis of this procedure serious congenital abnormalities can be detected more often at an earlier stage of gestation, resulting in more early terminations of pregnancy.[23-25] Secondly, policies on termination of pregnancy differ, which may affect the frequency with which pregnancy terminations are performed too. In the Netherlands, for example, pregnancies may be terminated only up to 24 weeks of gestational age, that is, before the age at which viability is held to be reached. Performed after this period, the termination is required to be reported as non-natural death.[27-29] In the United Kingdom, the Abortion Act allows termination of pregnancy under specific conditions at any gestational age.[28,30]

If fewer pregnancies are terminated, more severely ill children may be expected to be born in the Netherlands. There may, therefore, simply be more cases in which an end-of-life decision needs to be considered.

Initiating the decision to hasten death

We found that in most cases where drugs aimed at hastening death were used, this was done at explicit request of parents, both in the Netherlands and in Belgium. This holds for only one third of the rest of the end-of-life decisions. It is claimed that when a physician decides to withdraw treatment in a severely ill patient who suffers hopelessly and unbearably, but the patient does not die, it is the physician's responsibility to take the next step to end the life of the patient with the help of drugs.[31] However, our data show that physicians often do not want to initiate such a decision, possibly because they feel it is not part of their medical-professional domain. It is known that the decision to use drugs aimed at hastening death is not made on medical grounds only, but that other factors also play a role. The decision to end the life of a severely ill child is definitive and irreversible and can therefore place an onerous burden on physicians. Most physicians oppose such decisions, for reasons such as their moral life stance,

religious background or fear of conviction.[32-36] Such opposition can recede somewhat, when parents explicitly request for the hastening of the death of their child. In such cases, physicians may become willing to end the suffering of the child. (Chapter 3)

End-of-life decision-making for children beyond the neonatal period

In 36% of all deaths of children from one to 17 years old, one or more end-of-life decisions were made. (Chapter 4) In children who die after the neonatal period, the frequency of end-of-life decisions was much lower than in neonates and infants, (Chapter 2) and also somewhat lower than in adults.[37] This lower percentage was partly due to the higher number of sudden and unexpected deaths in this age group. Still, even when the percentage of end-of-life decisions is calculated only on the basis of non-sudden deaths, the percentage of end-of-life decisions for children from one to 17 years old was still lower than for neonates and infants and adults (61%, compared to 66% for adults, and 85% for neonates and infants). Apparently, suffering and perspectives due to congenital and perinatal problems, relatively often lead to end-of-life decision-making. The somewhat lower number of end-of-life decisions for children compared to adults was due to a lower number of non-treatment decisions (12% compared to 20% of all deaths). It appears that in children, physicians more often continue to give all treatments until no treatment option is left. The frequency of decisions to alleviate pain and symptoms was similar for children and adults, which is an indication that choices that are made concerning the relief of suffering for children and adults are comparable.

Some 3% of all deaths, both of children and adults, involved cases in which life had been ended.[1,37,38] However, the percentage of life-terminating acts performed without a request of the child was higher than the percentage for adults, probably due to incompetence of the children because of their young age. As the total number of deaths in children is about 600 per year (adults about 140,000), the estimated absolute number of cases in which life is terminated is much lower than in adults: euthanasia, which is per definition only performed at the child's explicit request, occurs about 5 per year (adults about 3500), whereas life is ended other than at the request of the child in about 15 cases per year (adults about 800).[1,37,38]

The interviews with paediatrician-oncologists, paediatrician-intensivists, and paediatric neurologists showed that, due to its young age or unconscious state the child itself was involved in the decision-making only in a minority of cases. Nurses were involved in the majority of cases. However, their role in the decision-making differed from the role of physicians. (Chapter 5) Not surprisingly, physicians often discussed medical issues

such as prognosis or expected quality of life with their colleague-physicians, whereas with nurses, the discussion often centered on aspects of care. The discussion about medical issues with their peers was reportedly also more important to their decision-making than the discussion with nurses.

Although in all cases, paediatricians discussed the end-of-life decisions with the parents of the child, the decision was based on an explicit request of the parents in only one third of the cases. Drugs aimed at hastening death were more often used at the explicit request of the parents. These numbers were comparable with those of decision-making in neonates and infants. (Chapter 3) For older children, it was found that parents more often requested the termination of their child's life than other end-of-life decisions. This strengthens the hypothesis given in the last section of the previous paragraph, that physicians probably do not want to initiate a discussion about such decision, as they do not feel it is part of their medical-professional domain.

