



# Chapter 7

## **Physician-assisted dying for children is conceivable for most Dutch paediatricians, irrespective of the patient's age or competence to decide**

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## **ABSTRACT**

### **Aim**

Paediatricians caring for severely ill children may receive requests for physician-assisted dying (PAD). Dutch euthanasia law only applies to patients over 12 who make well-considered requests. These limitations have been widely debated, but little is known about paediatricians' positions on PAD. We explored the situations in which paediatricians found PAD conceivable and described the roles of the patient and parents, the patient's age and their life expectancy.

### **Methods**

We sent a questionnaire to a national sample of 276 Dutch paediatricians, and carried out semi-structured interviews with eight paediatricians.

### **Results**

The response rate was 62%. Most paediatricians said performing PAD on request was conceivable (81%), independent of the patient's age and whether the patient or parent(s) requested it. The paediatricians interviewed felt a duty to relieve suffering, irrespective of the patient's age or competency to decide. When this was not possible through palliative care, PAD was seen as an option for all patients who were suffering unbearably, although some paediatricians saw parental agreement and reduced life expectancy as prerequisites.

### **Conclusions**

Most Dutch paediatricians felt PAD was conceivable, even under the age of 12 if requested by the parents. They seemed driven by a sense of duty to relieve suffering.

## 7.1 INTRODUCTION

If a child is terminally ill, difficult end-of-life decisions need to be made by the patient, parents and paediatricians (1, 2). If the illness is causing severe suffering despite optimum palliative care, the patient and parents may develop a desire to hasten the child's death and request physician-assisted dying (PAD) (2, 3). In the Netherlands, such requests are granted approximately 15 times a year (3, 4). Although PAD in children is rare, it is heavily debated in the international literature (5, 6).

In the Netherlands, physicians who carry out PAD can avoid prosecution if they adhere to strict criteria (7). These criteria include a voluntary and well-considered request by a well-informed patient who is suffering unbearably and without hope, in the absence of reasonable treatment alternatives (7). A physician is always free to refuse a request for PAD, even if all the criteria have been met. The Dutch Euthanasia Act only applies to children over the age of 12. If the children are aged 12 to 15, the parents need to consent to their child's request for PAD. Children who are aged 16-17 can decide for themselves, but physicians must involve their parents in decision-making (7).

Ever since the enactment of the Dutch Euthanasia Act, the strict age limits have been a topic of debate. Some Dutch paediatricians argue that well-considered requests for PAD from children under the age of 12 should be legally valid (8, 9). Others take it a step further and argue that the regulations should also apply to requests for PAD made by the parents of children who are not competent to decide and are suffering unbearably (9, 10).

The opinion of paediatricians is crucial in the debate. However, few studies have been carried out to identify the factors influencing paediatricians' attitudes towards PAD for children. The most recent Dutch study was conducted in 2002, and this showed that 60% of the 63 paediatricians who were surveyed were willing to perform PAD if the child explicitly requested it and, more importantly, if the parents agreed (11). Many of these paediatricians disagreed with strict age limits for euthanasia (8). A study in Belgium in 2007-2008 yielded similar results (12). The role of life expectancy in paediatricians' decisions on PAD is unknown, but it has been reported to influence other physicians' attitudes to PAD in adult patients (13).

To explore the attitudes of Dutch paediatricians to PAD, this study aimed to answer four research questions. The first was how many paediatricians had experience of PAD or requests for PAD and in which situations they had carried out PAD? The second was whether paediatricians found PAD conceivable for children in the event of a request by the patient or by the parents or without a request. Thirdly we wanted to know what role the patients and parents played in decisions about PAD, and

fourthly we wanted to explore the roles of legal age limits and life expectancy in paediatricians' decisions about PAD.

