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The age limit for euthanasia requests in the Netherlands: a Delphi study among paediatric experts

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ABSTRACT

Background The Dutch Euthanasia Act applies to patients 12 years and older, which makes euthanasia for minors younger than 12 legally impossible. The issue under discussion specifically regards the capacity of minors to request euthanasia.

Objective Gain insight in paediatric experts' views about which criteria are important to assess capacity, from what age minors can meet those criteria, what an assessment procedure should look like and what role parents should have.

Methods A Delphi study with 16 experts (paediatricians, paediatric nurses and paediatric psychologists) who work in Children Comfort Teams in Dutch academic hospitals. The questionnaire contained statements concerning criteria for capacity and procedural criteria. Consensus was defined as ≥80% agreement.

Results The experts agreed that five criteria for capacity, found in a previous literature study, are all important. They agreed that some children between ages 9 and 11 could meet all the criteria. Consensus was reached for the statements that the entire medical team should be involved in the decision making and that a second independent expert must assess the case. Experts agreed that the parents' opinion is relevant and should always be taken into account, but it need not be decisive.

Conclusion This study shows that the age limit of 12 years in the Dutch Euthanasia Act is too strong according to paediatric experts. Letting go of the age limit or lowering the age limit combined with adequate capacity assessment for minors younger than 12 are options that should be discussed further.

INTRODUCTION

The Dutch Euthanasia Act has been in practice since 2002. Euthanasia is described as intentionally ending another person's life, on their request, by administrating a lethal drug.[1 2] The physician must act according to the statutory due care criteria (box 1).[1 3] The Euthanasia Act applies to patients 12 years and older because patients younger than 12 are juridically incompetent.[4] Looking at the Euthanasia Act specifically, statutory due care criteria A and C (box 1) seem most difficult to meet for patients younger than 12. Can young patients make a well-considered request, and fully understand the situation and prospects?

Since euthanasia is legally impossible for patients younger than 12 in the Netherlands, burdensome symptoms at their end of life can only be relieved with palliative care. Nevertheless, paediatricians have stated that there are cases in which palliative care is insufficient to relieve the suffering.[5] Parents have also voiced their opinions about the shortcomings of palliative care and the necessity of looking into allowing euthanasia for severely ill children younger than 12.[5 6]

Ever since the Dutch Euthanasia Act was implemented, the age limit has been a point of discussion and research.[7 8] The (international) debate intensified when Belgium removed the age limit in their Act in 2014.[9 10] Additional due care criteria apply to minors, making euthanasia more restricted for minors (box 2).[10] In the other countries with euthanasia legislation (Canada, Luxembourg, Australia, New Zealand, Spain and a few states in the USA), legislation applies to patients 18 years and older.[11 12] In Colombia, euthanasia is possible from the age of six, however, only in the terminal phase.[11 13]

In the Netherlands, several studies on paediatricians' and ethicists' opinions have been published throughout the years.[5 7 8 14 15] According to these studies, a substantial number of paediatricians did not agree with the age limit of 12 years.[5 8 14] Only a minority (15%) of physicians felt that euthanasia is never acceptable for children younger than 12.[7] Fifty-seven per cent of paediatricians would use a lethal drug if a 11-year-old explicitly requested this, and if the parents agreed.[7] In a 2006 study, paediatricians stated that some 10-year-olds can make a well-considered decision, and about half of the 63 paediatricians in that study agreed that the age limit is too strict and that cases should be considered individually instead.[8] In a recent 2019 study report, paediatricians stated that very young children already can have insight in the end of life and they concluded that children aged 7–9 could understand their disease sufficiently enough to have a voice in (parts of) decision making around the end of life. Furthermore, most paediatricians did not want to burden parents with the responsibility of making decisions about shortening their child's life. However, some paediatricians were willing to include the parents in these decisions more. Most paediatricians believe that parents are better at determining their child's suffering than professionals.[5]

These studies show that the age limit of 12 is under discussion and that there is reason to believe that some children younger than 12 may have the capacity needed to make decisions about euthanasia. To explore expert opinions among paediatric healthcare workers, this study aimed to answer the following research questions: what criteria are relevant for assessing the capacity needed for a valid euthanasia request? From what age can children meet these criteria for capacity? How should a

Box 1 Statutory due care criteria in the Dutch Euthanasia Act

The physician must:

(A) Be satisfied that the patient's request is voluntary and well considered.

(B) Be satisfied that the patient's suffering is unbearable, with no prospect of improvement.

(C) Have informed the patient about his situation and his prognosis.

(D) Have come to the conclusion, together with the patient, that there is no reasonable alternative in the patient's situation.

(E) Have consulted at least one other, independent physician, who must see the patient and give a written opinion on whether the due care criteria set out in (a–d) have been fulfilled.

(F) Have exercised due medical care and attention in terminating the patient's life or assisting in his suicide.

procedure for assessing capacity be set up? What can be the role of parents in determining their child's capacity?