Views on using drugs with the intention of hastening death and the Euthanasia Act

Special attention in the debate on end-of-life decision-making goes to using drugs with the intention of hastening death with or without an explicit request of the patient, and the legal regulation of this practice. A considerable number of paediatricians is willing to hasten death with or without an explicit request of a child in the event of the child's unbearable and hopeless suffering. (Chapter 6) Agreement or a request of parents was the most important condition for their willingness to end the life of a child in such a state. More often than other physicians, paediatricians considered such decisions acceptable for a child incapable of protecting his or her interests. They had about the same opinion on the effects of the Euthanasia Act as other physicians: about half thought the Act would contribute to their willingness to be open about their practice, to the quality of the review procedure, to careful decision-making, and to an increasing reporting rate. (Chapter 7) Paediatricians were divided on the age limit of 12 years in the Euthanasia Act.

Even though the hastening of death by the use of drugs is, in practice, the least-performed of all end-of-life decisions, the existence and acceptability of this practice is often debated. In most countries, although prohibited by law, it is nevertheless performed with or without request of the patient.[1,6-9,20,33,37-39] Whereas euthanasia is allowed in the Netherlands for competent patients from the age of 12 and up if the rules for prudent practice are applied, and for minors with the additional requirement that parents agree or are involved, life ending for incompetent patients is, as in the other countries, legally prohibited. Nevertheless, paediatricians report that they are

willing to end the life of a child without its request in exceptional circumstances. In those cases, parents and physicians decide in the best interest of the child. However, making such decisions in the best interest of a child is very difficult. [40-45] For example, can physicians judge unbearable and hopeless suffering in children with spina bifida?[46-48] The present study found that physicians considered it important that an open debate about the appropriateness of an irreversible decision such as hastening the death of a young child be possible and that consensus about the criteria on which to base such a decision be available. (Chapter 7)

Implications for health policy and practice

One of the main conclusions from this thesis is that the practice of end-of-life decision-making in neonates and infants seems stable. In neonates, the frequency of end-of-life decisions has not risen significantly, and the situation in the Netherlands is virtually similar to the practice in Belgium. Furthermore, the frequency of end-of-life decisions hardly differs between older children and adults. For policy evaluation though, developments that might influence the number of end-of-life decisions should be considered. In April 2004, the Dutch Health Council advised the Minister of Health that prenatal screening for Down's syndrome and neural tube defects should be made available to all pregnant women in the first or second semester of gestation.[26] Pending approval by the government, a local initiative was developed in the Rotterdam region to implement a screening program for all pregnant women.[49] In September 2005, the government announced that all pregnant women should be informed about possibilities of prenatal screening to detect Down's syndrome, but that screening costs would only be reimbursed to women with a medical indication and women older than 36 years.[50] About a month later, following a report on perinatal mortality,[51] the Minister of Health announced that from January 2006, the second trimester echo is reimbursed to all pregnant women.[52] Furthermore, recent discussion in the Netherlands concentrated on the fact that treatment decisions should not be based on gestational age alone, but that the decision to initiate treatment should be judged per individual case. However, medical advances seemed to be increasing chances of these children.[53-55]
These developments, the rising age of pregnant women, and the societal debate should also be taken into account when interpreting research data on the occurrence of end-of-life decisions in neonatology.

Secondly, although Dutch physicians appear to have administered drugs to neonates and infants with the explicit intention of hastening death no more often than was the case in 1995, and just as often as in Belgium, only a fraction of all cases were reported to the Public Prosecutor. In Groningen, the number of reported cases in which neonates' and infants' lives were actively ended increased after introduction of a

protocol.[56,57] This increased openness has contributed to the opinion of the Royal Dutch Medical Association and the Dutch Paediatric Association that such a protocol should be used nationwide. They also proposed to install a special review committee, similar to the regional review committees for competent adults, in order to guarantee careful decision-making in these cases. Recently the government announced that such a committee will be installed.[58] The effect of such a policy should be monitored.

Thirdly, the Medical Treatment Contract Act (WGBO) states age limits above which children are allowed to decide about their treatment.[59] The Euthanasia Act specifies age limits above which physicians are allowed to grant a request for euthanasia with agreement of parents and when the child is capable of assessing the situation.[60] However, children are mostly either too young to be involved in decision-making at the end of their lives, or are unconscious. The guideline about end-of-life decision-making for neonates and infants "Doen of laten" issued by the Dutch Pediatric Association[61] could therefore also be used for older incompetent children. However, it is questionable as to whether an additional guideline is needed which can be used for competent children, about to what extent a child –whether or not younger than 12 years old- can or should be involved in the decision-making at the end of its life.

Fourthly, it seems that the rules on children in the Euthanasia Act are in accordance with medical practice. Children requesting euthanasia mostly tend to be 12 years or older and their parents are virtually always involved and in agreement with the decision. The influence of the euthanasia Act on the frequency of euthanasia in children, and on the reporting of cases of euthanasia to the Regional Review Committees remains to be seen.

