

## ORIGINAL ARTICLE

# What hinders and helps in the end-of-life decision-making process for children: Parents' and physicians' views

Ilse H. Zaal-Schuller<sup>1</sup>  | Rosa Geurtzen<sup>2</sup>  | Dick L. Willems<sup>3</sup> | Mirjam A. de Vos<sup>3</sup> | Marije Hogeveen<sup>2</sup>

<sup>1</sup>Emma Children's Hospital, AmsterdamUMC location AMC, Amsterdam, the Netherlands

<sup>2</sup>Amalia Children's Hospital, Radboudumc, Nijmegen, the Netherlands

<sup>3</sup>Section of Medical Ethics, University of Amsterdam, Amsterdam, the Netherlands

## Correspondence

Ilse H. Zaal-Schuller, Emma Children's Hospital, AmsterdamUMC location AMC, Amsterdam, the Netherlands.  
Email: [i.h.schuller@amsterdamumc.nl](mailto:i.h.schuller@amsterdamumc.nl)

## Funding information

In this manuscript, original transcripts from 4 interview studies were merged into one data set and then analysed. For two of these studies (16,17), funding from Fonds Nuts Ohra was received (grant number 1405-135). Another study (18) was funded by the Rehabilitation Fund (het Revalidatiefonds) (grant number R2011131), the Fund for Intellectual Disabilities (het Fonds Verstandelijk Gehandicapt) (grant number L2011057) and the Erasmus Medical Centre, Department of Intellectual Disability Medicine (grant number SC200007). The fourth study did not receive any funding. The funds did not in any way influence the data acquisition, data analysis or drafting of this manuscript

## Abstract

**Aim:** To investigate the main factors which facilitate or hinder end-of-life decision-making (EoLDM) in neonates and children.

**Methods:** A qualitative inductive, thematic analysis was performed of interviews with a total of 73 parents and 71 physicians. The end-of-life decisions mainly concern decisions to withhold or withdraw life-sustaining treatment.

**Results:** The importance of taking sufficient time and exchanging clear, neutral and relevant information was main facilitators expressed by both parents and physicians. Lack of time, uncertain information and changing doctors were seen as important barriers by both parties. Most facilitators and barriers could be seen as two sides of the same coin, but not always. For example, some parents and physicians considered the fact that parents hold strong opinions as a barrier while others considered this a facilitator. Furthermore, parents and physicians showed differences. Parents especially underlined the importance of physician-related facilitators, such as a personalised approach, empathy and trust. On the contrary, physicians underlined the importance of the child's visible deterioration and parents' awareness of the seriousness of their child's condition and prognosis as facilitators of EoLDM.

**Conclusions:** This study gained insight into what parents and physicians experience as the main barriers and facilitators in EoLDM for neonates and children.

## KEYWORDS

communication, decision-making, end-of-life decisions, ethics, paediatrics

## 1 | INTRODUCTION

End-of-life (EoL) decisions are among the most difficult decisions to make, from a medical, emotional, ethical and legal point of view. Decision-making regarding EoL (EoLDM) in paediatrics, that is deciding for another person who (partially) lacks decision-making

capacity, is even more complex. In the Netherlands as well as in other developed countries, EoL decisions (Box 1) are not an uncommon phenomenon (1-3). Almost all deaths (95%) occurring in Dutch NICU's are preceded by EoLDM (4). Of all deaths in Dutch children aged 0 to 1 year, 66% is the consequence of EoLDM (5); for the age group 1 to 16 years, this rate is approximately 48% (5,6)

**Abbreviations:** EoL, end-of-life; EoLDM, end-of-life decision-making; LST, life-sustaining treatment; NICU, neonatal intensive care unit; PICU, paediatric intensive care unit; SDM, shared decision-making.

This is an open access article under the terms of the [Creative Commons Attribution-NonCommercial](https://creativecommons.org/licenses/by-nc/4.0/) License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited and is not used for commercial purposes.

© 2022 The Authors. *Acta Paediatrica* published by John Wiley & Sons Ltd on behalf of Foundation Acta Paediatrica.

**BOX 1 Main end-of-life decisions in children (1)**

Foregoing treatment:

*Withholding treatment:* refraining from medical treatment that is potentially life sustaining

*Withdrawing treatment:* interrupting medical treatment that is potentially life sustaining

Alleviating pain or other symptoms by using drugs with a possible life-shortening effect  
Deliberate ending of life

Parents consider communication of decisions an essential part of the decision-making process (7-9). Physicians must provide understandable information while communicating with empathy and sensitivity to the parent's needs (7). Most parents prefer to actively participate in EoLDM as is recommended by patient and professional organisations (10,11). The effects seem positive: parents who shared in EoLDM in the NICU reported less grief symptoms (12). The degree to which parents' values and opinions are being heard and consequently integrated into the decision shows considerable variation in and over hospitals (13-15).

Studies investigating the perspectives of both parents and physicians on what hinders and facilitates the EoLDM process in children are scarce. Therefore, we performed a secondary analysis of previously collected transcripts of interviews and focus groups with a wide variety of parents and physicians. All parents had been confronted with EoLDM for their child. All physicians had been actively involved in making EoL decisions for their patients.

Our aim was to identify the main factors which according to parents and physicians facilitate or hinder EoLDM in critically ill neonates and children and to formulate practical recommendations how to improve EoLDM in neonatology and paediatrics, based on these findings.

## 2 | METHODS

### 2.1 | Study design

We performed a secondary, qualitative analysis on semi-structured interviews and focus groups that were held with parents and doctors in various paediatric end-of-life settings. These interviews were conducted in the Netherlands and involved 15 different hospitals.

### 2.2 | Setting and study population

A total of 88 original transcripts were included from formerly held semi-structured interviews and focus groups (16-18). In these interviews and focus groups, a total number of 73 parents of 54 children aged prenatal until 18 years for whom an EoL decision had been made participated. Moreover, 71 physicians participated who were involved in EoLDM on a regular basis. These EoL decisions

### Key notes

- Knowledge is lacking about the factors which facilitate or hinder end-of-life decision-making in neonates and children.
- According to both parents and physicians, it helps when sufficient time is taken to exchange clear, neutral and relevant information.
- Physicians name parents' awareness of the seriousness of their child's condition and prognosis as an important facilitator, while parents consider a personal, empathic approach and support by non-medical professionals to be important facilitators.

concerned withholding or withdrawing life-sustaining treatment (LST) and/or administering drugs with a possible life-shortening effect to alleviate pain or other symptoms. Participants were either parents or physicians involved in a) prenatal decision-making in extreme prematurity at 24 weeks of gestation (16,17), b) EoLDM in children with profound intellectual and multiple disabilities (18) or c) EoLDM concerning (acute) critically ill children aged 0 until 18 years of age<sup>1</sup>. All transcripts were derived from earlier performed studies and conducted in various hospitals and clinical settings. The professionals regarding prenatal decision-making participated in focus group interviews, and all other professionals and all parents participated in individual interviews. All interview guides contained comparable questions on the process of decision-making (guides are available upon request).