## 7.2 METHODS

### Design and population

We used a mixed-method approach to gather both representative data and in-depth data. The results of the survey of paediatricians provided a quantitative framework that covered research questions one, two and four, and we then used qualitative face-to-face interviews to explore research questions three and four in more detail. The survey involved sending a questionnaire by post to a random nationwide sample of 300 paediatricians. Addresses were obtained from the Bohn Stafleu-van Loghum medical database, a national database of registered physicians, which holds the details of 1,179 of the 1,449 paediatricians in the Netherlands (14). The inclusion criteria were working as a paediatrician in the Netherlands in the last year and having a registered work address, and the exclusion criteria were working solely as neonatologist or for a communal public health service. At the end of the questionnaire, paediatricians were asked whether we could invite them for an interview and 16 paediatricians said they were willing to be interviewed. For the interview study, we deliberately selected a sample of paediatricians that we felt would reflect diverse opinions, by inviting paediatricians with and without experience of PAD, males and females, those who were religious and not religious, and those working in academic hospitals and general hospitals and in different sub-specialisations. Unfortunately, none of the paediatricians who found performing PAD to be inconceivable agreed to be interviewed. In the course of sampling, we invited 13 paediatricians to take part and eight agreed to be interviewed. In accordance with Dutch legislation, the study did not need to be reviewed by a medical ethical committee because the participants were not subject to procedures or required to follow rules of behaviour (15).

### Questionnaire

The questionnaire was adapted from a questionnaire about PAD for non-paediatric physicians that was used in 2005 and 2011 and validated in 2005 (16, 17). Anonymity was ensured by using unnumbered questionnaires. In an accompanying letter, the Ministry of Justice gave a guarantee that physicians would not be prosecuted on the basis of information given to the researchers. Data was collected in 2012. Two reminders were sent and non-responders were asked to state their reason for not responding using a response card. At the beginning of the questionnaire, PAD was

defined as “intentionally hastening a patient’s death by administering lethal drugs or by providing a patient with lethal drugs, with or without the patient’s request”. It clearly stated that the questionnaire only concerned patients aged one to 17. Respondents were first asked about their experiences with requests for PAD by patients and parents. They were then asked whether they had ever intentionally hastened a patient’s death in 11 different situations, namely different age groups and conditions, at the request of the patients, at the request of the parents, or without explicit request. Following this, we asked them to answer yes or no to whether they found it conceivable to hasten a patient’s death in the same 11 situations. The questionnaire ended with a section on respondent characteristics. The relevant sections of the questionnaire are shown in Appendix 1.

### **Interviews**

Semi-structured interviews were conducted in 2014-2015 and lasted an average of 46 minutes. The interviews were conducted by two of the authors (EF and EB) and took place at the paediatricians’ practices. The participants were informed about the study and consented to participate and to be audiotaped. We used a semi-structured topic list, based on the findings from the survey (see Appendix 2). Field notes were made after each interview and the interviews were transcribed verbatim. An important topic that arose from the interviews, was a child’s level of competence. In Dutch law competence is a legal status and children over the age of 12 are normally deemed to be competent. However, paediatricians often refer to competence as the gradually developing ability to make medical decisions and they assess this ability individually in each child. In this paper, we refer to competence as it is used in clinical practice, unless otherwise stated (18).

### **Data analysis**

The survey data was analysed with IBM SPSS Statistics for Windows, Version 20.0 (IBM Corp. Armonk, New York, USA). Confidence intervals were calculated using the adjusted Wald method. Conceivability in different situations was compared and the significance of the differences was tested with McNemar’s test. Some categories were combined for analysis. This approach was chosen so that comparisons could be made between different age groups and between requests by a patient and a parent or parents, both separately and in combination. For instance, the two categories of had performed PAD on the request of a patient aged one to 11 and had performed PAD on the request of the parents of a patient aged one to 11 were combined as had performed PAD on request for a patient aged one to 11. Combined categories are indicated in the tables.