Fifthly, overlap between end-of-life decisions might influence policymaking on end-of-life decisions. In the interviews with paediatricians, we found that very similar end-of-life practices were sometimes defined and interpreted differently. For example, we encountered two cases in which the pediatrician used about the same dosage of an opiate and a sedative. Both physicians indicated that the primary aim of using these drugs was to alleviate pain and other symptoms, but only one of them admitted that, deep inside, he knew he was also aiming at hastening death. Both children died shortly afterwards with an estimated shortening of life of less than a week. One physician presented the case as an example of terminal sedation, while the other said it was a case of active ending of life. Hence, on the basis of their intentions, the paediatricians came to different conclusions.
An important criterion to distinguish active ending of life from other end-of-life decisions is that death is the consequence of a drug that was used with the explicit intention of

hastening death. However, accurately determining 'intent' can be difficult for a physician, as the example shows, and it can be questioned whether these cases should be classified and judged differently solely on the basis of intention. Other aspects, such as life expectancy, the type, dosage and life-shortening effect of drugs used, whether the use of potentially life-ending drugs follows the forgoing of treatment, and the intention with which such treatment is forgone seem important as well.

The estimation of life expectancy is known to be rather unreliable in individual cases and it is known that the longer a cancer patient lives the more physicians tend to overestimate survival.[62] In cases where life was actively terminated, Dutch physicians estimated that life was shortened by more than a week in infants and adults more often than in other cases.[1] (Chapter 3) This finding suggests that some physicians take life expectancy into account in the decision-making about ending life, although it is doubtful whether the estimation is accurate.

Furthermore, it is claimed that death is usually not hastened when opiates and sedatives are used for alleviation of pain or other symptoms, even high dosages are concerned.[63-66] However, a study about the use of life-shortening drugs in end-of-life care in neonates and infants showed that the administration of extreme dosages of opioids with the explicit intention to hasten death could have such effect.[67] This thesis shows that these drugs were often used in cases where the physician was explicitly aiming at hastening death. (Chapter 2 and 4) It can be questioned whether the disease or these drugs actually caused the death of the child, as even high dosages of opioids or sedatives do not seem to have that effect.[66] Although these findings are not evidence of the life-shortening potential of these drugs, any physician intending to end the patient's life would probably sometimes be better off with the use of additional drugs, like barbiturates or neuromuscular relaxants. Additionally, whether the use of opioids or sedatives should be classified as actively ending of life, on the basis of the physician's intention to hasten death is debatable, as 'hastening death' or 'shortening life' are arguably broader concepts than 'deliberately ending life'.[68]

Another issue in the discussion about the definition of the active ending of life is whether there is a difference between using life-ending drugs after having forgone a treatment with the explicit intention to hasten death and using life-ending drugs without such a prior non-treatment decision. In our study of end-of-life decisions in neonates and infants, we made such a distinction. (Chapter 2) In our studies on older children and adults, no such distinction was made.[2,3,37] (Chapter 4) How, in practice, physicians would label their acts and decisions is questionable and probably dependent on the specific situation. The use of life ending drugs to prevent suffering that may result from the decision to withdraw medical futile treatment like mechanical ventilation with the intention to hasten death might not always be seen as active ending of life: the withdrawal of treatment might be seen as the primary cause of death. A decision to

withhold antibiotics, taking into account that death might be hastened, before administrating a life-ending drug might be considered less relevant, but might also be seen as the active ending of life. However, it can also be reasoned that using life-ending drugs should always be considered as the active ending of life, regardless of which treatment is forgone.
It can be concluded that distinguishing the active ending of life from other end-of-life decisions is complex. The physician's intention and his or her estimation of the effect of the drugs used are crucial, but these criteria do not provide a sharp demarcation for all cases. Additional criteria may be helpful in determining which cases should be legally reviewed and which should not. However, the gray zone between obvious cases in which life is actively ended on the one hand and palliative care for dying patients on the other cannot be totally resolved by adapting definitions. Misclassifications and differences in judgment probably remain present under any classification scheme. Policymakers have to decide whether the political aims of transparency and legal review will be served by using additional criteria to distinguish the active ending of life from other end-of-life decisions. Such criteria include the type of drugs that are used, the estimated life expectancy, whether or not potentially life-sustaining treatment is forgone, and the intention with which such treatment is forgone.

Recommendations for future research

To evaluate the effect of developments in health care and changes in health policy, the frequencies of end-of-life decisions in neonates and infants as well as older children should be regularly studied. Relevant characteristics such as diagnoses, the age of the mother, the duration of pregnancy, time between birth and death of the child, should be part of these studies.