METHODS

Study design

We conducted a conventional Delphi study, with online questionnaires taking place over two rounds from September 2020 to January 2021. Between rounds, analysis and adjustments took place based on the results and feedback of the previous round.[16] We used the online survey platform Survalyzer.

Experts and selection

The group of experts consisted of paediatricians, paediatric nurses and paediatric psychologists, representing opinions of those who work closest with children under the age of 12 in end-of-life situations in the Netherlands. By including these three types of experts we gathered the opinions of a multidisciplinary team with all different medical backgrounds.

To find these experts, we approached all eight Children Comfort Teams, active in academic hospitals in the Netherlands. These teams aim to support families who have a child with a severe illness and to guide doctors who seek their advice for such cases. They can be seen as paediatric palliative care teams. These teams are multidisciplinary and contain experts in working with severely ill minors.[17]

Box 2 Additional due care criteria for minors in the Belgium Euthanasia Act

Minors must:

(A) Make multiple and sustained requests that are both voluntary and free of pressure.

(B) Suffer physically as opposed to psychological suffering.

(C) Die within a short period of time.

(D) Be conscious until the moment of euthanasia. Advance directives cannot be used.

(E) Be seen by a paediatric psychiatrist or psychologist additionally to assess the case and the minor's capacity.

(F) Have legal representatives who consent to the euthanasia, and this consent should be written down and stored in the medical file.

We invited all Children Comfort Teams to participate in the study by selecting one paediatrician, one paediatric nurse and one paediatric psychologist from each team, aiming for eight experts per category and 24 experts in total.

The coordinators of the Children Comfort Teams discussed our question within the team and provided us with experts who were willing to participate. We invited experts from one of the Children Comfort Teams directly because we had personal contacts with them.

Questionnaire

The questionnaire (online supplemental appendix 1) was developed based on findings from a literature review and elaborate discussion within the research team.[18] Based on the two most prominent themes found in literature, capacity and parental consent, we developed statements to address the research questions. Experts were asked to answer the statements on a 5-point Likert scale and to add explanations for their answers.[16]

The first questionnaire consisted of 25 statements divided into sections A and B. In section A, we discussed five different criteria of capacity that emerged in literature and group discussion; (1) understanding the consequences, (2) understanding the disease and prognosis, (3) sufficient reasoning, (4) emotional stability, and (5) life experience.[18] Each criterion was covered by four statements. The first statement was whether or not the criterion should be seen as a criterion for capacity regardless of age. Then we asked if some minors from three different age categories could meet this criterion. The age categories used were 10–11, 6–9 and younger than 6.

In section B, we formulated statements about how a procedure for assessing capacity in children younger than 12 should look and what the role of parents or guardians should be in acknowledging their child's capacity (figure 1).

The second questionnaire (for round 2) consisted of 3 adjusted and 12 new statements (figure 1).

ANALYSIS

Agreement rates were automatically generated by the questionnaire programme Survalyzer. Consensus was defined as minimally 80% of experts (strongly) agreeing or (strongly) disagreeing with a statement. Often in Delphi studies consensus is defined as 70%– 80% (dis)agreement.[19 20] Due to the topic's sensitivity we decided to adhere to the stricter definition of consensus.

The explanations given by the experts for their answers in round 1 were analysed by the research team to prepare the questionnaire for round 2. Issues that arose and comments that were pointed out by multiple experts were used to create the questionnaire for round 2.

RESULTS

In total, 16 experts from five Children Comfort Teams filled in the first round questionnaire. The group consisted of five paediatric psychologists, four paediatricians and seven paediatric nurses. Of the participants, 94% were female. The average age of the experts was 49 and they had an average of 16.5 years of experience in the field. Most experts had experience working on a paediatric intensive care unit, in paediatric oncology or in paediatric palliative care. The psychologists worked for various children's wards.

All experts who joined round 1 received an invitation to the round 2 questionnaire, which 14 experts (87.5%) completed.