The first two interviews were discussed by three authors (EF, EB and RP) and some adaptations were made to the topic list. The Qualitative Analysis Guide of Leuven method was used for the analysis (19). First, two authors (EF and EB) read the interviews and made narrative interview reports. These were compared and discussed and a conceptual summary was made of each interview. In the second phase, the conceptual interview summaries were compared by the same two authors and used as the basis for the coding tree. The codes were structured around the research questions. One of the authors (EB) reread and coded the interviews. There was a high level of consensus among the interviewees and no new codes emerged after five interviews. The data were analysed manually.

## 7.3 RESULTS

### Participants

Of the 300 paediatricians in the sample, 24 did not meet the inclusion criteria and 172 participated (62.3%). Of the non-respondents, 33 described their reason for not responding and the main reasons were lack of time (n=25) and no experience of the subject (n=5). The respondent characteristics are shown in Table 1.

The eight paediatricians who were interviewed were five men and three women, aged 44-62, working in four academic and three general hospitals spread over the Netherlands. They were one general paediatrician, two paediatric oncologists, two paediatric pulmonologists, one paediatric neurologist, one paediatrician specialising in infectious diseases and immunology and one paediatrician specialising in hereditary and congenital diseases. Two had performed PAD, two were involved in decisions by a colleague who had performed PAD, two had received requests for PAD but had never performed PAD and two had no experience with PAD. All felt that performing PAD was conceivable.

### Experience with PAD

The paediatricians' experience with PAD is shown in Table 2. A quarter had received an explicit request for PAD, with 7% in the last two years, the requests were mostly made by parents (25%) and sometimes by patients (6%). Requests for physician-assisted dying were granted by 16% of paediatricians, including 4% in the last two years, and, this was mostly in the age group 1-11 at the request of the parents (13%). Table 3 describes the experiences of two interviewed paediatricians who had received a request for PAD.

**Table 1: Respondent characteristics**

	n=172
	%
<b>Gender</b>	
Male	45
<b>Age</b>	
Mean	49
(range)	(34-64)
<b>Religious</b>	
Yes	32
<b>Specialist field*</b>	
General paediatrician	59
Specialist paediatrician	48
Oncology/haematology	11
Pulmonology	7
Endocrinology/diabetology	5
Gastroenterology and hepatology	4
Intensive care	4
Other <sup>†</sup>	20
<b>Working experience (years)</b>	
Mean	16
(range)	(2-35)
<b>Number of patient deaths in last two years</b>	
None	30
1-2	30
>2	40
<b>Received extra training in palliative care</b>	
Yes	13

0.0-2.3% missing

\* More than one answer possible

† Other sub-specialisations: cardiology 3%; hereditary and congenital diseases 3%; neurology 3%; immunology and infectious diseases 3%; social and behavioural paediatrics 3%; allergology 2%; nephrology 2%; metabolic diseases 1%; acute paediatrics 1%; rheumatology 1%; neonatology (combined with another specialty) 1%.

**Table 2: Experience with physician-assisted dying (PAD), n=172 (rounded percentages).**

	Yes		Patient's request		Parents' request	
	%	(95% CI)	%	(95% CI)	%	(95% CI)
<b>Received requests for PAD</b>						
A request for PAD in the far future	19	(13-25)	-*		-*	
An explicit request for PAD in the very near future	26	(20-33)	6	(4-11)	25	(19-32)
<b>Performed PAD on request</b>						
Yes, all	16 <sup>†</sup>	(11-22)	5	(2-9)	14	(10-20)
Yes, without discussing with patient	11	(7-16)	‡		11	(7-16)
Yes, age 1 to 11	13 <sup>†</sup>	(9-19)	1	(0-4)	13	(9-19)
Yes, age 12 to 17	6 <sup>†</sup>	(3-10)	5	(2-9)	2	(1-6)
<b>Was involved in PAD performed by family physician</b>	9	(5-14)	*		*	

0.0-1.2% missing

\* Not asked

† Combined category (patient's request and, or, parents' request)

