

University of Groningen

At the boundaries of life

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DOI:
[10.33612/diss.159020586](https://doi.org/10.33612/diss.159020586)

IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

Document Version
Publisher's PDF, also known as Version of record

Publication date:
2021

[Link to publication in University of Groningen/UMCG research database](#)

Citation for published version (APA):
Brouwer, M. (2021). *At the boundaries of life: Suffering and decision-making in children with life-threatening conditions (1-12 years)*. University of Groningen. <https://doi.org/10.33612/diss.159020586>

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CHAPTER 3

Quality of Living and Dying: Pediatric Palliative Care and End-of-Life Decisions in the Netherlands

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Abstract.

In 2002, the Netherlands continued its leadership in developing rules and jurisdiction regarding euthanasia and end-of-life decisions by implementing the Euthanasia Act, which allows euthanasia for patients 12 years of age and older. Subsequently, in 2005, the regulation on active ending of life for newborns was issued. However, more and more physicians and parents have stated that the age gap between these two regulations—children between 1 and 12 years old—is undesirable. These children should have the same right to end their suffering as adults and newborn infants. An extended debate on pediatric euthanasia ensued, and currently the debate is ongoing as to whether legislation should be altered in order to allow pediatric euthanasia. An emerging major question regards the active ending of life in the context of palliative care: How does a request for active ending of life relate to the care that is given to children in the palliative phase? Until now, the distinction between palliative care and end-of-life decisions continues to remain unclear, making any discussion about their mutual in- and exclusiveness hazardous at best. In this report, therefore, we aim to provide insight into the relationship between pediatric palliative care and end-of-life decisions, as understood in the Netherlands. We do so by first providing an overview of the (legal) rules and regulations regarding euthanasia and active ending of life, followed by an analysis of the relationship between these two, using the Dutch National Guidelines for Palliative Care for Children. The results of this analysis revealed two major and related features of palliative care and end-of-life decisions for children (1) palliative care and end-of-life decisions are part of the same process, one that focuses both on quality of living and quality of dying, and (2) although physicians are seen as ultimately responsible for making end-of-life decisions, the involvement of parents and children in this decision is of the utmost importance and should be regarded as such.

Introduction

Over the last few decades, the ongoing debate on euthanasia and active ending of life in the Netherlands has led to two major regulations. The first of these, the Euthanasia Act, came into force in 2002, and allows euthanasia for patients 12 years of age and older under the criteria of due care.¹ In 2005, a second regulation was drafted: a regulation derived from the Groningen Protocol that allows active ending of life for infants (0–1 year of age) under certain circumstances.^{2,3} But with the commencement of this second regulation, a gap was created. For children between 1 and 12 years of age, there are no existing regulations on active ending of life and euthanasia.

For a year now, voices have begun to surface stating that this gap is undesirable. This has marked the beginning of a debate on pediatric euthanasia. This debate has generated rapidly growing interest, both public and political, especially after the Pediatric Association of the Netherlands (NVK) published its official position on pediatric active ending of life. In this position paper, they advocated a re-evaluation of the current legislation and pleaded for research into the possibility of active ending of life in children between the ages of 1 and 12 years.⁴ The publication of this position paper has led to a broadening of the discussion, so that it now also includes legislation on pediatric euthanasia.⁵ One of the most important questions raised here involves active ending of life in the context of palliative care. How does a request for active ending of life relate to the care that is given to children in the palliative phase, and, more importantly, is it not possible to administer palliative care in such a way that active ending of life is unnecessary? This last question is of vital importance for the debate about and understanding of pediatric euthanasia. In order to make decisions about the active ending of life for children, the actual meaning, range, and content of palliative care for children need to be better understood, but so far, we do not know how pediatric palliative care and end-of-life decisions are interrelated. The Netherlands now stands on the verge of an influential development. The very first step to take in this development is to understand the moral values that underlie the care currently given to these children, in other words, what do we do and why are we doing it?