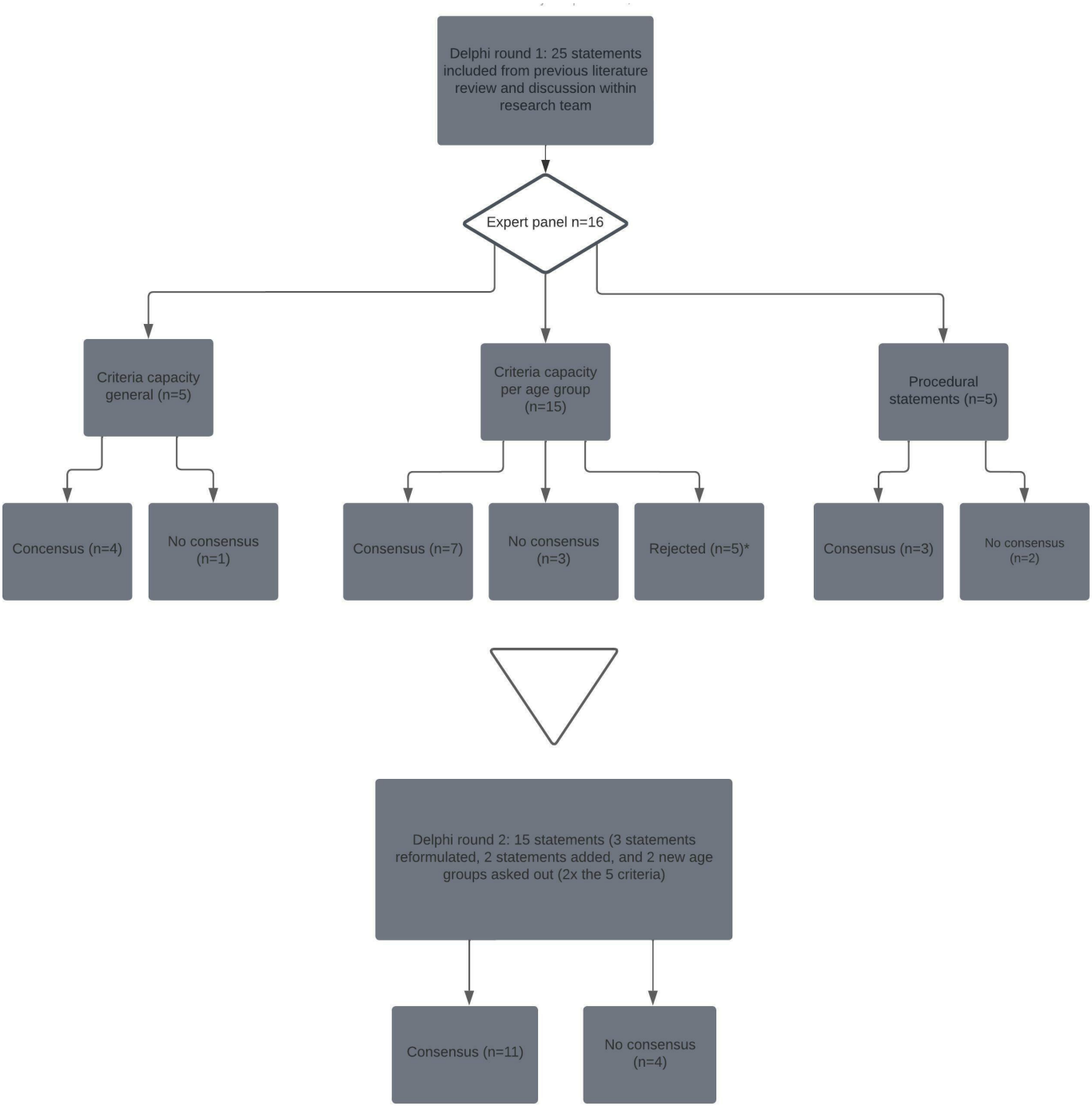

Figure 1 Overview Delphi rounds. *Statements rejected due to disagreement.

Two experts did not fill in the questionnaire before the set end date.

In round 1, 14 out of 25 statements reached consensus. In round 2, 11 out of 15 statements reached consensus (figure 1). On our first statement; that adhering to a strict age limit for euthanasia does not appropriately consider individual differences in capacity, 94% of experts agreed.

Criteria for capacity

In round 1, consensus was reached for four out of five criteria for capacity, regardless of age (table 1). No consensus was reached for the criterion relevant life experience (69% agreed). Experts mentioned that it was unclear what relevant life experience meant. In round 2, the statement was reformulated by removing the word relevant and then 100% agreed (table 1).

Criteria for capacity per age group

For the age-specific statements, experts agreed on all five criteria that some children ages 10 and 11 can meet the criteria. For all criteria, at least 88% of experts agreed for this age group (table 2).

Most indecisiveness was for the age category 6–9. No consensus was reached for any criterion in round 1. Experts stated in the explanation box that there was a large difference in development within this age group. Therefore, many experts explained that the older children could meet a criterion and the

Table 1 Consensus rates for criteria of capacity

Round 1 (n=16)	Agreement	Round 2 (n=14)	Agreement
In order to have capacity regarding a request for euthanasia, a patient (regardless of age) must adequately understand the consequences of the euthanasia request. He or she must understand that their life will be ended.	**81%**	–	
In order to have capacity regarding a request for euthanasia, a patient (regardless of age) must understand their disease and it's prognosis.	**82%**	–	
In order to have capacity regarding a request for euthanasia, a patient (regardless of age) must be able to reason sufficiently, for example, give adequate reasons for their euthanasia request.	**87%**	–	
In order to have capacity regarding a request for euthanasia, a patient (regardless of age) must show emotional stability regarding the euthanasia request.	**87%**	–	
In order to have capacity regarding a request for euthanasia, a patient (regardless of age) must have relevant life experience, for example, experience with being sick and suffering.	69%	**In order to have capacity regarding a request for euthanasia, a patient (regardless of age) must have life experience based on being sick and suffering.**	**100%**