It is not always clear when active ending of life may be justified. An example is active ending of life in children with spina bifida, for whom it is discussed whether unbearable or hopeless suffering can be objectively judged.[46,48] Further understanding of which criteria play a role in the decision-making and are found to be important is needed to be able to reach consensus about such cases.

Our research concerned paediatricians and other physicians who treat severely ill children at the end of their lives. End-of-life decision-making also concerns attitudes and views of other healthcare providers and parents. Other studies have previously shown that they may have other perspectives on end-of-life decision-making compared to physicians. However, little is known about the perspectives of other healthcare providers, like nurses or parents. In the Dutch 2001 study on frequencies of end-of-life decisions in neonates and infants, we found a lower involvement in the decision-

making process of nurses. The interview study among paediatricians showed that they value the opinion of nurses less than the opinion of colleague physicians and that they virtually always involve parents in the decision-making. It can be questioned whether these findings correspond with the attitudes and opinions of nurses and parents themselves.

The experiences and perspectives of the children themselves have hardly been studied yet. Requests for euthanasia and the practice of end-of-life decisions could be better understood if severely ill but competent children could be asked about their experiences, needs and preferences.

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Summary

This thesis describes the practice of end-of-life decision-making in neonates and older children, the attitudes of paediatricians and other physicians towards physician-assisted dying and their opinion about the Euthanasia Act.

In **Chapter one** the background of end-of-life decision making in children is described and the following research questions are formulated:

1. How often are end-of-life decisions made and what are the characteristics of end-of-life decision-making in neonates and infants?
2. How did the Dutch practice develop over time, and is it different from Belgium?
3. How often are end-of-life decisions made in older children and what are the characteristics of the decision-making process?
4. What are the attitudes of paediatricians and other physicians towards assisted death in children and what are their opinions about the Euthanasia Act?

To study the practice of end-of-life decision-making in neonates and infants, questionnaires were sent to physicians who reported the death of a child who died under the age of one (Belgium: n=292, response 87%; Netherlands: n=249, response 84%). The questionnaires included structured questions about whether death had been preceded by end-of-life decisions, and about the decision-making process.

To study the practice of end-of-life decision-making in children beyond the neonatal period, two studies were performed. The first was a study in which all 129 physicians who had reported the death of a child aged between one and 17 years in a four-month period received a written questionnaire; the second was an interview study in which face-to-face interviews were held with 63 physicians working in pediatric hospital departments. Questions were asked about their practice concerning end-of-life decision-making, hypothetical cases, and their opinion about physician-assisted dying and the Euthanasia Act.

In **chapter two**, the proportion of deaths of infants younger than 1 year that were preceded by end-of life decisions is assessed. This proportion increased from 62% in 1995 to 68% in 2001, but the difference was not significant. Most of these decisions concerned the forgoing of life-sustaining treatment. The number of decisions to actively end the life of an infant not dependent on life-sustaining treatment remained stable at 1% of all deaths. The characteristics of the practice of end-of-life decision-making in neonatology of 2001 changed little since 1995.

In **chapter three**, a comparison of end-of-life decision-making practices in neonates and infants between the Netherlands and Belgium (Flanders) is made. In both countries, in about 25% of all deaths of infants under the age of one, life-sustaining treatment was withheld. In Belgium life-sustaining treatment was less often withdrawn than in the Netherlands (32% and 50%, respectively). In both countries, in about 40% of the cases, pain or other symptoms were alleviated, thereby taking into account that death might be hastened. Drugs were administered with the explicit intention of hastening death in similar percentages of all deaths (Belgium: 7%; Netherlands: 9%), but Dutch physicians more often estimated that life had been shortened by over a week than did Belgian physicians. In the Netherlands, the decision was discussed with parents (96%), and with colleague-physicians (94%) more often than in Belgium (81% and 80%, respectively). In Belgium, the decision was discussed with nurses in 32% of the cases, and in the Netherlands in 27%. We concluded that the practice of end-of-life decision-making in severely ill neonates and infants seems very similar in Belgium and the Netherlands.

In **chapter four**, frequencies of end-of-life decisions in children beyond the neonatal period, characteristics of the decision-making process and paediatricians' experiences are described. In 2001, 36% of all deaths of children between the ages of one and 17 years during a 4-months period were preceded by an end-of-life decision: 12% by a decision to refrain from potentially life-prolonging treatment; 21% by the alleviation of pain or symptoms with a possible life-shortening effect; and 2.7% by the use of drugs with the explicit intention of hastening death. The latter decision was made at the child's request in 0.7% and at the request of the family in 2% of the cases. While not inconsiderable, the percentage of end-of-life decisions was lower for deceased children aged one year or older than for deceased newborn infants, and somewhat lower than for deceased adults. The interview study examined 76 cases in which the death of a child older than 3 months was preceded by an end-of-life decision. This study showed that end-of-life decisions were discussed with all nine competent, and with three partly competent children, with the parents in all cases, with other physicians in 75 cases, and with nurses in 66 cases. Most children were not considered to be able to participate in the decision-making process.