In this report, we will provide an initial understanding of how Dutch pediatric palliative care and its relationship to end-of-life decisions should operate, according to current guidelines

and legislation. We first present an overview of the legal outline of euthanasia and active ending of life. Next, we analyze the most complete source on Dutch pediatric palliative care, the National Guidelines on Palliative Care for Children, in order to clarify the relationship between palliative care and end-of-life decisions for children in the Netherlands. Our resulting analysis will then provide two major findings concerning this relationship: first, how palliative care and end-of-life decisions form a continuum, and, second, how end-of-life decisions are made. These themes will form the body of our analysis.

Methods

In order to grasp the state of the art for Dutch pediatric palliative care, we systematically collected all available data on the topic. First, we conducted a close reading of the Dutch regulations concerning active ending of life, in order to understand the legal basis for end-of-life decisions in the Netherlands. Next, we performed a systematic literature search in PubMed and Embase to collect all available research. So far, there has been very little literature concerning this topic.

We then proceeded to find guidelines and protocols describing pediatric palliative care for children between 1 and 12 years old. The 2013 National Guidelines on Palliative Care for Children gives an extended and complete overview of this topic.⁶ The information in their guidelines is very densely packed and mostly consists of concrete, clinical recommendations. Because of this density and clinical orientation, underlying themes and values remain hidden between the lines. We performed a qualitative analysis to gain some insight into the underlying ethical themes and implicit moral values of the guidelines.

The qualitative analysis of the guidelines began with a close reading, after which different themes were identified. The text was then coded using *Atlas.ti*, a program designed for qualitative data analysis. Worksheets were composed, containing all the text elements per applied coding element, and these were subsequently analyzed. Two independent researchers checked the coding and analysis. Coding scheme and worksheets are available on request. The results from the literature search were used to support the findings of the qualitative analysis.

We will illustrate our findings with quotes from a semistructured interview with the parents of a boy diagnosed with severe cardiac anomalies, from whom, after a trajectory of palliative care, the decision was made to withdraw life-sustaining treatment. This interview is

taken from a currently running qualitative research project, in which 20 parents have been interviewed about the suffering of their children during their time in the pediatric intensive care unit (PICU). The interview is merely used to illustrate our findings and has not been used as evidence itself.

Definitions

In the Netherlands, a specific terminology concerning end-of-life practice is used that may differ from that in other countries. In this article, the Dutch definitions are used, which will be explained subsequently.

End-of-life decisions are specified as medical decisions that have life-limiting consequences, either intentionally (active ending of life) or as an anticipated but not primarily intended effect (passive ending of life). *Passive end-of-life decisions* are regarded as being a part of a normal medical procedure, and physicians are not obliged to make an official report in these cases.⁷

Active ending of life is often used as a synonym for euthanasia but has a different meaning. Active ending of life includes all medical decisions that intentionally shorten the life of a patient, whereas *euthanasia* is active ending of life upon explicit request of the patient. Therefore, strictly speaking, active ending of life in newborns is not euthanasia. In the international context, however, this practice is frequently (but incorrectly) described as euthanasia.⁸ Generally, the term “euthanasia” is used for situations in which the physician administers the lethal drug, but it can also include situations in which the patient drinks or swallows a drug (*physician-assisted suicide*).

Legal Outline

The Dutch Euthanasia Act (2002) allows physicians to perform euthanasia on patients 12 years of age and older, upon the request of the patient, if criteria of due care are met.⁹ Euthanasia for children in the age group between 12 and 16 is only possible if the parents are involved in the decisionmaking process and also give their consent for the final decision to perform euthanasia. Minors older than 16 do not need parental consent, but involvement of the parents in the decisionmaking process is required. Since 2005, active ending of life in infants below the age

of 1 year has been allowed under very specific circumstances.¹⁰ This modification of the law is based on the Groningen Protocol (2004),¹¹ and permits active ending of life in an infant (0–1 years of age) in cases of extreme suffering combined with very limited chances of survival. There exists a gap between both regulations: active ending of life for children between 1 and 12 years old. For them, there are no explicit regulations on active ending of life.

