

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 9

Between relieving suffering and ending life: a qualitative analysis of end-of-life decisions in children aged 1 to 12 years in the Netherlands.

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Abstract.

Background

In the Netherlands, there are currently regulations regarding actively ending life in both patients aged 12 years or older and newborns. However, such regulations do not exist for children aged 1 to 12 years. The debate about the absence of regulations for children in this age group is complicated due to the lack of data about end-of-life care and end-of-life decision-making.

Methods

In a nationwide qualitative interview study, parents (bereaved and non-bereaved) and physicians of children aged 1 to 12 years with various life-threatening conditions were interviewed.

Results

64 parents and 34 physicians were interviewed. A range of decisions with life-shortening effects were described. No cases of active life-ending were reported. Several participants described cases of unbearable suffering in which the current options were insufficient in terms of relieving the child's suffering. In such cases, parents and physicians sometimes wished there were legal options to actively end the child's life. Physicians reported that they experienced legal uncertainty about making end-of-life decisions and requested more guidance.

Conclusion

This study provides insight into the practice of end-of-life decision-making and the attitudes of parents and physicians toward active ending of life. Improving palliative care and clarifying current regulations might help physicians feel more secure when making end-of-life decisions. Expanding regulations to allow active ending of life in children (1-12y) might help physicians not to stand empty-handed in rare cases of unbearable suffering. This is a political decision that should include a profound analysis of the ethical foundation of such a regulation.

Introduction

When a child suffers from a life-threatening condition, the possibility of death will interfere with the hopes and expectations about the future that young people tend to have. In this context, difficult questions may arise: should physicians always do everything to prolong the lives of these patients? And if a child suffers unbearably, should it be possible for physicians and parents to decide to actively end the patient's life?

A decision in Belgium in 2014 to extend the right to request euthanasia to all competent minors^{1,2} sparked a debate in the Netherlands about active life-ending in children aged 1 to 12 years³⁻⁹. Some physicians and parents stated that it was unfair to deny children aged one to twelve years, unlike neonates and patients aged twelve years and older, the right to active life-ending if they suffered unbearably.

Current regulations on active life-ending in the Netherlands

End-of-life decisions are decisions that may intentionally or unintentionally hasten death¹⁰. Such decisions, which are legal in many countries, include withholding or withdrawing life-supporting or life-prolonging treatment and administering high-dose medication to alleviate symptoms¹⁰⁻¹⁴.

Euthanasia and/or physician-assisted suicide has been legalized in several countries around the world¹⁵. In the Netherlands, there are currently two regulations that allow active ending of life in case the patient suffers unbearably provided that a number of due care criteria have been met. The Dutch Termination of Life on Request and Assisted Suicide Act allows physicians to grant requests for euthanasia made by mentally competent patients aged twelve years or older¹⁶. Between 2002 and 2018, only eight cases of euthanasia in minors were reported¹⁷.

Since 2005, there has been an additional regulation that allows active life-ending of infants (0 to 1 years of age) if the child suffers severely and has only limited chances of survival¹⁸⁻²⁰. Among the safeguards in this regulation are the requirements of a well-considered parental request, independent second opinion and post-hoc review. Only three cases of active life-ending

have been reported since the implementation of this regulation ²¹. For children aged one to twelve years, there are no legal regulations allowing the active ending of life.

However, the Dutch Criminal Code contains a legal possibility to make use of an exemption from criminal liability. A physician may claim impunity based on the concept of necessity resulting from a conflict of duties, i.e. a conflict between his professional obligation to relieve unbearable suffering and his obligation to preserve life ²². Such claims were previously made about adult patients and neonates ²³⁻²⁵. This exemption might apply to cases involving children between 1 and 12 years as well, but no claims concerning this age group have been reported as yet.

The debate on end-of-life decisions in children has revealed two knowledge gaps. Firstly, although end-of-life practices in both neonates and adults have been thoroughly investigated and documented, little is known about current practices of end-of-life care and decision-making concerning children (1-12 years) ²⁶⁻²⁹. Secondly, although a regulation concerning active life-ending has been suggested in the public debate, there is no clear evidence that parents, physicians or children would consider or miss the option of active life-ending.