Note: bold denotes that 80% consensus was achieved.

younger children could not. One expert stated for the criterion understanding the consequences: '*This will vary enormously per child. By the age of nine I think so, those aged six I wonder.*' For the criterion understanding the disease and prognosis another expert stated: '*[…] For those younger than eight years old, I would have many doubts.*' For the criterion sufficient reasoning another expert stated: '*Especially those children close to nine years old can do this […].*'

To see if consensus for the older children within the age group 6–9 could be reached, we asked the criteria for two new age groups (8–11 and 9–11) in round 2. For the age group 9–11, consensus was reached for all five criteria. For the age group 8–11, consensus was only reached for the criterion life experience (table 2).

For the children younger than 6, consensus was reached for the criteria understanding the consequences and sufficient reasoning. For both criteria, 81% **dis**agreed that this age group could meet these criteria. For the other criteria, there was no consensus (table 2). Only one or two experts agreed and the majority disagreed. For this reason, we decided to eliminate this age group in round 2.

Procedure for assessing capacity

Table 3 shows the results of section B of the questionnaire. All experts agreed that there should be a procedure or guideline to assess capacity in minors younger than 12. According to the experts, a guideline will help create clarity for parents and children and the medical team will know what is expected during the process. Eighty-one per cent agreed that assessment of capacity should be a team decision. Experts argued that a psychologist as well as a nurse could have important information to share from their perspective and that input from the medical team should be considered. The experts did mention that they did not feel there has to be unanimity within the team.

Consensus was not reached for the statement that a second independent expert, for example, a paediatric psychologist or psychiatrist, must also assess the child's capacity. Some experts explained that for them it did not have to be a psychologist or psychiatrist, but rather someone with experience in the field. Others mentioned that it may be helpful in cases where there was uncertainty, but that it should not be mandatory. In round 2, we formulated two new statements with the goal to specify when exactly a second independent expert should be consulted. For both new statements (1) A second independent expert should be consulted when assessing capacity and (2) A second independent expert should be consulted when in doubt about the capacity) consensus was reached (table 3).

The experts agreed that assessing capacity should not be the responsibility of one person. They stated that it is a tough decision that asks a lot of paediatricians. Therefore, support from a second expert would be helpful. The experts mentioned that an expert is also important for assessing if the whole process is carried out carefully.

The role of the parents in determining their child's capacity

Furthermore, the statement that the loved ones'/parents' opinions and explanations about a person's capacity are relevant for the assessment did not reach consensus (62% agreed). A few issues were mentioned by the experts. First, they mentioned that parents tend to have their own norms and values which they use to judge the situation. Second, parents are emotionally very involved in the situation. Perhaps too involved to give an independent opinion. On the other hand, the experts stated that one should take into account the opinion of parents. Parents know their child best and the family situation will give valuable information about the child. Experts stated that the parents' opinion is highly relevant but does not have to be decisive. With this information we made a new statement (the parents' opinion and explanations are relevant and should always be considered, yet their opinion need not be decisive) which reached consensus (table 3). Even though consensus was reached for the statement about the parents, the experts still had side notes. For instance, the child's age did seem to play a role. If a child is younger, the parents should be involved in decision making more. Another difficulty mentioned was that if we decide that the opinion of parents is not decisive this could lead to a difficult situation where parents and child do not agree. Experts stated that in such situations they would act very cautiously and that they would focus on discussing the issue further in order to solve the disagreement. It is very important that the parents agree with the choice that is made as they have to live with the loss of their child.

DISCUSSION

This Delphi study achieved consensus on the relevance of five criteria for capacity: (1) understanding the consequences, (2) understanding the disease and prognosis, (3) sufficient