‡ Not applicable

**Table 3: Two requests for PAD (anonymised, derived from the interviews)**

Case 1
One paediatrician interviewed described a case in which a child, aged between four and six, was suffering severely from the aftermath of his acute illness:
<i>"You know, he had got through the acute phase of his illness, but he was so incredibly badly damaged that the request came from the parents and also from a lot of the other staff involved in treating him – orthopaedic surgery was involved, plastic surgery was involved, a neurologist, a paediatrician – and really all those groups were saying we shouldn't let this happen, it wouldn't be a good thing at all to keep this boy alive."</i>
Although the child was incapable of requesting PAD himself, the paediatrician became convinced PAD was the right thing to do, after careful deliberation with his colleagues.
R: <i>'It's a request from everyone. It all trickles in over one or two days, and you're thinking too: what's the point of this? Of everything that you're doing.'</i>
Although it was a team decision to terminate the child's life, the paediatrician felt the sole responsibility: <i>'It is something you do alone, but decide as a team.'</i>
(interview number seven)

**Table 3: Two requests for PAD (anonymised, derived from the interviews) (continued)**

## Case 2

Another paediatrician did not grant a request for PAD made by the parents of a patient aged between one and three with incurable cancer, who was suffering severely despite palliative care. Looking back, the paediatrician doubted this decision. She described how the parents were desperate to stop their child's suffering and felt abandoned when they learned that PAD was not an option.

*'And that boy had a very strange symptom, right at the end, he suffered from vertigo. He lay in bed and all he said was 'Mummy, Mummy, I'm falling.' ... You really end up with a kind of emotional exhaustion (in the parents); they really had no faith anymore in the course of things. Perhaps not even in the doctor, but in the regulations in the Netherlands, which they don't agree with. So a kind of panic develops: we can't help our child. This mother explained it very well.... She said: 'I had to decide whether he should undergo this treatment, and that one and that one and that one, but the end result is that my child won't survive.*

*But I was allowed to take all those decisions, even when you told me there was only a really small chance (of cure), less than 5%. You're allowed to make all those choices. But then when there is a 100% chance that my child will die, I'm no longer allowed to stand up for him; I have to accept that my child will suffer.'*

(Interview number three)

Exact ages are not shown to ensure anonymity.

## Conceivability

Table 4 describes and compares the conceivability of performing PAD in various situations, based on the 172 responses to the questionnaire. Most paediatricians found that PAD on request was conceivable (81%) and those who felt that PAD was inconceivable would all refer patients to another paediatrician. Four responses to this question were missing. Conceivability was high both in the case of a patient's request (76%) and a request by a parent or parents (71%) with no significant difference between the two categories. During the interviews, the paediatricians stated that they would consider PAD on request in cases of unbearable suffering.

*"I think that purely the fact that someone is going to die is no reason to end a life. But, if there is no hope of a cure, and the quality of life is so poor and the child himself is suffering as a result, then I can imagine doing it. First provide good supportive treatment, and if the effect is still not acceptable, then I would say yes, you could do that."* (Interview number five)

**Table 4: Conceivability of performing physician-assisted dying in different situations in the paediatrician survey (n=172)**

	Conceivable			P-value (McNemar's test)
	(%)	(95% CI)	OR	
<b>Presence of request</b>				
Request by patient and/or parent(s) <sup>†</sup>	81	(75-86)	1*	-
No explicit request by patient or parent(s)	9	(5-14)	0.02	<0.001
<b>Origin of request</b>				
<u>All ages (1-17 years)</u>				
Patient request <sup>†</sup>	76	(69-82)	1*	-
Parent request <sup>†</sup>	71	(64-78)	0.80	0.230
<u>1-11 years</u>				
Patient request	30	(23-37)	1*	-
Parent request	69	(62-76)	5.3	<0.001
<u>12-17 years</u>				
Patient request <sup>†</sup>	75	(68-81)	1*	-
Parent request	41	(34-48)	0.23	<0.001
<b>Comparison between age groups</b>				
<u>Request by patient and/or parent(s)</u>				
Age 1-11 <sup>†</sup>	72	(65-78)	1*	-
Age 12-17 <sup>†</sup>	78	(71-83)	1.4	0.078
<b>Parental consent</b>				
<u>16-17 years</u>				
Patient request	75	(68-81)	1*	-
Patient request, without consent from parents	39	(31-46)	0.208	<0.001
<b>Condition<sup>  </sup></b>				
Somatic disease <sup>§</sup>	83	(76-88)	1*	-
Life expectancy >6 months	39	(32-46)	0.13	<0.001

0.0-4.1% missing.