To address these knowledge gaps, the Dutch minister of Health, Welfare and Sport requested research into care and decision-making for children who may be facing death ³⁰. This study provides the first overview of attitudes and requests regarding the active ending of life in the context of end-of-life decision-making for children (aged 1 to 12 years), of their parents and physicians.

Methods

We conducted a nationwide qualitative study with in-depth interviews with parents and physicians of children (aged 1 to 12 years) suffering from life-threatening conditions.

Sample

We invited both bereaved and non-bereaved parents of children (aged 1 to 12 years) with a life-threatening condition to participate in our study. Bereaved parents were eligible if their child died less than 5 years ago. Physicians of children whose parents participated in this study

(matched interviews) as well as other physicians with experiences of care and decision-making regarding children with a life-threatening condition were recruited.

Recruitment

Various platforms were used to recruit participants: Parent support groups, pediatric hospitals, pediatric palliative care teams and the Pediatric Association of the Netherlands. The aim of the recruitment of parents was to achieve maximum variation in terms of parents' level of education, place of residence and cultural background, and the child's medical condition and location of care. During the interviews with the parents, we asked the parent's consent to interview the physician most involved in making the child's health care decisions. The aim of the recruitment of non-matched physicians was to maximize variety in terms of medical specialization and care centers. Non-matched physicians were interviewed about their most recent experience in treating a child (1-12 years) with a life-threatening condition.

Interviews

One in-depth, face-to-face interview was held with each participant at a location of the participant's choice, led by a topic guide (supplementary file 1). The interviews, held in Dutch, were audio recorded and subsequently transcribed verbatim.

Analysis

The constant comparative analysis method was used³¹. The first two authors selected all the content related to decision-making. All authors read selected parts of the transcript in order to become familiar with the content. Themes were identified by an iterative process of comparing and contrasting interview segments. The coding was performed by the first two authors and reviewed by all authors. Nine meetings were held with an advisory group of researchers, physicians and parents to discuss the progress of the study, the study results and their impact on current practice.

Results

Participants

We interviewed 64 parents of 44 children (during 42 interviews) and 34 physicians, of whom 17 had treated children whose parents were interviewed as well (matched interviews). Table 1, 2 and 3 show the characteristics of the parents, children and physicians.

Table 1. Characteristics of parents (N= 42 interviews, 64 participating parents)

Relationship status	
Married/Living together	34 (81.0%)
Level of education, mothers (N=42)	
Low-level education	1 (2.4%)
Mid-level education (practical)	15 (35.7%)
Higher education (vocational)	14 (33.3%)
Academic education (university)	12 (28.6%)
Level of education, fathers (N=42)	
Low-level education	4 (9.5%)
Mid-level education (practical)	15 (35.7%)
Higher education (vocational)	14 (33.3%)
Academic education (university)	9 (21.4%)
Nationality (N=42)	
Dutch	36 (85.7%)
Other	6 (14.3%)
Religious/spiritual beliefs (N=64)	
None	39 (60.9%)
Christian	19 (29.7%)
Other	6 (9.4%)
Number of children per family (N=42)	
1 child	8 (19.0%)
2 children	22 (52.4%)
3 children	10 (23.8%)
4 or more children	2 (4.8%)

Table 2. Characteristics of children of interviewed parents (N=44)

Gender	
Female	24 (54.6%)
Male	20 (45.4%)
Age (years) at death or at the time of the interview	
1–3	15 (34.0%)
4–6	8 (18.2%)
7–9	9 (20.5%)
10–12	12 (27.3%)
Diagnosis	
Malignancy	18 (40.9%)
Neurological/metabolic disease	17 (38.6%)
Cardiovascular disease	4 (9.1%)
Other	5 (11.4%)

Table 3. Characteristics of physicians (N=34)