Although the 1–12-year age group is not covered, strictly speaking, there might be a legal possibility for active ending of life in these children, because certain grounds for exemption from criminal liability are available.¹² In this instance, when a physician experiences a conflict between the law and the physician's obligation to relieve the suffering of a child, he or she can appeal on the grounds of "conflict of obligations." These grounds might apply to cases involving children, in which a physician sees no other way to end the suffering of a child. For adults, there have been successful appeals to these grounds,¹³ but no reports have been made so far. We speculate that the legal uncertainty constrains physicians from openly reporting a case.

The National Guidelines on Palliative Care For Children

In 2013, the NVK drafted guidelines for palliative care for children. These guidelines provide a framework for palliative care for children by providing evidence-based recommendations on various aspects of palliative care, such as symptom management, decisionmaking, and organization of care. The evidence-based guidelines are the most complete source of knowledge on Dutch pediatric palliative care. According to the guidelines, palliative care starts as soon as the child is diagnosed with a life-limiting disease, and this care is provided until the death of the patient.¹⁴ In many cases, this means that the child receives palliative care for several years, often initially in combination with curative treatment. Thus, although palliative care is sometimes mistaken for end-of-life care, it is much more than that.

The guidelines describe the aim of palliative care, as it is defined by the World Health Organization (WHO): the prevention and relief of suffering.¹⁵ However, the guidelines do not go on to define the term "suffering." This might lead to confusion, because it is a term that is still largely unexplored territory. Taking into account the descriptions found further on in the guidelines, we read that suffering is here understood as the quality of life that is directly and negatively affected by the patient's being ill. The guidelines stress that palliative care is

concerned with various aspects of being ill, such as the psychosocial, developmental, pedagogic, and spiritual aspects,¹⁶ But according to the guidelines, palliative care is also concerned with something else: quality of dying. This will be further explored.

Quality of Living and Dying: The Relationship Between Palliative Care and End-of-Life Decisions

Although the NVK guidelines follow the definition of palliative care as formulated by the WHO, there is an important difference in interpretation. Whereas the WHO sees palliative care as “a support system to help patients live as actively as possible until death,”¹⁷ the Dutch guidelines introduce a close relationship between palliative care and dying: “Primary aim [of palliative care] is quality of living *and* dying” (our emphasis).¹⁸ By stating that palliative care is not just about quality of living but about quality of dying as well, death and end-of-life decisions are incorporated into palliative care. The guidelines see palliative care and death as part of the same continuum: death is seen as an integral part of having a life-limiting illness.¹⁹ This explicit and close relationship between palliative care and dying is exemplary for the Dutch state-of-the-art in pediatric palliative care. We will describe this relationship further.

In the first stage of palliative treatment, the prognosis of the life-limiting disease is often uncertain, and curative treatment is often still provided,²⁰ but even in this stage, the probable but still uncertain death of the patient is discussed with parents. Physicians, parents, and—if at all possible—children talk about how palliative treatment can improve the quality of life of the child, but they also talk about the situation in which palliative care in itself is no longer sufficient to relieve the suffering. From this point of view, thinking about the start and end of palliative treatment is part of the same process. “In the Netherlands it is generally accepted that not everything that can be done, should be done. For palliative care for children this implies that life-prolonging treatment for children should always be legitimized by strong arguments.”²¹ This idea, in which thinking about end-of-life decisions is interwoven with providing palliative treatment, is illustrated by the following excerpt from the interview. The parents recall the first conversation with the cardiologist after palliative care was initiated – they were asked to describe what they perceived to be the limit of palliative treatment.

Quote 1a. “At a certain point the [child’s] prognosis was very bad: extremely spastic, very autistic, non-functioning senses ... complete lack of emotions and... parts of his body that would no longer be listening to what his head wanted....So that we were like, that is too much. And...that, that we just didn’t want. We had, we already indicated that in the earlier talk. I know it was already discussed during the first conversation.”

The parents appreciated the time that they were given to think this over carefully.