### 2.3 | Data collection and analysis

A thematic analysis was performed to analyse the transcripts(19). First, all transcripts were inductively coded to identify all factors that parents and/or physicians considered to contribute to or to hinder the EoLDM process. Second, these facilitators and barriers were categorised. For each facilitator and barrier, it was noted whether this arose from parents, physicians or both. The main researcher (IZ) performed the coding and categorisation together with two research assistants (RV and JV). Discrepancies were discussed until consensus was reached. Third, four researchers (IZ, RG, MH and MV) extensively discussed all categorised facilitators and barriers to check them once again and to look for overarching patterns.

We continued until we had coded all transcripts, although saturation was reached after having coded 2/3 of all transcripts. The analyses were conducted with the aid of the qualitative analysis tool MAXQDA (VERBI GmbH, Berlin, Germany). Our coding scheme is available upon request.

<sup>1</sup>Unpublished data, available upon request.

### 3 | RESULTS

A total of 88 transcripts were included. The main characteristics of the included children, parents and physicians are presented in Table 1. The barriers and facilitators named by the participating parents and physicians could be categorised into four overarching themes: 1) situation at the onset of the EoLDM process, 2) preparation and organisation of meetings regarding EoL decisions, 3) communication during these meetings and 4) overall support and follow-up. In Table 2, we present an overview of the main barriers and facilitators per theme and supplement them with illustrative quotes from all interviews. Below, we will discuss them in more detail.

#### 3.1 | Situation at the onset of the EoLDM process

##### 3.1.1 | Barriers

Both physicians and parents indicated that the absence of a physician in charge could hinder EoLDM. A physician said: *'We consulted the pediatric oncologist, an ethics consultant and the head of the department. It was a good thing to consider it all carefully. But I think it is a disadvantage to get so many different opinions while no one took the lead'*. A barrier indicated often by physicians was the inability of a (too young or too ill) child to express his or her<sup>2</sup> own wishes. This was especially important when a conflict in the interpretation of the child's non-verbal signs arose between parents and physicians. Parents mentioned mutual mistrust as an important barrier during EoLDM with a high negative influence. For example, one parent described the physician of her son as follows: *'That other doctor did not even know who we were. She made us feel like we were just production line work'*.

##### 3.1.2 | Facilitators

The presence of a trustful relationship was one of the most important facilitators during EoLDM. Both parents and physicians also underlined that it was helpful when parents were aware of their child's condition and/or prognosis. Furthermore, both considered it helpful when parents were able to clearly express their views and needs. As one physician explained: *'The parents pointed out very clearly which decisions were difficult and which ones were not. They told me when they needed more time to consider a decision'*. Parents especially valued their ability to read and interpret their child's non-verbal signs. For example, one parent said: *'You could see he did not want it anymore. He did go to school, which gave him a short revival until the next weekend when he was very tired. He did not recover from this exhaustion, it was over'*. Physicians considered

factors such as the child's visible deterioration or clarity of the prognosis as important facilitators.

#### 3.2 | Preparation and organisation of meetings regarding EoL decisions

##### 3.2.1 | Barriers

The absence of sufficient time was one of the most important barriers during EoLDM according to both parties. One physician explained: *'What I consider very difficult is when you sit with parents when the mother is in labor already. Then you give a lot of information and that's new information for most people. People have to process it and make a decision in a fairly short time frame'*. Furthermore, both stated that too many professionals attending a single meeting could also hinder EoLDM. One parent stated: *'On the day before he died, we had a meeting with the physician, a physician in training and of course the nurse. I did not like that there were so many people present at the meeting. I was so emotional, I didn't feel at ease anymore'*.

Parents especially considered subsequent conversations led by different physicians an important barrier. Several physicians also mentioned this factor. In the words of one physician: *'I really regret that it ended the way it did, with all other people involved, but there was no other way. You experience the negative effects of transferring the patient to the physician who has the next shift and has less history with a patient. It is very hard and difficult to transfer the nuances and everything that is going on'*.

##### 3.2.2 | Facilitators

Both parents and physicians considered having enough time to discuss EoL decisions to be very helpful. Furthermore, they stressed the importance of discussing EoL decisions during a planned meeting and pro-actively instead of incident-related. It was considered helpful when these meetings were properly prepared. As one physician said: *'In general I believe it is important to discuss this topic, even if it is not immediately necessary. To discuss what is known about how these things work with these children and to know each other's opinion concerning this. Not to draw consequences from this at that very moment'*.

Finally, both parents and physicians preferred more than one meeting to discuss and finally make an EoL decision.

#### 3.3 | Communication during meetings regarding EoL decisions

##### 3.3.1 | Barriers

Concerning the exchange of information, parents and physicians emphasised that the lack of clear, neutral and relevant information

<sup>2</sup>When he or his is written in the rest of the manuscript, he or she and his or her is meant

TABLE 1 Main characteristics of included patients, parents and physicians

Characteristics	Patients (n = 54)	Parents (n = 73, 47 mothers and 26 fathers)	Physicians (n = 71)
Age (y)			
prenatal	21		
0–4	12		
4–8	7		
8–12	6		
12–18	8		
*			
20–29		5	1
30–39		43	14
40–49		15	29
50–59		3	18
>60		0	8
unknown		7	1
Gender			
Male	31	26	31
Female	23	47	40
Main diagnosis			
Extreme prematurity	21		
Asphyxia	4		
Genetic condition	12		
Neurologic condition	2		
Metabolic condition	3		
Cancer	5		
Acute illness/trauma	4		
Unknown	3		
Final decision			
Initiating LST	18		
Withholding LST	21		
Continuing LST	2		
Withdrawing LST	6		
Withholding and withdrawing LST	3		
Administering drugs with a possible life-shortening effect to alleviate symptoms (including palliative sedation)	4		
Deceased			
No	24		
Yes	30		
Religion			
Christian		7	
Islamic		8	
Other		1	
No affiliation		24	
Unknown		33	
Educational level			
Low		3	
Middle		33	

TABLE 1 (Continued)

Characteristics	Patients (n = 54)	Parents (n = 73, 47 mothers and 26 fathers)	Physicians (n = 71)
High		34	
Unknown		3	
Marital status of parents			
Married/ living together		69	
Divorced/ living apart		3	
Widowed		1	
Specialty			
- Obstetrician			12
- Neonatologist			26
- Paediatrician			6
- Rehabilitation specialist			1
- Paediatric intensivist			13
- Paediatric neurologist			6
- Paediatric cardiologist			2
- Paediatric pulmonologist			1
- Paediatric oncologist			2
- Metabolic paediatrician			2

greatly hinders EoLDM. Furthermore, they both indicated that too much information could also become a barrier. In some cases, parents decided to audiotape the conversation, so they could relisten. Physicians sometimes felt they had to give too much information in situations where the clinical condition of a child rapidly deteriorated; they often noticed that parents had difficulties processing it. Moreover, several parents mentioned receiving contradictory information as another important barrier.