Interview	
Matched interview	17 (50%)
Non-matched interview	17 (50%)
Work setting	
Academic hospital	24 (70.6%)
Regional hospital	6 (16.7%)
Other	4 (11.8%)
Specialty	
General pediatrics	11 (32%)
Intensive care medicine	5 (15%)
Oncology	4 (12%)
Neurology	4 (12%)
Intellectual disability care	3 (9%)
Metabolic medicine	2 (6%)
Neonatology	1 (3%)
Immunology	1 (3%)
Cardiology	1 (3%)
Social pediatrics	1 (3%)
General practice	1 (3%)

Themes

The interviews revealed a range of experiences regarding decision-making and active ending of life. We identified three main themes. The first theme comprises (end-of-life) decision-making and the context in which end-of-life decisions are currently made. The second theme

considers the consequences of the context in which end-of-life decisions are currently made and is divided into two sub-themes, namely the fear of legal repercussions and withdrawal of artificial nutrition and hydration. The third theme comprises the active ending of life and discussions about attitudes toward active ending of life and reasons to request active ending of life.

Theme 1. (End-of-life) decision-making

Many parents were confronted with an end-of-life decision for their child. Participants described a wide range of decisions, including decisions regarding foregoing treatment aimed at recovery, limiting life-sustaining or life-prolonging treatment, withdrawing life-sustaining treatment or providing high-dose comfort medication to alleviate symptoms. Such decisions were frequently made well before the child's condition was terminal.

Participants emphasized that not everything should always be done to prolong a child's life when the child is severely suffering. However, a number of parents testified that physicians were often too focused on continuing life-prolonging treatment without discussing the costs and benefits of this approach or the possibility of death.

(Father 08): "I think it is the responsibility of hospitals and parents to discuss the possibility of [not prolonging life] as well, because maximizing the quality of life does not always imply lengthening of life. In my opinion, that is not emphasized enough. They should have talked to us about it and should have said: 'We want what is best for your child. Is that artificially lengthening her life? Or would it be better to offer her an opportunity to die?' They should discuss that."

Theme 2. Consequences of end-of-life decisions

2a. Fear of legal repercussions

During the interviews, physicians often mentioned their fear of legal repercussions when making end-of-life decisions. Many of them worried that attempts to relieve a patient's suffering would be perceived as active life-ending by the legal authorities. Physicians suggested that there is a grey area between palliative sedation and active ending of life.

(Physician 03): “I think that palliative sedation and active euthanasia are part of a continuum. When does the former end and the latter begin?”

Physicians stressed that they missed guidance on how to make end-of-life decisions and how to correctly interpret legislation. They often felt uncertain about how ‘far’ they could go in terms of relieving a patient’s suffering without crossing the line and actively ending the patient’s life. The participants’ perceptions varied: some physicians considered the administered dose of comfort providing medication to be indicative of whether an act involves actively ending a patient’s life or relieving their symptoms, whereas others considered the administration of muscle relaxants to be sole indicator of active life-ending. Several physicians conceded that their fear of making end-of-life decisions sometimes might have caused prolonged suffering in children. They often referred to a recent court case in the Netherlands in which a general practitioner faced legal charges for prescribing high doses of sedatives to alleviate suffering in an adult patient ³².

(Physician 18): “Unfortunately, unnecessary suffering of a child still occurs because we are too scared to relieve their symptoms if this has potentially life-shortening effects. We all remember [the court case] and fear legal consequences.”

Several physicians reflected on the currently available legal possibility of exemption from criminal liability. They stated that such a procedure would involve too much insecurity and many years of legal procedures and uncertainty.

(Physician 33): “You cannot ask that of a physician. It is ridiculous to think that you — as a physician — just put your head on the block and hope that nobody will swing the axe.”

2b. Withdrawal of artificial nutrition and hydration

Although at the end of life, palliative sedation was frequently reported as a measure to relieve suffering, several participants reported experiences where despite the presence of (unbearable) suffering, palliative sedation was no option due the child’s longer life expectancy (palliative sedation formally requires that the child is in the dying phase). If the child’s life expectancy did

not allow the initiation of palliative sedation, participants reported that the children sometimes continued to suffer unbearably. In these cases, the suffering of children reported by participants comprised physical symptoms which were difficult to control by symptom-relief (such as repeated epileptic seizures, pain and discomfort) in combination with a perceived lack of quality of life.