\* Reference group

† Combined category

‡ Combined category: 12-15 years: 65% (95% CI 58-72%), 16-17 years: 75% (95% CI 68-81%). Significant difference between ages 16-17 and 12-15 (OR 1.6, p&lt;0.001)

§ Combined category: cancer and other physical diseases. No significant difference between cancer and other (OR 1.1, p0.690).

|| With or without a request.

### Age and competence or lack thereof

There was no significant difference in how conceivable PAD was seen as being between the age groups 1-11 and 12-17, with an odds ratio (OR) of 1.4 ( $p=0.078$ ) (Table 4). In the interviews, paediatricians stated that it would seem unfair if the patient's age or level of competence was a determining factor in their decision.

*"That (age limit of 12) isn't there in practice... It can't be the case that if you're younger than 11 or 12, you just have to wait until you die and in the meantime you're in an awful lot of pain or have real difficulty breathing." (Interview number seven)*

*"But is it necessary for children ... that we say, you've got a bone glioma and you'll be dead in one, two or three weeks, but you know what, you're still going to go through all that and - even though we already know just what that will involve - you'll be forced to put up with it. An adult then has the right to say, well I don't see the point in that, I don't want to do that. But children have to put up with it, because of us, because of the Dutch medical profession, as things are arranged at the moment." (Interview number three)*

In children over the age of 12, the conceivability of PAD was higher if the request came from a patient than a parent or parents. In children under the age of 12, the opposite was found (Table 4). The paediatricians interviewed stated that some children under 12 were able to make a well-considered request for PAD, but in this age group, requests for PAD were almost always made by the parents instead of the child because the child was not competent. The paediatricians felt that where patients were not able to represent themselves, the parents – together with the paediatrician and medical team – should be able to represent the child. Although the paediatricians would be reluctant, they considered it unfair to deny children PAD because they were not competent to make the request.

*"I think that if a child is not mentally competent, someone else should be authorised to decide on their behalf. Instead of us saying well, nobody is authorised to take decisions, so we can't arrange that, with a feeling that we're also not responsible for it because (PAD) is not possible. The child can't make the decision themselves, so no one can make the decision." (Interview number three)*

If a child was not competent and the parents requested PAD, the paediatricians interviewed would still attach great value to the child's behaviour and both their verbal and non-verbal signals. This would let them assess the severity of suffering and the child's ability to cope with the symptoms.

*“A five-year old can show that he no longer wants to live, through his behaviour, because he cries all day long or is constantly in pain, whereas he always used to be a sweet, happy little child... So in my opinion they don't need to be mentally competent. You can tell from many different signs that someone no longer wants to live.” (Interview number eight)*

Moreover, some paediatricians described the importance of obtaining different perspectives on the patient's suffering:

*“If a child is too young it becomes very difficult to determine whether the parents' wish is also the wish of the child... I think that you get most support by taking due care, by having several people look at the case to really see that you're not projecting your own views on suffering too much onto the child or the parents.” (Interview number six)*

The paediatricians who were interviewed saw PAD as a team decision, made by the patient, parents and the medical team. This is described in Table 3, case 1.

Although parental consent is not legally required in children over the age of 16 who request PAD themselves, paediatricians were reluctant to perform PAD without it and the odds of finding PAD conceivable on request by a patient aged 16-17 was five times lower if the parents did not agree (Table 4). Although the patient's wish was their primary concern, the interviewed paediatricians stated that parents played a critical role in decisions about PAD for competent children. If the parents disagreed with their child's request for PAD, the paediatricians would question whether the child's decision was well considered. They also believed that the parents should have a say because a child's death would deeply affect the parents' lives.