In **chapter five**, additional characteristics of decisions to forgo potentially life-sustaining treatment and to use drugs aimed at hastening death of severely ill children beyond the neonatal period are described. Paediatricians felt that their most important discussion partners were staff members. Topics discussed with other physicians typically included the child's prognosis and the chances of survival. Topics discussed with the nursing staff included the child's condition, the parents' emotional capacity and

terminal care. The persons who were involved in the decision making process mostly all agreed with the decision. The forgoing of life-sustaining treatment was typically a physician-initiated decision that was based upon the acknowledgement that no effective treatment was available for a lethal disease in its final stage. Using drugs aimed at hastening death more often followed a parental request and seemed to be used as the final resort to stop severe suffering. Most paediatricians evaluated the dying process of the child with the parents, but such evaluation occurred more often when drugs had been used than when treatment had been forgone. The majority of the paediatricians were satisfied about the medical care preceding death, and thought that it had improved the quality of dying.

In **chapter six**, a hypothetical case study on the willingness of Dutch physicians to use potentially life-shortening or lethal drugs for severely ill children is described. We asked the 63 pediatricians about their approach to 10 hypothetical cases of children with cancer. The age of the child (15, 11, or 6 years), the child's (explicit) request, and the opinion of the parents varied. Two hypothetical cases were also presented to 125 general practitioners and 208 clinical specialists. Most pediatricians were willing to increase the morphine in all cases. A total of 48% to 60% of pediatricians were willing to use lethal drugs in children at the child's request, when the parents agreed; 13% to 28% of paediatricians were willing when parents did not agree with their child's request; when parents requested the ending of the life of their unconscious child, 37% to 42% of pediatricians were willing to do so. General practitioners and clinical specialists were as willing as pediatricians to use lethal drugs at the child's request, but less willing to grant a request made by the parents for their unconscious child. We concluded that many Dutch pediatricians are willing to use potentially life-shortening or lethal drugs for children, provided that parents give their consent.

Since 2002, the Euthanasia Act has regulated the conditions under which euthanasia is allowed in the Netherlands. Physicians are allowed to comply with requests from minors aged 12 to 16 years if parents agree with the euthanasia. In **chapter seven**, views of paediatricians on the effects of the Euthanasia Act and the rules on children in the Act are described. About half of Dutch pediatricians supported the act and expected it to contribute to the transparency and carefulness of the decision-making.

Finally, **chapter eight** contains a general discussion of the results of the studies described in this thesis. The first conclusion is that the practice of end-of-life decision-making in neonates seems stable. The frequency of end-of-life decisions has not risen significantly, and the practice is virtually similar to the Belgian practice. Further, the frequency of end-of-life decisions for older children is lower than the frequency among

deceased infants and is slightly lower than the frequency among adults. Possible effects of the societal debate, the rising age of pregnant women, policies on prenatal screening, late termination of pregnancy and end-of-life decisions, warrant careful monitoring of end-of-life decision making practices in minors.

Secondly, decisions to actively end the life of a child are more often made at the request of parents than other end-of-life decisions. Physicians may be reluctant to engage in this practice, because they do not consider it to be part of their professional domain.

Thirdly, only a small proportion of all cases of active ending of life are reported to the Public Prosecutor. The introduction of the so-called Groningen protocol with criteria for prudent practice may lead to more openness about this practice.

Fourthly, it was shown that children are mostly considered too young to be involved in end-of-life decision-making or are unable to do so because they are unconscious. The quality of decision-making could be further improved by extending current guidelines for neonates to competent children.

Fifthly, the rules on children in the Euthanasia Act seem appropriate, as the age of children who request for euthanasia was mostly 12 years or older and parents virtually always agreed with the decision

Lastly, the classification of different end-of-life decisions is shown to be complex. The intention of the physician and the life ending effect of drugs used are important considerations, but others, such as the type of drugs that are used, the estimated life expectancy, whether or not potentially life-sustaining treatment is forgone, and the intention with which the treatment is forgone may also be important to policy makers to define legal rules and criteria for review.

Recommendations for further research included regular monitoring of the practice of end-of-life decision making, further understand the criteria for life-ending in newborns, gaining broader insight into the end-of-life decision-making process by studying attitudes of other healthcare providers and parents, and research on the experiences, needs and preferences of the children themselves.