In two cases, it was stated that the decision was made to end the child's unbearable suffering by withdrawing artificial nutrition and hydration, causing the child to die. Parents and physicians considered this the only legally acceptable way to end the suffering of their child. Physicians mentioned that the decision to withdraw artificial nutrition and hydration was only made after long discussions within the medical team and additional ethical consultation.

The following quotes show the reflections of parents and physician on a trajectory where the decision was made to withdraw the artificial nutrition and hydration from a young girl suffering from a rare metabolic condition. Physicians provided midazolam during the process to relieve the child's suffering from the withdrawal of nutrition. The child, however, did not respond to the given medication. The process lasted eight days, during which the child was fully awake. After a week, the decision was made to provide increasing levels of morphine to increase comfort for the child, after which the child died. The physician reported it to be a very difficult process, and felt unsecure in knowing what was and what was not allowed in the relief of suffering during this process.

(Father and mother 08)

Father: “[It was agreed] to focus on her comfort. It was not the intention to put her to sleep permanently, because that would be palliative sedation which was not allowed. She would receive enough medication to be comfortable. (...) However, she was wide awake and did not respond to the midazolam at all.

(...)

“After a week, the general practitioner finally said: ‘We cannot go on like this. She is not comfortable, we have not fed her in a week.’ (...) So that is when they finally decided to sedate her. (...) She died on the eighth day”.

(...)

Mother: “In a way, we were lucky. In the end, she did not die of starvation. She died from the morphine which were given as emergency therapy because she did not respond to the [midazolam]. Otherwise she might have continued to live in such a state for another three full weeks.”

(Physician 08) I know from the parents and the GP that it was an extremely tough process. Even to a point where the GP said: “let’s bring on that debate about euthanasia, because this was almost inhumane, how it went. I wanted so badly to provide comfort, but with the plan of medication that we had drawn up, I just couldn’t...”

The parents felt betrayed because they had to put their child through this final process even though everyone agreed that the child was suffering unbearably. They felt that it was justified to let the child die.

(Mother 08): I cannot understand why a developed society like ours allows a child to suffer so unbearably that it is considered alright to let her go, but [only] by means of starvation. Why? We could also have given her something to let her go immediately.”

Theme 3. Active ending of life.

3a. Attitudes toward active ending of life

The interviews revealed no evidence of active life-ending actually being carried out in practice.

(Physician 21): “We do not perform euthanasia on children, we really don’t. However, we can be generous in terms of palliative sedation and pain control. I think that this happens in all pediatric intensive care units in the Netherlands. It means that once the decision has been made that a child has no (acceptable) future the entire treatment focuses on comfort. Even minor discomfort should be treated, no matter what the consequences of this treatment are.”

While some participants thought current possibilities to relieve suffering were in general sufficient, some parents and physicians thought that legal options for active life-ending in children (1-12years) should be available. They felt that the current regulations are sometimes insufficient in terms of relieving unbearable suffering.

Physicians stressed that regulations on active ending of life should be accompanied by how to interpret the regulations in terms of how and when physicians could use them.

(Physician 03): I think [regulations] should be a bit more progressive. So that we can act more actively in hopeless situations. But additionally, I hope for more clarity as well, so you don't leave [the interpretation of the regulations] to the professionals. Because then I would still always be afraid that I'd act in a certain situation, and would end up being prosecuted (...) If you know what the rules were, it would be easier.

3b. Reasons to request active ending of life

Several parents reported that they had considered or even requested active life-ending for their child. They stated that they had witnessed unbearable suffering and saw no other option to relieve this suffering than by active ending of their child's life.

(Mother07): "His situation is just... it is so hopeless. The constant realization that it will never get any better and will only get worse. Then why on earth does he have to go through that horrible final stage of his illness? It is so... meaningless. I just cannot think of any reason why we should put him through that."