Both parents and physicians stated that different opinions between physicians and parents about the course to follow could hinder EoLDM. Only physicians mentioned strong parental opinions about future treatment, as a potential barrier during EoLDM. As one physician explained: *'The child's mother did not accept that things could go slightly different. Patterns had arisen in how it should be and so it would have to go. For example, she regarded IC hospitalizations as bumps that needed to be taken, after which things would be okay again'*.

Parents mentioned the lack of opportunity for participation in the final decision-making as barrier. For example, one parent said: *'We felt incredibly powerless. In the local hospital things didn't go well: we wanted a lot to be done but it didn't happen. In the academic hospital it went better for a while, but then the roles were reversed because we wanted to stop the treatment, but the physicians in the academic hospital wanted to continue all the treatments. And in both situations, we had nothing to say about it'*. Another barrier considered important by parents only was the restraint they felt to disagree with their child's physicians about the proposed decision.

Concerning the overall communicative aspects, both parents and physicians considered emotions as a barrier, at least if parents felt

overwhelmed by them. Physicians found it a hindering factor if parents were clearly reluctant to discuss EoLDM for their child.

### 3.3.2 | Facilitators

Parents and physicians stressed the provision of clear, neutral and relevant information as greatly helpful for EoLDM. It was also considered helpful when this information was based on the input of multiple specialists. Furthermore, both parents and physicians indicated a strong parental opinion about what is best to do as important facilitator of EoLDM.

Parents and physicians put emphasis on different facilitators. Parents found it helpful if physicians valued their opinions. Furthermore, they considered having the same opinion as their partner as an important facilitator in EoLDM for their child. Physicians on the other hand valued it if their colleagues provided them with additional medical information and wanted to discuss the decision at stake with them.

Concerning the overall communicative aspects, both parents and physicians considered a personalised approach to be highly helpful throughout EoLDM. Moreover, especially parents considered physicians' empathy as an important facilitator. Some parents and physicians indicated that when parents got the opportunity to share their emotions, this could be helpful during EoLDM. Some parents found it helpful if physicians also expressed their emotions. As one parent explained: *'Then, one of the IC doctors told us nothing could be done anymore, but he did shed a tear in the parents' room. He was very committed to us. He had also seen the course of our child in*

TABLE 2 Overview of all identified barriers and facilitators per category, illustrated by representative quotes

1) Situation at the onset of the EOLDM process						
Facilitators	Parents	Physicians	Barriers	Parents	Physicians	
Trustful relation between physician(s) and family	++	++	Mutual mistrust between physician(s) and family	++	+	
<i>Parent: 'Their honesty, openness and the confidence they gave us was the most helpful element. I got the feeling that I was not alone in this situation - they were there to support me. We would do this together.'</i>			<i>Parent: 'That other doctor did not even know who we were. She made us feel like we were just work and part of a "conveyor belt".'</i>			
Parents aware of child's condition/prognosis	++	++				
<i>Parent: 'We learned that she had four stenoses, which they tried to repair twice. They repaired it with so-called 'patches', but by doing so, caused scar tissue leading to subsequent stenosis'. It felt unrealistic to assume it would be successful the next time. These types of considerations make you decide not to try again.'</i>						
Parents able to read and interpret child's non-verbal signals	++	++				
<i>Parent: 'You could see he did not want it anymore. He went to school, which gave him a short revival until the next weekend, when he was very tired again. He did not recover from this exhaustion and so it was over.'</i>						
Parents able to express themselves clearly	++	++				
<i>Physician: 'They pointed out very clearly which decisions were difficult, and which were not. Also, they told me when they needed more time to consider a decision.'</i>						
Visible deterioration	-	++				
<i>Physician: 'And in the past he regained his own level of quality of life, but it became more and more clear with recurrent pneumonias that his pulmonary condition deteriorated beyond the point of no return.'</i>						
Clear prognosis	-	++	Unclear prognosis	++	++	
<i>Physician: 'This severely abnormal MRI scan, together with the clinical symptoms, were considered to be devastating. As a result, we suggested limiting treatment. The parents, of course, needed some time to process this. The boy was admitted with epileptic seizures, which often ends well. However, during the weekend we made the transition together from 'probably ending well' to a "severe prognosis".'</i>			<i>Physician: 'It was very difficult because we did not know. If the situation had been clear, the ambiguities in the beginning might not have been there. Then we might have gone on a different track sooner. At least, we would have had clearer insights.'</i>			
Physicians able to read and interpret child's non-verbal signals	+	++	Parents and physicians interpret child's non-verbal signals differently	+	-	
<i>Physician: 'When he arrived it was a boy who smiled at you when you stroked his head. There was real contact, something was happening between the two of us. This totally disappeared. He looked right through you. There was no way he could express if he felt good. Though he could express very clearly the pain he was suffering from.'</i>			<i>Parent 'They brought him to me and removed the ventilation. I felt him fighting. I said this, and that I thought they should not remove the ventilation. If he had not fought, then I would have stayed calm. but when someone is fighting, it made me feel that he wants salvation.'</i>			
Child able to express wishes	+	+	Child unable to express wishes	+	++	
<i>Physician: 'The proposed therapy was medication and consideration of an internal defibrillator. And he chose to live his life like he did. He was very compliant in taking his meds, but he did not want the defibrillator.'</i>			<i>Physician: 'The father himself pointed out that he would not have wanted to live this way, but that's very difficult. Everyone would say the same. I think if you would ask each child 'do you want to continue living disabled?' than every child would say "no".'</i>			
Parents get the opportunity to be present at the multidisciplinary consultations from early on	+	+				
<i>Physician: 'I want to show that our message of "no resuscitation" or "there is nothing more we can do" is preceded by many considerations and discussions [in our multidisciplinary consultations]. It is sometimes wise to let parents witness the preceding process to accept the final conclusion.'</i>						

TABLE 2 (Continued)