Quote 1b. “And I am very glad that we had those conversations beforehand. So you can think about that rationally and you have already thought about it rationally. Before you find yourself in a situation, where you suddenly have to make a decision without ever having thought about that.”

These quotes are illustrative of how talking about the limits of continuing treatment (implying possible end-of-life decisions) is integrated into palliative care from the very start. But, as the illness progresses, physicians, parents, and patients might be confronted with a situation in which palliative treatment can no longer adequately relieve suffering. The guidelines state that, in such circumstances, an end-of-life decision can be an option to end further suffering.²² The guidelines perceive this decision to be not merely about quality of living but about quality of dying as well: about granting a child a dignified death. In the interview, the parents describe the moment the decision was made to withdraw the life-prolonging treatment. The son died in the arms of his mother, surrounded by his family.

Quote 2. “[A]t a certain moment he had...an MRI scan and...well, it showed that his brain was so severely damaged that, everything that we had ever mentioned during our talks with the cardiologist that in our view constituted a dignified existence, eh, would be absent from the life that [child] was going lead. And in consultation with the doctors, we indeed did decide then that if his life would be that bad, and if his abilities would be so restricted, that that...would not be fair to him.”

Palliative care may be continued for several years, but in most cases the child will eventually die. Sometimes a child dies a natural death, and sometimes end-of-life decisions are made.

End-of-life decisions are hardly ever spur-of-the-moment decisions. They are part of a continuing process that starts with the first talks with parents and children about the limits of palliative care. During this process, all kinds of decisions can be made that influence the life-span of the child: decisions to stop curative treatment, to limit or end life-prolongation, or, ultimately, to make an end-of-life decision such as withholding or withdrawal of life-sustaining treatment. By making quality of dying an integral part of palliative care, the guidelines emphasize the importance of the quality of dying: having a dignified death. The guidelines do not define what a good death might be, but acknowledges that this is eminently personal. For some it might be important to die of natural causes; others might want to be able to die before a certain stage is reached. These different views explain the importance attached to end-of-life decisions in the Netherlands. Not only is dying in itself important, equally important is *how* children die: the quality of dying.

From Quality of Living Toward Quality of Dying

As was described in the legal outline, in the Euthanasia Act it is always the patient who initiates euthanasia.²³ For newborns, the official regulation describes that both parents and physicians can take the initiative in the procedure.²⁴ However, the regulation is an attempt on the part of physicians to document their point of view of how to act in cases of unbearably suffering infants. In the documents that describe their practice in more detail, we see that the ultimate emphasis is on the parents and their wishes.²⁵ For children between 1 and 12 years of age, it is still unclear where the emphasis should be. Looking at the way these end-of-life decisions are currently made can possibly improve this lack of clarity.

The guidelines distinguish different types of end-of-life decisions: the withholding of treatment, the withdrawal of treatment, and palliative sedation. The guidelines stress that these end-of-life decisions are ultimately medical decisions based on the perceived futility of further treatment. Therefore, the guidelines stress that ultimately it should be the physician who makes such a decision: “It is the duty of a doctor to inform the parents and child of his decision to withhold, limit, or withdraw treatment, and guide them in this process. Contrary to commencing or continuing treatment, a doctor does not need the consent of the parents (and child) for withholding or withdrawing treatment on the basis of perceived medical futility.”²⁶ The section on palliative sedation does encourage facilitating parental involvement in the decisionmaking

process, but it also cautions that involvement might put too much pressure on them. End-of-life decisions are thus described as decisions that are predominantly made by physicians, preferably, but not necessarily, together with parents.

This description of end-of-life decisions as medical decisions made by physicians seems to conflict with our earlier observation that end-of-life decisions are decisions about something of a very personal nature: someone's suffering, and the quality of living and dying. Describing end-of-life decisions either as medical decisions about the perceived futility of treatment or, instead, as decisions about the medical treatment of someone's suffering has implications for the question of who should ultimately decide. If one perceives end-of-life decisions as merely medical decisions, it is understandable that physicians should make the decisions, as they are the experts in assessing the medical aspects of a situation. But if end-of-life decisions mainly concern personal aspects, a different type of knowledge is needed: knowledge about aspects of a person's life, and in that case, parents and children are the experts. Starting from the aim of palliative care and end-of-life decisions, the second option seems to be the most appropriate one, and this begs the question: Shouldn't the guidelines give parents a more prominent role in the decisionmaking process?