Table 2 Consensus rates for meeting criteria of capacity per age group

Round 1 (n=16)	Agreement	Round 2 (n=14)	Agreement
Understanding the consequences			
Some children ages 10 and 11 can adequately understand the consequences of their euthanasia request. They understand that their life will be ended.	**94%**	–	–
Some children between the ages 6–9 can adequately understand the consequences of their euthanasia request. They understand that their life will be ended.	31%	**Some children between ages 9–11 can adequately understand the consequences of their euthanasia request. They understand that their life will be ended.**	**92%**
		Some children between ages 8–11 can adequately understand the consequences of their euthanasia request. They understand that their life will be ended.	64%
Some children under the age of 6 can adequately understand the consequences of their euthanasia request. They understand that their life will be ended.	**81% disagree**	–	–
Understanding disease and prognosis			
Some children ages 10 and 11 can understand their disease and its prognosis.	**100%**	–	–
Some children between the ages 6–9 can understand their disease and it's prognosis.	40%	**Some children between ages 9–11 can understand their disease and its prognosis.**	**100%**
		Some children between ages 8 to 11 can understand their disease and it's prognosis.	77%
Some children under the age of 6 can understand their disease and it's prognosis.	50% disagree	–	–
Sufficient reasoning			
Some children ages 10 and 11 can reason sufficiently, for example, give adequate reasons for their euthanasia request.	**94%**	–	–
Some children between ages 6 and 9 can reason sufficiently, for example, give adequate reasons for their euthanasia request.	31%	**Some children between ages 9–11 can reason sufficiently, for example, give adequate reasons for their euthanasia request.**	**100%**
		Some children between ages 8–11 can reason sufficiently, for example, give adequate reasons for their euthanasia request.	57%
Some children under the age of 6 can reason sufficiently, for example, give adequate reasons for their euthanasia request.	**81% disagree**	–	–
Emotional stability			
Some children ages 10 and 11 can show emotional stability regarding the euthanasia request.	**88%**	–	–
Some children between ages 6–9 can show emotional stability regarding the euthanasia request.	33%	**Some children between ages 9 and 11 can show emotional stability regarding the euthanasia request.**	**93%**
		Some children between ages 8 and 11 can show emotional stability regarding the euthanasia request.	78%
Some children under the age of 6 can show emotional stability regarding the euthanasia request.	69% disagree	–	–
Life experience			
Some children ages 10 and 11 can have relevant life experience, for example, experience with being sick and suffering.	**88%**	**Some children ages 10 and 11 can have life experience based on being sick and suffering.**	**100%**
Some children between ages 6 and 9 can have relevant life experience, for example, experience with being sick and suffering.	75%	**Some children between ages 9 and 11 can have life experience based on being sick and suffering.**	**100%**
		Some children between ages 8 and 11 can have life experience based on being sick and suffering.	**92%**
Some children under the age of 6 can have relevant life experience, for example, experience with being sick and suffering.	51% disagree	–	–

Note: bold denotes that 80% consensus was achieved.

reasoning, (4) emotional stability, and (5) life experience. The experts agreed that some children aged 9–11 can meet these five criteria and thus possibly have the capacity needed for a valid euthanasia request. After two rounds, a consensus was reached for all statements about procedural issues, stating that a second independent expert must also assess cases, the medical team should be involved in the decision-making, and that a guideline or protocol should be created for the assessment procedure. A consensus was also reached for the statement that the parents' opinion is relevant and should always be considered, however, it does not have to be decisive.

Adjusting the age limit?

In line with the opinion of paediatricians in earlier studies, experts in this study do not support the strict age limit of 12 in the current Dutch Euthanasia Act.[5 7 8 14] The experts believe children younger than 12 can have the capacity to ask for euthanasia.

Table 3 Consensus rates procedural statements and the role of the parents round 1 and 2

Round 1 (n=16)	Agreement	Round 2 (n=14)	Agreement
There should be a procedure/guideline to assess capacity regarding a request for euthanasia in children under the age of 12.	**100%**	–	
The assessment of capacity is a team decision which must involve the entire medical treatment team including nurses and psychologists.	**81%**	–	
Should it become possible for children under the age of 12 to have a request for euthanasia honoured, the capacity must be assessed by a second independent expert, such as a child psychiatrist or child psychologist.	69%	**A second independent expert must be consulted when assessing the capacity of children under the age of 12.**	**85%**
		When in doubt about the capacity of children under the age of 12, a second independent expert must be consulted.	**100%**
The opinion and explanations of loved ones are relevant when assessing a patient's (regardless of age) capacity regarding a request for euthanasia.	62%	**The parents' opinion and explanations are relevant and should always be considered when assessing their child's capacity. However, their opinion need not be decisive.**	**86%**

Note: bold denotes that 80% consensus was achieved.

The experts pointed out the importance of individual assessment, as there can be huge differences between children. This is in agreement with what has been said by paediatricians in an earlier study, namely, that a minor's intelligence, age, and the degree to which they are cognizant about their disease all play a role in their capacity.[8] This shows that the current strict age limit could be reconsidered.

The question that arises is how the age limit should be adjusted. There seem to be two options, namely: (1) letting go of the age limit or (2) lowering the age limit. The first option is currently adopted in Belgium, where the debate about euthanasia for minors led to the removal of the age limit of 18 years.[10 21] Minors of all ages, who are judged to have capacity, can request euthanasia. A paediatric psychiatrist or psychologist must examine the child's capacity and the suffering must be physical and not psychological in order to get a euthanasia request granted.[10] The legal representative must permit euthanasia in writing.[10] In Belgium, four cases of euthanasia in minors have been reported between 2014 and 2019. The cases were described in detail in the registration document that is needed according to the Belgium law and public information was provided in the yearly reports of the Federal Control and Evaluation Committee Euthanasia.[22] In all cases, capacity was explicitly confirmed by a paediatric psychiatrist or psychologist. In three cases, the children were 9, 11, and 17 years old and suffered from severe and progressive physical conditions. The fourth case was not specified in the report. The paediatricians involved consulted more healthcare workers than mandatory. This is in line with the Dutch experts agreeing on input from the whole medical team. All cases were unanimously approved by the Federal Control and Evaluation Committee Euthanasia.