1) Situation at the onset of the EOLDM process					
Facilitators	Parents	Physicians	Barriers	Parents	Physicians
			Not one doctor in charge	++	++
			Physician: 'We consulted the pediatric oncologist, an ethics consultant and the head of the department. It was a good thing to consider so many opinions so deeply, I think it is a disadvantage to get so many different opinions with no one taking the lead'.		
2) Preparation and organization of meetings regarding EoL decisions					
Facilitators	Parents	Physicians	Barriers	Parents	Physicians
Enough time for meeting(s)	++	++	Lack of enough time for meeting(s)	++	++
Physician: 'Well, I think it was good that we took our time. These parents felt we listened to them. We did not force anything'.			Physician: 'What I consider very difficult is the timing of the first consultation. You often sit with parents when the mother is in labor already. Then you give a lot of information. That is new information for most people and they have to process it [...] and make a decision about it in a fairly short time frame'.		
More than one meeting	++	++			
Physician: 'If you have time to meet with them again after they have spoken to each other about it, then you might end up with a more mixed opinion compared to when you ask them immediately after you talked to them for the first time. It might be difficult for them to decide right after you have provided them with all the information'.					
Planned meeting instead of ad-hoc	++	++	Meeting ad-hoc or incident-related	++	+
Physician: 'In general I believe it is important to discuss this topic, even if it is not immediately necessary. To discuss what is known about how these things work with these children and to know each other's opinion concerning this. Not to draw conclusions from this at that very moment'.			Parent: 'It was never discussed at the start what I should expect. And I didn't know. This was the way it went in the hospital: first they started the entire treatment, and then they stopped it all again. Now I discuss everything with the regular physician. Now I think: if we had discussed this earlier, it would have been very different. I think the whole treatment would have been much more human'.		
Meeting in familiar environment	++	-	Meeting in unfamiliar environment	++	0
Parent: 'I do not want to enter that room again during my life. But at that time, the room was not too clinical - it was just fine. It is very good that there is a room for this. Nevertheless, it is a room which I shall never enter again'.			Parent: 'At a certain point, during his stay in the hospital, we went to another room to have a conversation. This conversation did not take place on the hospital ward anymore. Therefore, we knew beforehand: it is not going well'.		
Meeting properly prepared	++	++	Meeting improperly prepared	++	+
Parent: 'It was very clear to us that there was a choice. It was a well-organized conversation in which the different choices were explained, and the subsequent consequences of each choice was outlined'.			Parents: 'She never expected us to ask her so many questions. I think she was not prepared. We asked her thirty questions and she gave no answer to any of these 30 questions. I just do not think that's right'.		
			Conversations led by different physicians	++	++
			Physician: 'I really regret that it ended the way it did with all other people involved, but there was no different way. You run into the negative effects of transferring the patient to the physician of the next shift who has less history with a patient. It is very hard and difficult to transfer the nuances and everything what is going on'.		
			Too many professionals attend meeting	+	+
			Parent: 'We had the same physicians for a while. But on Wednesday before he died, we had another physician. Also, a physician in training and of course nurses were present at the meeting. I am not used to saying: 'I don't want you to be there'. But I just did not like that. I was so emotional, I didn't feel at ease anymore'.		

(Continues)



TABLE 2 (Continued)

3) Communication during meetings regarding EoL decisions					
Facilitators	Parents	Physicians	Barriers	Parents	Physicians
Physicians provide clear, neutral and relevant information about condition, prognosis and options	++	++	Physicians do not provide clear, neutral and relevant information about condition, prognosis and options	++	++
<i>Physician: 'And during every step you take, you need to consider whether it is in the child's interest. We need to be fair when providing information, which can also result in the conclusion that it is too much and future treatment is not possible; it will not be successful'.</i>			<i>Physician: 'Well sometimes—whether its correct or not, I don't know—but sometimes you have a strong personal opinion on what should be done and what should not be done. In those cases, I counsel—consciously or unconsciously towards a certain direction. And then it might be possible that I don't leave enough space for the parents in a conversation and the parents notice that. That is something I need to think about'.</i>		
Information based on input of multiple specialists	++	++			
<i>Parent: 'For me it felt good that is was a mixed group. That there were different disciplines together providing different approaches to the same story. There was a neonatologist who said: this is how we are going to do it and subsequently we will do this. At the same time, it was really nice that the doctor who we had seen the most up to that moment, the gynecologist, also attended the meeting. I felt like there was a plan and it did not bother me so much who would take the lead'.</i>					
			Parents have difficulty to understand information about condition, prognosis and options	++	++
			<i>Parent: 'That second cardiac surgery. We did not decide on that. We didn't really know what we were talking about. We thought: the doctor knows what's the best thing to do. We were living in a kind of rush and we really didn't have the knowledge'.</i>		
			Physicians provide too much information	++	++
			<i>Parent: 'Well, you know at the moment that something like that happens, it feels like you are in a tornado and there is so much you have to do. So much happens and what will happen, and you must find your way there. So if you get too much information, a lot of the information will be forgotten'.</i>		
			Physicians provide contradictory information	++	-
			<i>Parent: 'In the beginning she said: 'He is chronically ill, and you cannot do anything about it.' But later I was told: 'Possibly he will qualify for a liver transplant' and then you suddenly have a solution. So, I started reading everything about liver transplants, I had hope again. But the next day the doctor said: 'You can forget about that liver transplant, because your child has no quality of life.' Well, I really did not like that'.</i>		
Physicians value parents' opinions	++	++	Physicians ignore parents' opinions	++	+



TABLE 2 (Continued)