*“Here (in the case of children over 16) you have the sliding scale again, and here too one 16-year-old is not the same as the next. ... One may have a perfectly clear idea of the situation while another may have no idea at all. So if there's a discrepancy between what the parents think and what the child thinks, then as paediatricians we're used to looking at the situation with the parents anyway.” (Interview number two)*

### **Life expectancy**

The conceivability of performing PAD was low (39%) in the case of life expectancy of more than six months (Table 4), according to the survey responses. In the interviews, two paediatricians described cases of unbearable suffering without a reduced life expectancy (see also Table 3, case 1).

*“Of course we keep on trying to save the situation for an awful long time, and by the time you reach the conclusion that there’s so much damage - as a result of disease or treatment - that you should want it to be over. The body doesn’t always give up the ghost of its own accord.” (Interview number six)*

Although most paediatricians interviewed could imagine PAD in such cases, they felt reluctant, as terminating a life when death was not imminent would feel more extreme. It could also be difficult to predict the extent of future suffering in these cases.

*“It does actually make it easier if the life expectancy is short. Whereas I do think that (a request by) someone with a long life expectancy who is suffering severely should also be considered. But on the other hand, it does make it easier if you know that the remaining life span will be short anyway, even if you do nothing.” (Interview number six)*

## 7.4 DISCUSSION

Although PAD in children is rare, a quarter of the Dutch paediatricians who took part in our survey had received requests for PAD and one in eight had performed PAD. In addition, 81% found it conceivable to perform PAD on request. Parental consent and life expectancy played an important role in decision-making, while age and the presence of a request from a competent patient played a minor role. To structure our findings and to analyse the ethical issues that are important for paediatricians, we used one of the most common ethical frameworks used in clinical ethics, namely the four topics approach developed by Jonsen, Siegler and Winslade (20).

The first of these four topics was medical indications, in which the ethical principles of beneficence and non-maleficence were reflected. At the end of life, palliative care can be indicated, but sometimes it may not relieve all suffering. In those cases, a request for PAD can be made. Because PAD is not normal medical practice, there is no medical indication for PAD and physicians are never obliged to perform PAD (21). Nevertheless, most of the paediatricians in our study found it conceivable to perform PAD if a patient was suffering unbearably and without hope. The high degree to which paediatricians found PAD to be conceivable seemed to be driven by beneficence and a sense of duty to relieve suffering. If unbearable suffering could not be relieved by the optimum palliative care, PAD could be seen as the only way to fulfil this moral duty.

The second topic related to quality of life. Before considering PAD, the paediatricians in our study said that they needed to be certain that the suffering was unbearable and without hope of improvement and that PAD was the only way to relieve that suffering, which are legal criteria for PAD. To ensure this, they would involve the patient, parents, other caregivers, experts and independent outsiders in their decision-making. If the patient was not competent to make a decision, it was especially hard to assess suffering and in those cases, a holistic assessment could be made by combining the complementary perspectives on suffering expressed by the parents, nurses and physicians (22). Finally, paediatricians said they might refrain from PAD if they felt uncertain about the prognosis and predicted level of future suffering in children with a longer life expectancy.

The third topic was the patient's preferences, or the principle of respecting patient autonomy. In paediatrics, it can be challenging to act in accordance with the principle of autonomy. Children may only be able to make their wishes implicitly known, or they may be completely incapable of participating in decision-making (23). Parents can make other medical decisions on behalf of a child who is not competent, such as the decision to forgo treatment, but the Euthanasia Act does not allow them to decide on PAD (Table 3, case 2). However, our study revealed that the majority of Dutch paediatricians would consider PAD for children who were not competent based on requests made by their parents. Paediatricians are used to parents being surrogate decision-makers for children who are not competent (24) and may apply the same principle to decisions on PAD (see also Table 3, case 2). Nevertheless, the paediatricians in our study said they would involve the child as much as possible in decision-making. The child would also need to show clear signs of discomfort for the paediatrician to be certain that PAD was in the patient's best interest.