Whereas the authors of the guidelines seem to claim that end-of-life decisions are purely medical decisions about perceived futility of treatment, in our view, these statements should be understood in the context of communication with parents and children, and therefore we conclude otherwise. Parental involvement and engagement is seen as being of the utmost importance in Dutch pediatric palliative care.^{27,28} Throughout the whole process of palliative care, parents and children have a major influence on the decisions that are made. For that reason, they are unmistakably involved in the decisionmaking process, starting with the first conversations about the limits of palliative care, as was shown in the interview. The comments on end-of-life decisions should be seen in this context. When placed in the context of parental and child involvement, the comments in the guidelines do not state that parents and children should not be involved, but rather that the ultimate responsibility for the decision lies with the physician. At the same time, this means that in the case of a difference of opinion, physicians cannot be forced to continue life-prolonging treatment that they consider to be harmful for the child. Hence, the whole process leading up to an end-of-life decision is much more than the actual making of that decision: It entails all the conversations and decisions earlier in the process, as is illustrated by this quote from the interview.

Quote 3 “That they [the team of physicians] unanimously decide that continuing treatment is actually not an option. And... at first your reaction is definitely something like come on, really, no way you will pull the plug. But, well, quite soon you start to realize... and then it becomes really important that as a doctor you have a good relationship with your patients. Because we knew that this would happen, that they would say it out of... yeah really out of love for [child]. Like, you shouldn’t do this to him. And, this is not what we are doctors for and not what you are parents for.”

In brief, an end-of-life decision is a process, not a spur-of-the-moment decision, on which parents and children have a major influence in judging what, for themselves or their child, quality of life and quality of dying mean. However, because of the way that the guidelines are formulated, room for diverse interpretations may lead to differences in opinion among physicians.^{29,30} Ongoing communication among physicians, parents, and patients is a crucial element in making end-of-life decisions; those conversations ultimately shape how end-of-life decisions are being made, because they determine where the limits of quality of living and quality of dying lie. Therefore, it is crucial to learn more about the way that physicians talk with patients and parents about death before we can understand how pediatric euthanasia would work within the framework of palliative care for children.

Conclusion

The Dutch debate on pediatric euthanasia is a first step in a long process. So far, very little is known about the care of children with life-limiting diseases and the decisions that are being made in that process. Our article is a first step in providing insight into the Dutch state-of-the-art on pediatric palliative care and the Dutch stance toward the death of children. Our qualitative analysis of the guidelines shows that Dutch palliative care and end-of-life decisions for children can be seen as one single and continuing process. The ultimate aim of pediatric palliative care is to relieve suffering. In the Dutch context, this not only refers to quality of living but also to

quality of dying. This explains the focus on proportionality of life-prolonging treatment, the importance of end-of-life decisions as part of palliative care, and the idea that relieving suffering also means that the patient should be able to die a dignified death. In the Netherlands, active ending of life is not—as some authors suggest—an alternative to palliative care,³¹ but rather its final chapter. The plea of the NVK to establish regulations for euthanasia in children should be understood from this perspective. In this article, we have also raised the question of who should make the ultimate decision concerning the end of the life of a child. Our analysis shows that, although the guidelines state that the physician should ultimately be responsible for the decision, in the entire process of end-of-life decisions, there is an ongoing cooperation and communication among physicians, parents, and children. Given the individual nature of suffering, which stretches beyond the medical domain, the involvement of parents and children is of vital importance: They are the experts on their own suffering, on quality of living, and on quality of dying. So far, however, very little is known about these themes. What is the nature of suffering in children and what kinds of care do they really need in the palliative phase? Before decisions about active ending of life for children can be made, further research is urgently needed in order to answer these questions.

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