3) Communication during meetings regarding EoL decisions				
Physician: 'I always ask: "What do you think? Do you agree or do you have additional or different ideas?" For sure, the doctor is the one with the knowledge, you need to guide them, but with the current social media environment; parents search and find many things. If they have a reasonable request, I will often agree to it. If I find their suggestion not useful, I will explain why. I have learned a lot from parents; to see things from their perspective, especially for these kids'.			Parent: 'I once told the neurologist: "I do not want this for her" in periods when I was sure she was really deeply unhappy. No smile, just arching and stretching. And I got reactions like: "Well, what do you want? Do you want to starve her to death or something?" But that made me feel like I was saying something not allowed at all, So I tried to discuss that, but I got the feeling that I had wrong thoughts. I didn't feel like I was taken seriously in this'.	
Physicians express their personal opinion about what is best to do	++	+	Physicians do not express their personal opinions about what is best to do	+
Parent: 'In my opinion be honest and tell me all options. And if you, being a physician, have a personal opinion and you are asked to share this opinion, well just do it. And when you give your personal opinion, tell me that: 'I have a medical opinion and you have your own opinion. You have to make a decision based on those two opinions. But I also have a personal opinion' Some physicians say: 'I can't give my personal opinion, I can only give my medical opinion so I can only tell you something about the percentages and chances' Well I think; also tell me what you think what is the best to do'.			Parent: 'The doctor stayed neutral regarding the decision. He informed us about the risks and that made it difficult for us to make that decision, because we felt that it was really only up to us. The doctor did not even say: "Oh well, I would go that way"'.	
Parents and physicians share same opinions	++	++	Parents and physicians hold opposite opinions	++
Parent: 'When I contacted the hospital, they knew they needed to arrange a bed straight away - I never had to ask. It felt like a real cooperation. It felt like we were equals with the same goal'.			Physician: 'The second opinion created confusion; I was not pleased with that. The parents were not at all happy, because the treatment was continued and actually they wanted to stop'.	
Couples share same opinions	++	++	Couples hold opposite opinions	++
Physician: 'In a next conversation, the parents persisted, against the advice of the pediatric cardiologist, in their disapproval for another intervention. They wanted nature to run its course and did not want to expose their daughter to this intervention with considerable risks'			Physician: 'The parents separated a year before and the mother was the main care-provider for their son. I remember a conversation where the mother was quite emotional, but she had the clear idea: 'I do not want him to suffer. If this is it, then this is it.' But the father was not ready for that yet. A joint conversation about what we would do if treatment didn't work anymore was not possible'.	
Physicians share same opinions	+	++	Physicians hold opposite opinions	++
Physician: 'I had to make a decision for this child although I had never seen her before. Therefore, I discussed the case with my colleagues. Everyone agreed: there was nothing we could do anymore for her. This cancer would beat her. After that decision, we tried to fulfil her last wish to go home'.			Physician: 'A number of people within our team had the idea that if there's only once chance - it should be tried. But it depends on how you look at such a case. As generalists you may have a different view than sub-specialists. Sometimes they are inclined to continue a certain treatment longer than you would do as the generalist, overseeing the entire patient. The IC team for a long time mainly looked at aspects of his daily situation and did not always have enough of a helicopter view'.	
Parents hold strong opinion about what is best to do	++	++	Parents hold strong opinions about what is best to do	-
Physician: 'And then his mother said very clearly this was not something she thought that we had to make him endure'.			Physician 'The mother is in charge of the whole entire care. She doesn't accept anymore that things could also be slightly different. Opportunities to change her view were not successful. The mother regards IC hospitalizations as bumps in the road that needs to be taken, expecting that after, things will be okay again. Topics as cardiopulmonary resuscitation are difficult, not to say impossible, to discuss with the mother'.	+
Parents clearly led by child's best interests	++	+		

(Continues)

TABLE 2 (Continued)

3) Communication during meetings regarding EoL decisions				
<i>Parent: 'We are very down to earth concerning this. Sure, you talk about your own child, but then again: should we be selfish and keep her in this world? In whose interest is that? She suffers and for me it seems selfish to say: "No, you stay here, in our world". She is at an end and we need to respect this, even though this is very hard'.</i>				
			Physicians seem too much influenced by their personal emotions	+ ++
			<i>Physician: 'My own emotions also play a role in counseling. But that also makes it shared I think - not to hide and not to keep too much distance. But you take your own professional standards and values into account. With emotions you have to be careful, you are on a slippery slope, because you should not counsel too directly because of these emotions'.</i>	
			Parents hold strong religious convictions	++ ++
			<i>Parent: 'I think everything is in the child's own hands. You as a doctor, you have studied for that, but you are no God. Eventually, it is God who commanded—will she stay or not'.</i>	
Physicians take all responsibility for making the (final) decision upon parental request	++	++	Parents do not get the opportunity to participate in making the (final) decision	++ -
<i>Physician: 'I think that parents want physicians to give advice in these kinds of matters. But the decision to start treatment, knowing that the treatment will probably lead to death, is a decision I have to make. You cannot expect parents to make that decision by themselves, that is psychologically too difficult. I think it is a medical decision which the physician has to make, but you need parents to agree'.</i>			<i>Parent: 'We felt incredibly powerless. In the local hospital things didn't go well: we wanted a lot to be done but it didn't happen. In the academic hospital it went better for a while, but then roles were reversed. Because we wanted to stop the treatment, but then the physicians in the academic hospital wanted to continue all treatments. And in both situations, we couldn't say anything about it'.</i>	
			Parents do not dare to disagree with physicians about the proposed (final) decision	++ +
			<i>Parent: 'When we said: "We want to stop the treatments" we suddenly found out that we couldn't say anything about our own child. We could have pushed it, but if necessary, our custody would have been denied—the last thing we wanted. We didn't want to waste energy on lawsuits, but we wanted to give all our time to our child—since time might be short. That was the reason for us thinking "we won't escalate this any higher, we will not take it that far"'</i>	
			Parents are not receptive to start conversation	+ ++
			<i>Physician: 'Her mother just doesn't want to talk about these decisions. She cuts off every conversation I start about this and starts talking about something else. And that is very difficult. Because I think we should avoid doing things not in her child's interest'.</i>	
Personalised approach	++	++	No personalised approach	++ ++
<i>Parent: 'In the end a physician's job is to heal. And if they do that, then I don't really mind if I don't like them as a person. It is more their behavior. Like, do they talk about the patient or about my son? Maybe it doesn't matter to them, but it does to me. I want them to feel they are treating my son, not some patient with chance this or that that things will work out or not'.</i>			<i>Parent: 'We once had a discussion with the cardiothoracic surgeon. He just said, "she has a bad heart and we must fix that". He wanted a nice new cow-valve. But I thought: "look at this child, what do you think?" And I think she is an extraordinary child, but he really considered her in a different way Yes, we disagreed on that'.</i>	

TABLE 2 (Continued)

3) Communication during meetings regarding EoL decisions					
Physicians show empathy	++	+			
Parent: 'We were supported very well, and we had a doctor with empathy. I really felt he supported us, and he sympathized with us. So, we had a very good experience there'.					
Physicians share their emotions	++	-			
Parent: 'Then, one of the IC doctors told us nothing could be done anymore, but he did shed a tear in the parents' room. He was very committed to us. He had also seen the course of our child in the last two weeks. Still, if we talk about this we feel this was very special: a doctor telling us and also shedding a tear'.					
Parents share their emotions	+	+	Parents are too overwhelmed by emotions to participate in the conversation	++	++
Physician: 'She started to talk when she started crying. I finally had the feeling that I could do something for her. It was after the second opinion that she snapped. This made the situation easier for me to deal with, at least it was clear what I could do to support. She was more open in her communication, which gives me the opportunity to share some thoughts and feelings, and to show her that I could understand that it was very hard. I could just put my arm around her, she was much more approachable'.			Physician: 'The father understood that there were no options left and that this would be the end. He understood that we would start morphine. But it was not possible to discuss it with him. The mother was also very emotional, but the father was so emotional that he was no longer able to participate in this conversation'.		
4) Overall support and follow-up					
Facilitators	Parents	Physicians	Barriers	Parents	Physicians
Parents feel supported by non-medical professionals	++	++	Parents don't feel supported by non-medical professionals	+	-
Parent: 'Almost every day you see a doctor and a nurse. You speak with them about the current situation, but at a certain moment I felt like talking to a spiritual counselor, to talk about things in another way. I do not need to talk about God all the time, but it gives an extra dimension, a feeling, a deeper awareness, which I kind of needed'.			Parent: 'We were not coached by our physician. A friend had help from a social worker who was also present at all conversations with the physician, so she could discuss everything the physicians had told with the social worker afterwards. Certainly, in the beginning I would have needed that also'.		
Parents feel supported by family and friends	++	+	Parents don't feel supported by family and friends	+	+
Parent: 'At a certain day, she had a seizure which lasted very long. The doctor said we needed to talk about artificial respiration. The doctor preferred not to do this anymore. For sure, I struggled with this. Then, I discussed it with my brothers and sisters. We had our own opinion, of course, but we wanted to know what our family's thoughts were. We wanted to make sure we would not make a decision we would regret'.			Parent: 'There was not any understanding from my mother-in-law. When my wife was pregnant, my mother-in-law said very directly to her: "I cannot give it love and I will not accept it". She said about decisions my wife and I made together, "Well, we don't have to talk about that". We told her that we would stick to our choices, whether she accepted it or not. Then we were no longer welcome in her house, which was very hard'.		
Parents feel supported by their religion or belief	++	-			
Parent: 'I said a special prayer. We have a special prayer if you want to be guided. If you do not know what to do, you pray, you ask Allah: 'Guide me to do what is right.' Then, you just feel what you need to do. Even if only it brings you an inner calmness to look at things the way they are'.					