Children aged 16 and 17 are regarded as legally competent under Dutch law (24). We found that the paediatricians in our study would take their request seriously, but would involve the parents' perspective in the decision-making as well. Paediatricians would be reluctant to perform PAD if the parents disagreed with their child's request, because this would lead to doubt as to whether the child's request was well considered and because the interests of the parents also needed to be taken into account.

The fourth and final topic was the contextual features, with justice and fairness as important ethical principles. Even though patients did not have a right to PAD, the paediatricians who were interviewed did not exclude specific patients from the option of PAD. Fairness seemed an important motive for the paediatricians we surveyed and interviewed. The interviewed paediatricians argued that it would be unfair to

exclude patients solely on the basis of their age or level of competence. This explains why most of the participating paediatricians did not support two key criteria in the Dutch Euthanasia Act: the need for an explicit request (from the patient, not the parents and the age limit. In line with a 2002 study, we found that paediatricians' attitudes towards PAD did not differ for patients under and over 12 years of age (11). Furthermore, paediatricians would sometimes consider PAD for children who were not competent if their parents made a request on their behalf.

Both Dutch and Belgian euthanasia law require a well-considered patient request for PAD (7, 25). In Belgian law, legal competence for a request for PAD is assessed individually and is not bound to a specific age, as the age limit of 18 was dropped in 2014 (25). Children in the Netherlands are not seen as legally competent under the age of 12 and the Dutch Euthanasia Act does not apply to them (24).

Finally, paediatricians may refrain from performing PAD because it places such a heavy burden on them (26). The paediatricians in our study said that this was particularly the case when the child had a longer life expectancy, as terminating life in such cases would feel more extreme than bringing forward a child's expected death by days or weeks. A small minority of paediatricians found PAD inconceivable for all children. For these paediatricians, more general arguments against PAD may have been important, such as the basic argument that taking a human life is wrong, and the fear of giving the wrong message to other patients (20).

### **Strengths and limitations**

The main strength of this study was the combination of methods, as the quantitative and qualitative data complemented each other. While the survey data provided an overview of paediatricians' attitudes in general, the interview data gave insights into the nuances and complexities associated with end-of-life decisions regarding children. The survey's strengths were its anonymity and relatively good response rate, especially in comparison with similar survey studies that achieved response rates of 34% to 55% (27-29). Nevertheless, response bias might have distorted the results somewhat (30).

One possible limitation was misinterpretation of the questions and terms in the questionnaire. Although PAD was clearly defined in the questionnaire, some paediatricians might have overlooked this definition and have regarded palliative sedation or withdrawal of life-support as PAD, leading to overestimation of prevalence and conceivability. The term conceivable could have caused some confusion, because if a certain situation is inconceivable, for instance a patient who requests PAD although their parents disapprove, performing PAD in this situation would also be inconceivable. An important limitation of the interview study was that we only conducted a small number of interviews. Because agreement was high and no new themes arose

in the last three interviews, we assumed data saturation was achieved. However, we were unable to interview paediatricians who found PAD inconceivable, although several of the paediatricians we did interview were very reluctant to perform PAD.

## 7.5 CONCLUSION

Although very few of the Dutch paediatricians who took part in our study had performed PAD, most found it conceivable to do so. Relief of suffering was the paediatricians' key objective, and PAD was an option if unbearable suffering persisted despite optimum palliative care. Most paediatricians would consider PAD in children who were not competent and children under 12. These paediatricians did not seem to support the limitations in the Dutch Euthanasia Act, which is restricted to children over 12 who can make a well-considered request themselves. As long as this situation lasts, we can expect the debate on the criteria for PAD in children to continue.

## DECLARATIONS

### **Conflict of interest statement**

We declare that we have no conflicts of interest.

### **Finance statement**

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