The second option is to lower the age limit. Based on our results, 9 may be a suitable limit, keeping in mind that the experts agreed that some children between 9 and 11 could meet the criteria for capacity. However, lowering the age limit would again imply leaving no room for individual differences.

Regardless of whether the age limit is eliminated or lowered, a careful procedure would be necessary. The experts in this study agreed on some criteria for due care that they feel are important. They argued that cases should be assessed by a second independent expert with experience in the field. This is an extra rule for minors in the Belgium law as well.[10] In The Netherlands, the Euthanasia Code 2018 explains how the euthanasia review procedure works in practice. It states that euthanasia requests from patients with dementia or psychiatric illnesses must be assessed by a second independent physician with specific expertise (such as an elderly care physician or a psychiatrist).[3] These cases are more complex to assess and require someone with specific knowledge. This procedure might be suitable for euthanasia for minors as well.

The professional background of the second expert in case of euthanasia requests by minors needs to be discussed further. Should it be a paediatrician or a psychologist, who are both specialised in different aspects of care? Also the role of the medical team must be further discussed. Should the whole medical team agree; should unanimity be required? Policy-makers will have to discuss these issues with key stakeholders such as lawyers, ethicists and paediatric healthcare workers. They should also discuss if a protocol or guideline for the assessment procedure is needed. The five criteria established in this study could have a central place in this and a detailed evaluation of the first cases in Belgium could provide us with valuable suggestions.

The role of the parents

As for the role of the parents, it became evident that they are very important and that their opinion should always be taken into consideration. Yet, their opinion need not be decisive. Parents themselves, in other studies have stated that they would like to be more involved in end-of-life decisions for their children, whereas paediatricians felt the decision making for such difficult questions is their responsibility and they did not want to burden the parents with the responsibility for end-of-life decisions.[5] For this reason, we need to consider the involvement of parents in the decision-making process properly and consider developing a guideline on how to include parents in the process.

A specific issue is what to do in case of disagreement between parents and child. On the one hand, giving priority to the parents would mean overruling the child's autonomy, which can be assumed in case of capacity. On the other hand, parents can be regarded as guardians and they have to cope with the loss for the rest of their life. For this reason, the experts pointed out that it is important to try and solve the disagreement. The current Euthanasia Act states that consent of the parents or guardian is mandatory until the child reaches the age of 16.[1] This implies a tension with the child's capacity, on which the experts agreed. If a new regulation were to be created for minors younger than 12, the topic of parental consent must be discussed. Should parental consent be mandatory until the age of 16 or should parents have another role?

International importance

Worldwide the majority of countries that have euthanasia legislation, such as Canada, Luxembourg, Australia and Spain, only include patients aged 18 years and older. These countries could use the results from this study and the experiences from Belgium and The Netherlands with euthanasia for minors, to reconsider their age limit.

Strengths and limitations

This study has several strengths. The first is that it gathered the views of multiple paediatric healthcare workers. Not only paediatricians were included, as is the case in many previous studies,[5 7 14] but also paediatric nurses and psychologists. This gives us a multidisciplinary view on the topic of capacity regarding a euthanasia request in minors. Further, the high rate of agreement among the experts contributes to the efficacy of our findings. Third, this study is the first, to our knowledge, which focuses on what is important for an assessment procedure for minors. The issues that were discussed and brought up by the experts are important for policy-makers.

A limitation is that our number of participants is relatively low. We anticipated having 24 experts (eight per group), but we ended up having 16 after round 1 and 14 in round 2. However, relevant professional groups were adequately represented. In future studies, experts such as law experts, paediatric psychiatrists and parents should be included.

CONCLUSION

This study shows that the age limit of 12 years in the Dutch Euthanasia Act is too strong according to paediatric experts. There are large individual differences between minors concerning capacity, which makes an individual approach important. Letting go of the age limit or lowering the age limit combined with adequate and individual capacity assessment for minors younger than 12 are issues that should be discussed further. It is important to create a protocol or guideline, including the five criteria for capacity, the assessment procedure and the role of parents.

Contributors SCdK, GW and HRP were responsible for the study concept and design. All authors interpreted the data. SCdK wrote the original draft while GW and HRP reviewed and edited the draft and the visualisations. Additional adjustments were made after further input from EV. All authors critically revised the manuscript for important intellectual content. HRP supervised the study. All authors gave final approval for the work to be published. SCdK is the guarantor of this publication.