(Continues)

TABLE 2 (Continued)

4) Overall support and follow-up					
Facilitators	Parents	Physicians	Barriers	Parents	Physicians
Decision evaluated and adjusted if necessary	++	++	No opportunity presented to evaluate and adjust decision if necessary	+	+
Physician: 'What I consider very important is that when you decide to start treatment, that it doesn't mean you just go on and stop thinking. In the end we all want the same: that a child has the best possible life it can get with a good quality of life. With every new step in the treatment, we have to continue to think about whether that's the best thing to do for this specific child'.			Parent: 'After the resuscitation, we said, "We may want a second opinion". But in that conversation, we found a solution we considered satisfactory. But later that week we thought: "If you say on the one hand, 'we are not going to intervene', but in the meantime new things are happening". For us it felt like prolonged suffering'.		
Decision well documented	++	++	Decision(s) not documented	+	-
Physician: 'What I think we did really well is that we made really clear agreements. We had a really clear timeline with agreements about what we wanted to achieve at certain points in time, should the treatment be successful'.			Parent: 'It is very unpleasant to be confronted with that question every time she was admitted in the hospital. I think that we will end up at the ICU about 1 or 2 times any year. I had the experience to be increasingly asked what we want in resuscitation and ventilation. I once had a hospitalization where we were asked these questions both in the ambulance and when we arrived in the hospital. I had been asked that question 5 times! So, at one point I had a great need to put it down on paper'.		

Note: - = not mentioned by any interviewee / + = mentioned incidentally (eg by <5 interviewees) / ++ = mentioned more than incidentally (eg by >5 interviewees)

<sup>a</sup>For the readability, we selected one quote either belonging to the facilitator or the mirroring barrier.

the last two weeks. We still feel this was very special: a doctor telling us and shedding a tear'.

### 3.4 | Overall support and follow-up

#### 3.4.1 | Barriers

In general, no barriers of great importance were mentioned in this category by parents or physicians. A few parents and physicians felt that EoLDM was hindered when there was no opportunity to evaluate or re-adjust decisions when applicable. A few parents mentioned that they perceived it as a barrier when decisions were not well documented.

#### 3.4.2 | Facilitators

Mainly parents indicated support by non-medical professionals, family, friends or their religion as great facilitator of EoLDM. For example, one parent explained: 'Almost every day you see a doctor and a nurse. You speak with them about the current situation, but at a certain moment I felt like talking to a spiritual counselor, to talk about things in another way. I do not need to talk about God all the time, but it gives an extra dimension, a feeling, a deeper awareness, which I kind of needed'.

## 4 | DISCUSSION

Our study provides a comprehensive overview of the main factors that according to parents and physicians either facilitate or hinder EoLDM processes in neonatology and paediatrics. Both parents and physicians put great emphasis on the need of sufficient time to exchange clear, neutral and relevant information in an understandable way. Parents put more emphasis than physicians on support by non-medical professionals, and on a personalised approach, empathy and trust. Physicians consider it helpful when parents are aware of the seriousness of their child's condition and prognosis. Strong parental opinions may serve as a facilitator, but also as a barrier. The same holds true for strong parental emotions.

Our results highlight the wish for certainty in making EoL decisions for a child. In line with this result, physicians highly value the opinions from colleagues, as it provides more certainty or at least a sense of more certainty (20). When uncertainty about diagnosis and prognosis remains, recent guidelines on EoLDM in children recommend that this uncertainty is openly discussed with parents (11,21,22). Postponing a decision and taking the time to get a second opinion and/or observe whether a child still has chances to recover can be effective strategies to get more certainty about the prognosis and the remaining treatment options.

In our study, we observed some interesting differences between physicians and parents. Although both parents and physicians acknowledge the importance of a personalised approach,

parents highly value specific factors in line with this approach, such as one physician being in charge, physicians sharing their personal emotions with parents and physicians showing empathy. Physicians did not stress these factors. Furthermore, parents greatly valued a trustful relationship with the same physician. Another factor in our study that was especially mentioned by parents was their wish to actively participate in EoLDM. Letting parents share in EoLDM is recommended by professional organisations (11,23). This involvement can also imply that physicians make the final decision upon parental request, thereby taking into account parents' values and preferences (24). Involving parents requires advanced communication skills. Training of medical specialists may improve such skills as well as coaching 'on the job' (20). Our study confirms the outcomes of previous studies that parents consider the support by non-medical professionals and the support by their religion or belief as important facilitators in making EoL decisions for their child (25). Both facilitators were not mentioned by physicians. This may indicate that they are less aware of how these external types of support may facilitate the decision-making process. Previous research has also shown that parents' religion and belief may well help them to better cope with their emotions (25).

Strong parental emotions and opinions were mentioned as barrier as well as facilitator for a good EoLDM process. Previous research has confirmed that parents experience intense emotions when their child is seriously ill (26,27). These emotions can have a negative impact on their ability to actively participate in making EoL decisions for their child (28,29). Moreover, physicians may feel uncomfortable when faced with these intense emotions (27). Yet, in our study several physicians mentioned that strong parental emotions—if acknowledged—could also lead to more mutual trust and understanding. Seen in that light, they were experienced as a facilitator rather than a barrier.