All requests discussed in this study were made by parents whose child was incapable of making a well-considered request themselves. Two types of requests could be distinguished, namely requests made for children during the process of dying and requests made for children suffering unbearably with a longer life-expectancy. No requests from children for active life-ending were found.

Requests for active ending of life during the process of dying.

The interviews revealed that most of the requests for active ending of life were made in the terminal phase, i.e. when the life expectancy of the child was limited to a maximum of weeks, or the process of dying had already started. During this phase, parents and several physicians saw unbearable suffering of the child. In children with brain tumors in particular, it was frequently observed that the mass effect of the tumor caused pain, nausea or seizures. In several cases, medication could not fully relieve the child's suffering, as physicians feared that by

further increasing the amount of sedatives, they might cross the border between symptom-relief and active life-ending.

(Mother18): “They told us: ‘We will start sedation on Saturday. Then she will become more relaxed, so that you can start to say goodbye. (...) But she did not respond well to the sedation. Her face was distorted from pain and she was very stressed and moving restlessly. She was so stressed that we sometimes had to restrain her to prevent her from jumping out of bed. She looked almost like a tiger in a cage. It was really awful and we kept asking: ‘Give her more [sedatives], please give her more.’ But that was not allowed.”

A prolonged process of dying was sometimes considered to be a cause of a child’s suffering as well. In a few cases, the dying process lasted weeks and in one case not less than almost three weeks. Physicians were not always able to sedate a child sufficiently to relieve the suffering or discomfort in this phase. Parents and physicians reported that they found it inhumane to force the child to go through this final phase.

(Mother 27): “[As a parent] you don’t sleep for two weeks and you see your child slowly slipping away. At some point, he is no longer your child and no longer there. (...) Having to go through that process was inhumane and degrading for everyone, the child as well as the family. (...) For me, it was a very traumatic experience. (...) I also would have liked to have a conversation [about the possibility of hastening death]. Would that have been active euthanasia? I’m not sure, but it would have provided the opportunity to end someone’s life in a dignified manner.”

Although many physicians agreed with the parents that a prolonged process of dying could cause suffering to both child and parents, some considered this to be natural.

(Physician 18): “I think it is okay that dying sometimes takes longer. That is part of the process and if you explain it carefully to the parents, you don’t need to hasten it. It can be beautiful as well, so that parents may say: ‘He took his time and did not give up just like that.’”

Requests for active ending of life for children with a longer life expectancy

In some cases, parents made a request for euthanasia for a child with an unknown, or longer life-expectancy. They saw unbearable suffering of their child without any quality of life. In these cases, other end-of-life decisions to stop the child's suffering could not be made because there were no life-supporting treatments to withdraw and their life expectancy was not limited enough to meet the criteria and initiate palliative sedation.

(Mother 02): “After seven or eight years, the combination of symptoms made us think: ‘Is this life really worth living for a child, without any progress?’ At some point we asked: ‘This is it?’ That makes the situation hopeless for her. We also think that she is constantly suffering because of her epileptic seizures in particular. I just do not want that for her. (...) But the problem is — and I do think this is a problem — that she has a very strong body despite her illness. Her heart will not give up very easily. As a result, there is not an appropriate time for you and the physician to decide to withdraw treatment, which will lead to her death.”

Although the conditions of these children were terminal, their precise life expectancy was difficult to determine. Several physicians acknowledged that prolonged suffering could justify a request for active ending of life whereas others emphasized the difficulty of making end-of-life decisions for children based on a perceived lack of quality of life rather than on physical suffering, which may take more visible forms, especially when the child's life expectancy is uncertain.