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REFERENCES

1 National Government the Netherlands. Euthanasia, assisted suicide, and non-resuscitation on request. Available: https://www.government.nl/topics/euthanasia/euthanasia-assisted-suicide-and-non-resuscitation-on-request [Accessed 20 Nov 2021].
2 Rietjens JAC, van der Heide A, Onwuteaka-Philipsen BD, *et al*. A comparison of attitudes towards end-of-life decisions: survey among the Dutch General public and physicians. *Soc Sci Med* 2005;61(8):1723–32.
3 Regional Euthanasia Review Committees. Euthanasia code 2018. Available: https://english.euthanasiecommissie.nl/the-committees/documents/publications/euthanasia-code/euthanasia-code-2018/euthanasia-code-2018/euthanasia-code-2018 [Accessed 20 Nov 2021].
4 Nederlandse Vereniging voor Kindergeneeskunde. Herzien standpunt "Levensbeëindiging kinderen 1-12 jaar" [Dutch Pediatric association. Revised point of view "Ending life in children ages 1-12"]. Available: https://www.nvk.nl/themas/kwaliteit/overige-kennisdocumenten/document?documentregistrationid=58982400 [Accessed 20 May 2021].
5 Brouwer M, van der Heide A, Hein I. Onderzoeksrapportage. Medische beslissingen rond het levenseinde van kinderen (1-12) [Research report. Medical decisions regarding a child's end of life (1-12)]. Available: https://www.kinderpalliatief.nl/professionals/onderzoek/detail/onderzoek-medische-beslissingen-rond-het-levenseinde-voor-kinderen-1-12-jaar [Accessed 05 May 2022].
6 Nieuwsuur, 28-09-2019. Onderzoek: Kinderartsen willen euthanasie kinderen als mogelijkheid [Study: Pediatricians want euthanasia for minors to be optional]. Available: https://nos.nl/nieuwsuur/video/2303791-onderzoek-kinderartsen-willen-euthanasie-kinderen-als-mogelijkheid.html [Accessed 20 May 2021].
7 Vrakking AM, van der Heide A, Looman CWN, *et al*. Physicians' willingness to grant requests for assistance in dying for children: a study of hypothetical cases. *J Pediatr* 2005;146(5):611–7.
8 Vrakking AM, van der Heide A, Onwuteaka-Philipsen BD, *et al*. Regulating physician-assisted dying for minors in the Netherlands: views of paediatricians and other physicians. *Acta Paediatr* 2007;96(1):117–21.
9 Siegel AM, Sisti DA, Caplan AL. Pediatric euthanasia in Belgium: disturbing developments. *JAMA* 2014;311(19):1963–4.
10 Raus K. The extension of Belgium's euthanasia law to include competent minors. *J Bioeth Inq* 2016;13(2):305–15.
11 Davis N. Euthanasia and assisted dying rates are soaring. But where are they legal? the guardian, July 15th 2019. Available: https://www.theguardian.com/news/2019/jul/15/euthanasia-and-assisted-dying-rates-are-soaring-but-where-are-they-legal [Accessed 04 Apr 2022].
12 Emanuel EJ, Onwuteaka-Philipsen BD, Urwin JW, *et al*. Attitudes and practices of euthanasia and physician-assisted suicide in the United States, Canada, and Europe. *JAMA* 2016;316(1):79–90.
13 Benavides LLL. The right to die with dignity in Colombia. *FRCIJ* 2018;6(6):426–9.
14 Bolt EE, Flens EQ, Pasman HRW, *et al*. Physician-assisted dying for children is conceivable for most Dutch paediatricians, irrespective of the patient's age or competence to decide. *Acta Paediatr* 2017;106(4):668–75.
15 Brouwer M, Kaczor C, Battin MP, *et al*. Should pediatric euthanasia be legalized? *Pediatrics* 2018;141(2):e20171343.
16 de Villiers MR, de Villiers PJT, Kent AP. The Delphi technique in health sciences education research. *Med Teach* 2005;27(7):639–43.
17 Kenniscentrum kinderpalliatieve zorg. Kinder Comfort Teams [Pediatric Comfort Teams]. Available: https://www.kinderpalliatief.nl/professionals/consultatie/kinder-comfort-teams [Accessed 05 May 2021].
18 De Keijzer SC, Widdershoven GAM. Expanding euthanasia legislation to include minors aged 1-12 in the Netherlands: a philosophical analysis of the arguments for and against. master thesis Vrije Universiteit Amsterdam. In: *Philosophy, bioethics, and health*, 2020.
19 Diamond IR, Grant RC, Feldman BM, *et al*. Defining consensus: a systematic review recommends methodologic criteria for reporting of Delphi studies. *J Clin Epidemiol* 2014;67(4):401–9.
20 Jünger S, Payne SA, Brine J, *et al*. Guidance on conducting and reporting Delphi studies (CREDES) in palliative care: recommendations based on a methodological systematic review. *Palliat Med* 2017;31(8):684–706.
21 Carter BS. Why palliative care for children is preferable to euthanasia. *Am J Hosp Palliat Care* 2016;33(1):5–7.
22 Federale Controle- en Evaluatiecommissie Euthanasie. Zevende, achtste en negende verslag aan de wetgevende kamers. Jaren 2014- 2019. [Federal control and evaluation committee euthanasia. Seventh, eight, and ninth report for the legislative chambers]. Available: https://overlegorganen.gezondheid.belgie.be/nl/advies-en-overlegorgaan/commissies/federale-controle-en-evaluatiecommissie-euthanasie [Accessed 20 Apr 2022].