A substantial part of the participating parents considered strong parental opinions to be a facilitator for a good EoLDM process. Several physicians shared the same point of view, while others thought this factor to be an important barrier, especially if parents' opinions appear not to be in line with the opinions of the medical team. Conflicting points of view between parents and the medical team about EoL decisions occur regularly, as recent studies have underlined (5,15,30). These studies also show that in almost all cases, these conflicts can be solved by taking more time, planning more conversations and/or organising a second opinion. Moreover, it is stressed that these conflicts may well help to improve the quality of

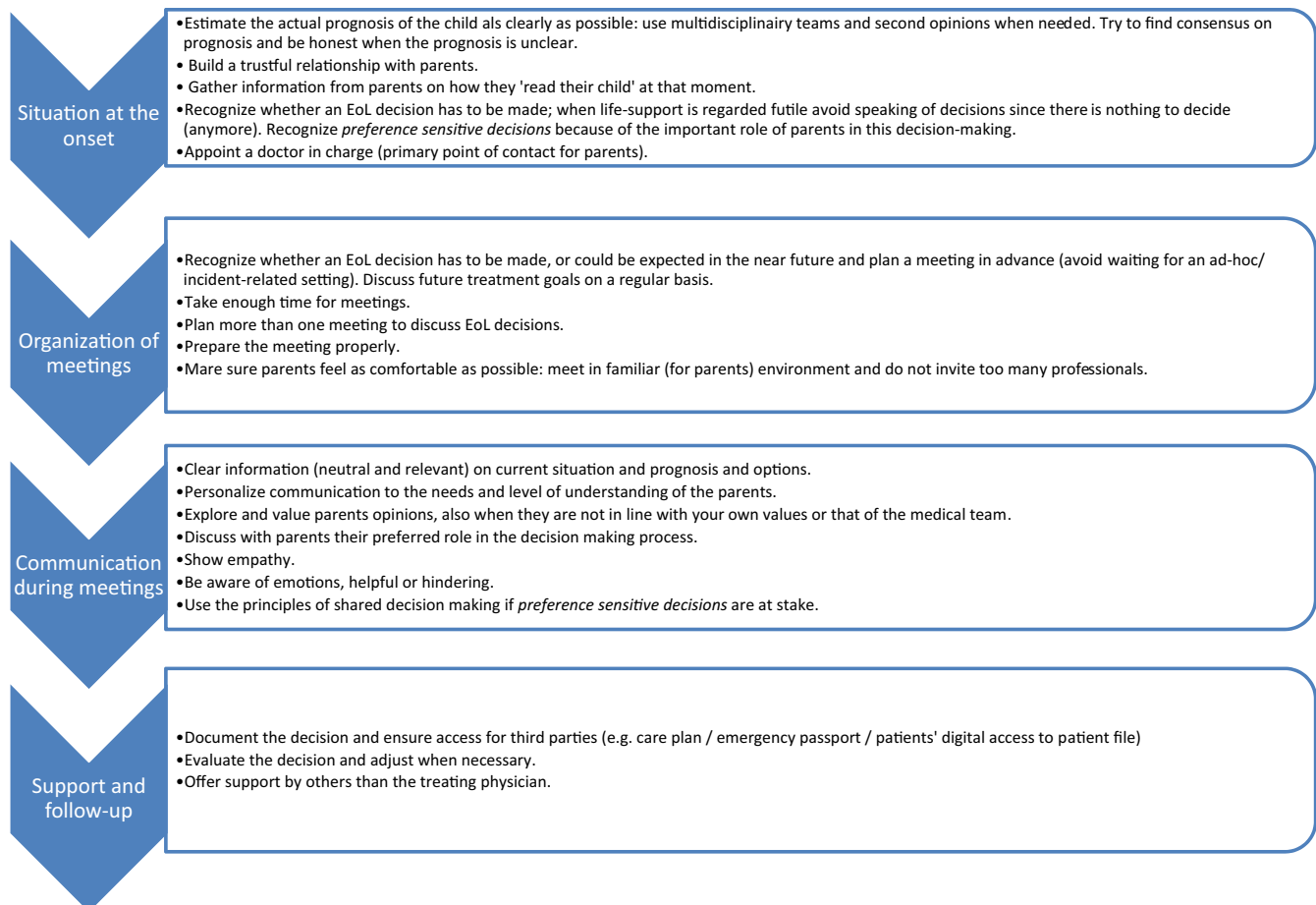


FIGURE 1 Recommendations for paediatric EoLDM in clinical practice

the EoLDM process and in this way help to reach a decision which is the most appropriate for the child and with which all participants can agree.

The abovementioned findings of our study indicate important issues in EoLDM. Our results show that parents and physicians identify a multitude of barriers and facilitators regarding the EoLDM process. The appropriate use of shared decision-making, currently the recommended decision model for preference-sensitive decisions, might help to minimise important barriers and to maximise facilitators, for example by actively involving parents in the decision-making process while letting physicians make the final decision in case of parents' explicit request (24).

Our overview leads to several recommendations for clinical practice (Figure 1). More research is needed to investigate whether the implementation of these recommendations may lead to an improvement of EoLDM processes according to all parties involved.

This study has several limitations. First, since subgroup analyses were not performed, differences in barriers and facilitators among the different patient groups could not be established. Yet, our overall analysis enabled us to make a comprehensive overview of barriers and facilitators for EoLDM in neonatology and paediatrics. Second, recall bias is possible because parents and physicians were interviewed about EoL decisions that had been made in the past. However, this also gave parents some time to process their thoughts and emotions, potentially providing a more objective review of their experience. At last, due to the design of this study (secondary analysis), it was not possible to perform iterative data collection during the course of data collection. Strengths of this study are the double perspectives being studied and the large sample size. The different clinical settings incorporated ensure that we explored EoLDM processes across a variety of clinical problems and throughout the entire range of ages in paediatric care: from prenatal to adolescence.

## CONFLICT OF INTEREST

The authors declare that they have no conflict of interest.]

## AUTHORS' CONTRIBUTIONS

All authors have participated in the study's concept and design, in the analysis and interpretation of the data and in the drafting or revising of the manuscript. All have approved the manuscript as submitted.

## ETHICS APPROVAL

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. One study was approved by the central institutional review board (IRB) and confirmed by local boards (NL nr. 42996.91.13) (17). The other study protocols were exempted from IRB approval (16,18). In all studies, participants signed informed consent.

## CONSENT TO PARTICIPATE

Informed consent was obtained from all individual participants included in the study.

## CONSENT FOR PUBLICATION

The authors affirm that human research participants provided informed consent for publication of the data in Tables 1 and 2.

## DATA AVAILABILITY STATEMENT

The data (original manuscripts) that support the findings of this study are available from the corresponding author, [IZ], upon reasonable request.