Samenvatting

Dit proefschrift beschrijft de praktijk van beslissingen rond het levenseinde bij pasgeborenen en oudere kinderen en de opvattingen van kinderartsen en andere artsen over levensbeëindiging en de Euthanasiewet.

In **hoofdstuk een** wordt de achtergrond van medische besluitvorming rond het levenseinde bij kinderen beschreven. De volgende onderzoeksvragen zijn geformuleerd:
1. Hoe vaak worden beslissingen rond het levenseinde bij pasgeborenen en zuigelingen genomen en wat zijn de kenmerken van de besluitvorming?
2. Hoe ontwikkelde de Nederlandse praktijk zich gedurende de afgelopen jaren en is deze anders dan de Belgische praktijk?
3. Hoe vaak worden beslissingen rond het levenseinde bij oudere kinderen genomen en wat zijn de kenmerken van het besluitvormingsproces?
4. Wat zijn de opvattingen van kinderartsen en andere artsen ten aanzien van levensbeëindiging bij kinderen en wat is hun mening over de Euthanasiewet?
Om de praktijk van besluitvorming rond het levenseinde bij pasgeborenen en zuigelingen te onderzoeken werden vragenlijsten gestuurd aan artsen die het overlijden van een kind jonger dan één jaar hadden gemeld (België: n=292, responspercentage 87%; Nederland: n=249, responspercentage 84%). De vragenlijst bevatte gestructureerde vragen, onder andere of het overlijden was voorafgegaan door een medische beslissing rond het levenseinde, met name een besluit om levensverlengende behandeling te staken of niet in te stellen of om mogelijk levensbekortende medicatie toe te dienen, en vragen over het besluitvormingsproces.
Om de praktijk van besluitvorming rond het levenseinde bij kinderen na de neonatale periode te onderzoeken werden twee studies uitgevoerd. De eerste was een vier maanden durend onderzoek waarin alle 129 artsen die het overlijden hadden gemeld van een kind tussen één en 17 jaar oud een vragenlijst opgestuurd kregen; de tweede was een onderzoek waarbij interviews werden gehouden met 63 artsen die op kinderafdelingen in een ziekenhuis werkten. Vragen betroffen hun praktijk ten aanzien van beslissingen rond het levenseinde, hypothetische gevalsbeschrijvingen en hun mening over levensbeëindiging en de Euthanasiewet.

In **hoofdstuk twee** is de proportie van alle sterfgevallen bepaald die waren vooraf gegaan door een beslissing rond het levenseinde bij zuigelingen jonger dan één jaar. Deze proportie steeg van 62% in 1995 naar 68% in 2001, maar het verschil was niet significant. De meeste van deze beslissingen betroffen het afzien van

levensverlengende behandeling. Het percentage beslissingen tot actieve levensbeëindiging bij kinderen die niet afhankelijk waren van levensverlengende behandeling bleef stabiel op 1% van alle sterfgevallen. De kenmerken van de besluitvorming rond het levenseinde in de neonatologie in 2001 veranderden weinig ten opzichte van 1995.

In **hoofdstuk drie** is de praktijk van medische besluitvorming rond het levenseinde bij pasgeborenen en zuigelingen in Nederland met de praktijk in België vergeleken. In beide landen werd in ongeveer 25% van alle sterfgevallen van kinderen jonger dan een jaar een levensverlengende behandeling niet ingesteld. In België werd minder vaak een levensverlengende behandeling gestaakt dan in Nederland (respectievelijk 32% en 50%). In ongeveer 40% van de gevallen in beide landen werden pijn of andere symptomen bestreden, rekening houdend met bespoediging van het overlijden. Medicatie met het uitdrukkelijk doel het levenseinde te bespoedigen werd in vergelijkbare percentages toegediend (België: 7%; Nederland: 9%), maar Nederlandse artsen schatten de mogelijke levensbekorting vaker langer dan een week dan Belgische artsen. In Nederland werd de beslissing vaker overlegd met ouders (96%) en met collega-artsen (94%) dan in België (respectievelijk 81% en 80%). In België werd de beslissing in 32% van alle gevallen overlegd met verpleegkundigen en in Nederland in 27%. Wij concludeerden dat medische besluitvorming rond het levenseinde vergelijkbaar lijkt in België en Nederland.