Discussion

In this article, we report the findings of a pioneering study into end-of-life decision-making practices for children aged one to twelve years. We studied this particular age group to bridge knowledge gaps arising from the public debate about the desirability of legal regulations allowing active life ending in these children. Our study shows that a range of end-of-life decisions are made for children with life-threatening conditions. When parents and physicians make these decisions, they navigate between providing life-prolonging treatment aimed at recovery and relieving suffering while accepting a potentially reduced life expectancy as an effect. This approach is in accordance with the Dutch care policy for these children, which states that every decision to provide life-lengthening treatment should be based on whether such a decision is in the child's best interest: not everything that can be done should always be done

Participants report a lack of clearness in guidelines about current possibilities in end-of-life decision-making for children. Especially with regard to the reported ‘grey area’ between palliative sedation and active life-ending, physicians mention a lack of clarity. As a result, some physicians may hesitate to increase the doses of morphine or sedatives for fear of inadvertently crossing the line between legally allowed end-of-life decisions and active ending of life, resulting in prolonged suffering.

In situations where all other options to relieve a child’s suffering fail, parents and physicians may feel that the only way to relieve the suffering is to discontinue artificially provided nutrition and hydration.³⁴ Both parents and physicians considered this to be the last resort in terms of ending their child’s suffering. In their perspective, withdrawing nutrition and hydration added to the suffering, which was especially unacceptable because this suffering could, according to the participants, have been alleviated through increased doses of sedatives, which were denied. This is related to the mentioned lack of clarity about how and when the increased use of morphine or sedatives is allowed.

We did not find any evidence of physicians intentionally and actively ending the lives of children aged 1 to 12 years. Notably, both for neonatal and adult patients cases of active ending of life were reported before the implementation of regulations regarding euthanasia and active ending of life²³⁻²⁵. Some parents and physicians were in favor of extending legal regulations on active ending of life to children aged 1 to 12 years. They reported that they had witnessed unbearable suffering and felt that they had not had enough reasonable options to end the child’s suffering.

The practice of voluntary euthanasia is based on self-determination.³⁵ Euthanasia requested by a patient younger than 12 years might conceptually be possible: the Belgian legislation is based on this presupposition^{1,2}. However, in this study, all requests were made by parents of children who were not mentally competent to express their wishes in an explicit manner, due to their age or neurological condition. Therefore, a regulation for the patient group reported in this study would significantly differ from regulations on euthanasia in terms of ethics and should include a deliberation of what the ethical foundation and safeguards of such practice would be.

Strengths and limitations

This study is a qualitative exploration of end-of-life decision-making in children aged 1 to 12 years. Therefore, the results cannot be generalized to other age groups. As the results are based on retrospective reports, they cannot be used to objectively judge the decisions that were made in individual cases. The strengths of this study are the considerable sample size, the participant variability and the direct approach to the topic.

Conclusion

In 2015, a nationwide debate was started in the Netherlands on active ending of life in children aged 1 to 12 years who suffer unbearably. Although the debate on regulations on active life-ending may be specific for the Dutch context, the broader question as to how far physicians should go to relieve unbearable suffering is highly relevant for an international context as well. This study provides insight into the current practice of end-of-life decision-making and the attitudes of parents and physicians toward active ending of life. Although a range of decisions with life-shortening effects were reported, we found no cases of active ending of life. Several participants, however, described cases of unbearable suffering in which the current options were not sufficient or not clear in terms of relieving the child's suffering. In such cases, parents and physicians sometimes wish there were legal options to actively end the child's life.

There is a lack of clearness on what the current limits of treating suffering are, which hinders both the treatment of suffering children and the debate on regulating active ending of life. A constructive debate on regulating active ending of life should be preceded by further clarifying the current practice of end-of-life decision-making, so physicians know what the options are, and how these options can be used to relieve suffering without fearing legal consequences. Educational efforts to clarify current legal possibilities, especially with regard to the distinction between palliative sedation and active life-ending, might help physicians feel more secure when making end-of-life decisions.

In rare cases where high-quality palliative care and proactive symptom-relief does not suffice, expanded regulations to allow active ending of life in children (aged 1-12 years) might help physicians not to stand empty-handed in cases of unbearable suffering. The (political) decision for such an extension should be preceded by a profound analysis of the ethical foundation and safeguards.

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Supplementary file: topic guide