Appendix 1

Questionnaire Delphi round 1

a) Criteria capacity

1. In order to have capacity regarding a request for euthanasia, a patient (regardless of age) must adequately understand the consequences of the euthanasia request. He or she must understand that their life will be ended.

2. Some children ages 10 and 11 can adequately understand the consequences of their euthanasia request. They understand that their life will be ended.

3. Some children between the ages 6 to 9 can adequately understand the consequences of their euthanasia request. They understand that their life will be ended.

4. Some children under the age of 6 can adequately understand the consequences of their euthanasia request. They understand that their life will be ended.

5. In order to have capacity regarding a request for euthanasia, a patient (regardless of age) must understand their disease and it's prognosis.

6. Some children ages 10 and 11 can understand their disease and it's prognosis.

7. Some children between the ages 6 to 9 can understand their disease and it's prognosis.

8. Some children under the age of 6 can understand their disease and it's prognosis.

9. In order to have capacity regarding a request for euthanasia, a patient (regardless of age) must be able to reason sufficiently, e.g., give adequate reasons for their euthanasia request.

10. Some children ages 10 and 11 can reason sufficiently, e.g., give adequate reasons for their euthanasia request.

11. Some children between ages 6 to 9 can reason sufficiently, e.g., give adequate reasons for their euthanasia request.

12. Some children under the age of 6 can reason sufficiently, e.g., give adequate reasons for their euthanasia request.

13. In order to have capacity regarding a request for euthanasia, a patient (regardless of age) must show emotional stability regarding the euthanasia request.
14. Some children ages 10 and 11 can show emotional stability regarding the euthanasia request.

15. Some children between ages 6 to 9 can show emotional stability regarding the euthanasia request.

16. Some children under the age of 6 can show emotional stability regarding the euthanasia request.

17. In order to have capacity regarding a request for euthanasia, a patient (regardless of age) must have relevant life experience, e.g., experience with being sick and suffering.

18. Some children ages 10 and 11 can have relevant life experience, e.g., experience with being sick and suffering.

19. Some children between ages 6 to 9 can have relevant life experience, e.g., experience with being sick and suffering.

20. Some children under the age of 6 can have relevant life experience, e.g., experience with being sick and suffering.

b) Assessing capacity

21. Adhering to a strict age limit for euthanasia does not appropriately consider individual differences in capacity.

22. Should it become possible for children under the age of 12 to have a request for euthanasia honored, the capacity must be assessed by a second independent expert, such as a child psychiatrist or child psychologist.

23. There should be a procedure/guideline to assess capacity regarding a request for euthanasia in children under the age of 12.

24. The assessment of capacity is a team decision which must involve the entire medical treatment team including nurses and psychologists.

25. The opinion and explanations of loved ones are relevant when assessing a patient's (regardless of age) capacity regarding a request for euthanasia.

<u>Questionnaire Delphi round 2</u>

a) New statements

1. In order to have capacity regarding a request for euthanasia, a patient (regardless of age) must have life experience based on being sick and suffering.

2. Some children ages 10 and 11 can have life experience based on being sick and suffering.

b) New age categories

3. Some children between ages 9 to 11 can adequately understand the consequences of their euthanasia request. They understand that their life will be ended.

4. Some children between ages 8 to 11 can adequately understand the consequences of their euthanasia request. They understand that their life will be ended.

5. Some children between ages 9 to 11 can understand their disease and it's prognosis.

6. Some children between ages 8 to 11 can understand their disease and it's prognosis.

7. Some children between ages 9 to 11 can reason sufficiently, e.g., give adequate reasons for their euthanasia request.

8. Some children between ages 8 to 11 can reason sufficiently, e.g., give adequate reasons for their euthanasia request.

9. Some children between ages 9 to 11 can show emotional stability regarding the euthanasia request.

10. Some children between ages 8 to 11 can show emotional stability regarding the euthanasia request.

11. Some children between ages 9 to 11 can have life experience based on being sick and suffering.

12. Some children between ages 8 to 11 can have life experience based on being sick and suffering.

c) Assessing capacity

13. The parents' opinion and explanations are relevant and should always be considered when assessing their child's capacity. However, their opinion need not be decisive.

14. A second independent expert must be consulted when assessing the capacity of children under the age of 12.

15. When in doubt about the capacity of children under the age of 12, a second independent expert must be consulted.