In **hoofdstuk vier** zijn de frequenties beschreven van beslissingen rond het levenseinde bij kinderen na de neonatale periode, en kenmerken van het besluitvormingsproces en ervaringen van kinderartsen. In 2001 werd gedurende de periode van vier maanden 36% van de sterfgevallen van kinderen tussen één en 17 jaar voorafgegaan door een beslissing rond het levenseinde: 12% door een beslissing af te zien van een mogelijk levensverlengende behandeling, 21% door pijn- of symptoombestrijding met een mogelijk levensverkortend effect en 2,7% door het gebruik van een middel met het uitdrukkelijke doel het levenseinde te bespoedigen. De laatste beslissing werd in 0,7% op verzoek van het kind en in 2% op verzoek van de familie genomen. Alhoewel niet onaanzienlijk was het percentage beslissingen rond het levenseinde lager voor overleden kinderen van één jaar of ouder dan voor overleden pasgeborenen en zuigelingen en iets lager dan voor overleden volwassenen. In de interviewstudie werden 76 casussen onderzocht, waarbij de dood van een kind ouder dan drie maanden was voorafgegaan door een beslissing rond het levenseinde. Deze studie liet zien dat beslissingen werden besproken met alle negen wilsbekwame en met drie deels wilsbekwame kinderen, met de ouders in alle gevallen, met andere artsen in 75 gevallen en met verpleegkundigen in 66 gevallen.

Kinderartsen achtten de meeste kinderen niet in staat te kunnen participeren in het besluitvormingsproces.

In **hoofdstuk vijf** zijn aanvullende kenmerken beschreven van beslissingen tot afzien van mogelijk levensverlengende behandeling en tot het gebruik van een middel met het doel het levenseinde te bespoedigen bij ernstig zieke kinderen na de neonatale periode. Kinderartsen zagen de andere stafleden hun belangrijkste discussiepartners. Onderwerpen die met andere artsen werden besproken betroffen vooral de prognose en de kansen op overleving. Onderwerpen die met verpleegkundigen werden besproken betroffen met name de conditie van het kind, de emotionele draagkracht van de ouders en de terminale zorg. De betrokkenen in het besluitvormingsproces waren het vrijwel altijd eens met de beslissing. Het afzien van levensverlengende behandeling was typisch een door de arts geïndiceerde beslissing die was gebaseerd op de wetenschap dat effectieve behandeling ontbrak in de laatste fase van een letale ziekte. Het gebruik van middelen met het doel het levenseinde te bespoedigen was vaker gebaseerd op een verzoek van ouders en leek te worden gebruikt als een laatste oplossing voor het beëindigen van ernstig lijden. De meeste kinderartsen evalueerden het sterfproces van het kind met de ouders, maar zo'n evaluatie kwam vaker voor als middelen waren gebruikt om het levenseinde te bespoedigen dan als was afgezien van behandeling. De meeste kinderartsen waren tevreden over de medische zorg voorafgaand aan de dood van het kind en dachten dat de beslissing de kwaliteit van het overlijden had verbeterd.

In **hoofdstuk zes** is een studie beschreven met hypothetische gevalsbeschrijvingen over de bereidheid van Nederlandse artsen om mogelijk levensverkortende of letale middelen te gebruiken bij ernstig zieke kinderen. Wij vroegen 63 kinderartsen naar hun aanpak bij 10 hypothetische gevalsbeschrijvingen. De leeftijd van het kind (15, 11 of 6), het (uitdrukkelijk) verzoek van het kind en de mening van ouders varieerden. Twee van de tien beschrijvingen werden tevens voorgelegd aan 125 huisartsen en 208 klinisch specialisten. In alle gevallen waren de meeste kinderartsen bereid de hoeveelheid morfine te verhogen. In totaal was 48 tot 60% van de kinderartsen bereid om letale medicatie toe te dienen op verzoek van het kind als de ouders instemden; 13 tot 28% van de kinderartsen was ertoe bereid als ouders het niet eens waren met het verzoek van hun kind; als ouders verzochten om levensbeëindiging bij hun kind dat buiten bewustzijn was, was 37 tot 42% van de kinderartsen ertoe bereid. Huisartsen en klinisch specialisten waren net zo bereid als kinderartsen om letale medicatie toe te dienen op verzoek van het kind, maar minder bereid om aan een verzoek te voldoen van ouders voor hun kind dat buiten bewustzijn was. Wij concludeerden dat veel

Nederlandse kinderartsen bereid zijn mogelijk levensverkortende of letale middelen bij kinderen te gebruiken, onder voorwaarde dat ouders hiermee instemmen.

Vanaf 2002 regelt de Euthanasiewet de voorwaarden waaronder euthanasie in Nederland is toegestaan. Artsen mogen voldoen aan verzoeken van minderjarigen van 12 tot 16 jaar als ouders het eens zijn met de euthanasie. In **hoofdstuk zeven** zijn de meningen van kinderartsen over de effecten van de Euthanasiewet en de regels over kinderen in de wet beschreven. Ongeveer de helft van de kinderartsen ondersteunde de wet en verwachtten dat het bijdraagt aan de openheid en zorgvuldigheid van de besluitvorming.