## ORCID

Ilse H. Zaal-Schuller  <https://orcid.org/0000-0001-8640-5292>

Rosa Geurtzen  <https://orcid.org/0000-0002-5640-6160>

## REFERENCES

- Moratti S. End-of-life decisions in Dutch neonatology. *Med Law Rev.* 2010;18(4):471-496.
- Vrakking AM, van der Heide A, Provoost V, Bilsen J, van der Wal G, Deliens L. End-of-life decision making in neonates and infants: comparison of The Netherlands and Belgium (Flanders). *Acta Paediatr.* 2007;96(6):820-824.
- Namachivayam P, Shann F, Shekerdemian L, et al. Three decades of pediatric intensive care: Who was admitted, what happened in intensive care, and what happened afterward. *Pediatr Crit Care Med.* 2010;11(5):549-555.
- Koper JF, Bos AF, Janvier A, Verhagen AA. Dutch neonatologists have adopted a more interventionist approach to neonatal care. *Acta Paediatr.* 2015;104(9):888-893.
- de Vos MA, van der Heide A, Maurice-Stam H, et al. The process of end-of-life decision-making in pediatrics: a national survey in the Netherlands. *Pediatrics.* 2011;127(4):e1004-e1012.
- Onwuteaka-Philipsen B, Legemaate J, van der Heide A, et al. *Derde evaluatie Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding.* ZonMw, mei; 2017.
- Ekberg S, Bradford NK, Herbert A, Danby S, Yates P. Healthcare Users' Experiences of Communicating with Healthcare Professionals About Children Who Have Life-Limiting Conditions: A Qualitative Systematic Review. *J Palliat Med.* 2018.
- Baker JN, Levine DR, Hinds PS, et al. Research Priorities in Pediatric Palliative Care. *J Pediatr.* 2015;167(2):467-70 e3.
- Butler A, Hall H, Willetts G, Copnell B. Parents' experiences of healthcare provider actions when their child dies: an integrative review of the literature. *J Spec Pediatr Nurs.* 2015;20(1):5-20.
- Lipstein EA, Brinkman WB, Britto MT. What is known about parents' treatment decisions? A narrative review of pediatric decision making. *Med Decis Making.* 2012;32(2):246-258.
- NVK. [Paediatric Association Of The Netherlands]. Richtlijn palliatieve zorg voor kinderen [Guideline Palliative Care for Children]. NVK. Augustus 20132013
- Caeymaex L, Jousseme C, Vasilescu C, et al. Perceived role in end-of-life decision making in the NICU affects long-term parental grief response. *Arch Dis Child Fetal Neonatal Ed.* 2013;98(1):F26-31.
- Zaal-Schuller IH, de Vos MA, Ewals FV, van Goudoever JB, Willems DL. End-of-life decision-making for children with severe developmental disabilities: The parental perspective. *Res Dev Disabil.* 2016;49-50:235-246.

14. Boland L, Graham ID, Legare F, et al. Barriers and facilitators of pediatric shared decision-making: a systematic review. *Implement Sci.* 2019;14(1):7.
15. Richards CA, Starks H, O'Connor MR, Bourget E, Hays RM, Doorenbos AZ. Physicians Perceptions of Shared Decision-Making in Neonatal and Pediatric Critical Care. *Am J Hosp Palliat Care.* 2018;35(4):669-676.
16. Geurtzen R, van Heijst A, Draaisma J, et al. Professionals' preferences in prenatal counseling at the limits of viability: a nationwide qualitative Dutch study. *Eur J Pediatr.* 2017;176(8):1107-1119.
17. Geurtzen R, van Heijst A, Draaisma J, et al. Prenatal counseling in extreme prematurity - Insight into preferences from experienced parents. *Patient Educ Couns.* 2019;102(8):1541-1549.
18. Zaal-Schuller IH, Willems DL, Ewals FVPM, van Goudoever JB, de Vos MA. How parents and physicians experience end-of-life decision-making for children with profound intellectual and multiple disabilities. *Res Dev Disabil.* 2016;59:283-293.
19. Braun V, Clarke V. What can "thematic analysis" offer health and well-being researchers? *Int J Qual Stud Health Well-being.* 2014;9:26152.
20. Odeniyi F, Nathanson PG, Schall TE, Walter JK. Communication Challenges of Oncologists and Intensivists Caring for Pediatric Oncology Patients: A Qualitative Study. *J Pain Symptom Manage.* 2017.
21. Geurtzen R, van Heijst AFJ, Draaisma JMT, et al. Development of Nationwide Recommendations to Support Prenatal Counseling in Extreme Prematurity. *Pediatrics.* 2019;143 6.
22. Weise KL, Okun AL, Carter BS, et al. Guidance on Forgoing Life-Sustaining Medical Treatment. *Pediatrics.* 2017;140 3.
23. Lemyre B, Daboval T, Dunn S, et al. Shared decision making for infants born at the threshold of viability: a prognosis-based guideline. *J Perinatol.* 2016;36(7):503-509.
24. Stiggelbout AM, Pieterse AH, De Haes JC. Shared decision making: Concepts, evidence, and practice. *Patient Educ Couns.* 2015;98(10):1172-1179.
25. Madrigal VN, Carroll KW, Faerber JA, Walter JK, Morrison WE, Feudtner C. Parental Sources of Support and Guidance When Making Difficult Decisions in the Pediatric Intensive Care Unit. *J Pediatr.* 2016;169(221-6):e4.
26. Feudtner C, Carroll KW, Hexem KR, Silberman J, Kang TI, Kazak AE. Parental hopeful patterns of thinking, emotions, and pediatric palliative care decision making: a prospective cohort study. *Arch Pediatr Adolesc Med.* 2010;164(9):831-839.
27. Longden JV. Parental perceptions of end-of-life care on paediatric intensive care units: a literature review. *Nurs Crit Care.* 2011;16(3):131-139.
28. Mitchell S, Spry JL, Hill E, Coad J, Dale J, Plunkett A. Parental experiences of end of life care decision-making for children with life-limiting conditions in the paediatric intensive care unit: a qualitative interview study. *BMJ Open.* 2019;9(5):e028548.
29. Michelson K, Clayman ML, Ryan C, Emanuel L, Frader J. Communication During Pediatric Intensive Care Unit Family Conferences: A Pilot Study of Content, Communication, and Parent Perceptions. *Health Commun.* 2016;1-8.
30. Verhagen AAE, de Vos MA, Dorscheidt JHHM, Engels B, Hubben JH, Sauer PJ. Conflicts about End-of-Life decisions in NICUs in the Netherlands. *Pediatrics.* 2009;124(1):e112-e119.

**How to cite this article:** Zaal-Schuller IH, Geurtzen R, Willems DL, de Vos MA, Hogeveen M. What hinders and helps in the end-of-life decision-making process for children: Parents' and physicians' views. *Acta Paediatr.* 2022;111:873-887. doi:[10.1111/apa.16250](https://doi.org/10.1111/apa.16250)