Ten slotte betreft **hoofdstuk acht** een algemene discussie van de resultaten van de in dit proefschrift beschreven studies.
Ten eerste lijkt de praktijk van besluitvorming rond het levenseinde bij neonaten stabiel. De frequentie van beslissingen rond het levenseinde is niet significant gestegen en de praktijk komt overeen met de Belgische praktijk. Verder is de frequentie van beslissingen rond het levenseinde bij oudere kinderen lager dan de frequentie bij pasgeborenen en iets lager dan de frequentie bij volwassenen. De mogelijke effecten van het maatschappelijke debat, de toenemende leeftijd van zwangere vrouwen, het beleid van prenatale screening, de late afbreking van een zwangerschap en beslissingen rond het levenseinde vragen om zorgvuldig monitoren van besluitvorming rond het levenseinde bij kinderen.
Ten tweede worden beslissingen tot actieve levensbeëindiging bij een kind vaker op verzoek van ouders genomen dan andere beslissingen rond het levenseinde. Artsen zijn er mogelijk huiverig voor hier zelf over te beginnen, omdat zij het niet tot hun professionele domein beschouwen.
Ten derde wordt maar een klein deel van de gevallen waarbij actieve levensbeëindiging wordt uitgevoerd gemeld bij de officier van justitie. De introductie van het ‘Groningen protocol’ met criteria voor een zorgvuldige praktijk zou kunnen leiden tot meer openheid over deze praktijk.
Ten vierde werd aangetoond dat kinderen meestal te jong geacht worden om betrokken te worden in de besluitvorming of dat zij daartoe niet in staat geacht worden omdat zij buiten bewustzijn zijn. De kwaliteit van de besluitvorming zou verder verbeterd kunnen worden door het uitbreiden van de huidige richtlijnen voor neonaten met richtlijnen voor wilsbekwame kinderen.
Ten vijfde lijkt het erop dat de regels in de Euthanasiewet adequaat zijn, omdat de leeftijd van kinderen met een euthanasieverzoek vrijwel altijd 12 jaar of ouder was en ouders het altijd eens waren met de beslissing.

Als laatste wordt aangetoond dat het onderscheid tussen verschillende beslissingen rond het levenseinde complex is. De intentie van de arts en het levensverkortende effect van gebruikte middelen zijn belangrijke overwegingen. Andere overwegingen, zoals het type medicijn dat wordt gebruikt, de geschatte levensbekorting, het al dan niet afzien van een mogelijk levensverlengende behandeling en de intentie waarmee van de behandeling is afgezien, kunnen ook belangrijk zijn om de wettelijke regels en de beoordelingscriteria te formuleren.
Aanbevelingen tot verder onderzoek bevatten regelmatig monitoren van de praktijk van beslissingen rond het levenseinde, het verder begrijpen van de criteria voor levensbeëindiging bij pasgeborenen, het verkrijgen van meer inzicht in het besluitvormingsproces door het bestuderen van de attitudes van andere zorgverleners en ouders en onderzoek naar de ervaringen, behoeften en voorkeuren van de kinderen zelf.

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Curriculum Vitae

Astrid Vrakking werd 4 mei 1966 geboren te Bussum. Zij groeide op in Oud-Beijerland en behaalde in 1984 haar HAVO-diploma. Van 1984 tot 1988 deed zij de inservice opleiding tot A-verpleegkundige in het toenmalige Academisch Ziekenhuis Dijkzigt in Rotterdam. In dit ziekenhuis specialiseerde zij zich als Intensive Care verpleegkundige en werkte er vervolgens van 1991 tot 2000 op de Intensive Care Inwendige Geneeskunde en Beademing. Van 1992 tot 1994 deed zij de HBO-Kaderopleiding Gezondheidszorg aan de Hogeschool Rotterdam & omstreken te Rotterdam. Van 1995 tot 2000 deed zij de deeltijdstudie Beleid en Management Gezondheidszorg met een specialisatie Health Services Research aan de Erasmus Universiteit. Vanaf oktober 2000 werkte zij op het Instituut Maatschappelijke Gezondheidszorg van het Erasmus MC te Rotterdam, waar zij onderzoek deed naar medische en niet-medische criteria voor beslissingen over de behandeling van ernstig zieke oudere patiënten. Vervolgens werkte zij mee aan de evaluatie van de toetsingsprocedure euthanasie, waar dit proefschrift uit is voortgekomen. Vanaf april 2005 werkt zij als zorgonderzoeker op de Intensive Care van het Erasmus MC.