Voices of experience in periviable decision-making and artificial placenta technology

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Chapter 4

Voices of experience: what parents teach us about values and intuition in periviable decision-making

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Abstract

Objective: When extremely premature birth at the limits of viability is imminent, shared decision making with parents regarding the infant's treatment is widely recommended. Aligning decisions with parental values can be challenging. So, this study aims to get insight into (I) what values parents considered important in their decision, (II) whether their decision was based on intuition and/or rational analysis, and (III) parental suggestions on how to help explore and articulate values during prenatal counselling.

Design: A qualitative study was performed among Dutch parents who experienced (imminent) extremely premature birth. Diversity was aimed for through purposive sampling. Semi-structured interviews were conducted until saturation was achieved. Transcripts were coded and themes derived from the data.

Results: Nineteen interviews were performed. Results show what parents considered important in their decision, such as the infants' future, family life, and "giving a chance". Most parents made their decision more intuitively rather than rationally, for others both co-existed. Particularly fathers and parents who opted for palliative comfort care experienced the decision as rational. Parents would have liked to explore values, but found it challenging. They suggested strategies and conditions to help explore and articulate their values during counselling, such as a multidisciplinary approach.

Conclusions: Various considerations and underlying values were found to be important. Parents recognize the influence of emotions and intuition in decision-making and struggle to articulate their values, emphasizing the need for guidance. Healthcare providers should engage in open, personalized discussions to facilitate value exploration, enabling informed decisions aligned with parental values.

Background

Complex prenatal decisions arise when extremely premature birth is imminent between 22+0 and 26+0 weeks of gestation.[1] In this period, of which the exact application varies between countries and institutions, roughly two treatment options exist: early intensive care (EIC)-treatment or palliative comfort care (PCC).[2] Initiating EIC-treatment results in great prognostic uncertainty; some infants will not survive and others will survive with or without morbidities.[3] Since there is no 'best decision', most guidelines recommend a shared decision-making (SDM)-approach involving parental values.[4,5]

Within the context of SDM in case of extremely premature birth, value clarification (VC) can help in aligning a medical treatment decision with parental goals and circumstances.[6,7] It is essential to explore and incorporate the preferences and values of parents to guide their decision.[7] Studies have shown a variety of parental values playing a role in prenatal decision-making; values regarding quality of life (Qol), spirituality, religion, or the perception of the infant's suffering are examples of values that could be essential to parents.[8,9] However, some of these values (e.g. 'giving a chance') are multi-interpretable or require further exploration.[8] Additionally, parents commonly experience emotions such as anxiety and grief when extremely premature birth is imminent, which may affect their decision.[10-12]

Clarifying values appears to be challenging for healthcare providers (HCPs).[9,13,14] Understanding of values and the role of intuition in decision-making at the limit of viability is crucial for providing personalized counselling and further improving SDM.[15] This study aims to explore what parents considered important when faced with an imminent extremely premature birth, whether they relied on their intuition during this decision, and how they think VC should be performed. With these insights, counselling may be improved contributing to more value-congruent decisions.

Methods

Study setting and design

This qualitative research is part of the Dutch study called Toward INdividualized care for the Youngest (TINY), including qualitative research with extremely premature born adults (TINY-1) and experienced parents (TINY-2) to explore periviability guidelines, personalization, and parental values in the grey zone. In the Netherlands, the 24-to-26-week GA period is considered the grey zone allowing both EIC-treatment and PCC.[16] This article presents the TINY-2 results on parental values in prenatal decision-making. A more detailed description of the method with the COREQ-checklist is provided in *Appendix I*.

A Castor-database was developed including parents who either had experienced an imminent extremely premature birth <26 weeks GA but gave birth beyond 26 weeks, or if they were parents of an extremely prematurely born infant born between 24-26 weeks GA.

All parents in the database were invited to fill out a brief online questionnaire enabling purposive sampling to select a diverse group of participants (e.g., both PCC- and EIC-decisions, parents of survivors and non-survivors).

Based on literature and the research team's expertise, an interview guide was developed.[8] Two researchers conducted the interviews and were performed until thematic saturation was reached. Interviews were recorded, transcribed verbatim and analysed independently by two researchers (AB, LP) using thematic content analysis.

The codebook (*appendix II*) and analysis underwent several rounds of discussion and revision until all authors reached consensus. Results are presented in themes with subthemes, supported by illustrative quotations along with the corresponding interview number and treatment decision.

Results

Characteristics of participants

Nineteen out of 63 parents from the TINY-database were selected to participate. Semi-structured interviews were conducted between September 2022 and April 2023 with either the mother (n=12) or with two parents (n=7) (*Table 1*). The participants experienced imminent extremely premature births between 23+6 and 26+2 weeks GA. In four cases, PCC was chosen, while EIC was initiated in the remaining cases.

Results are represented in three sections corresponding with the interview questions.

Table 1 Demographic information

Characteristics of interviewed parents	
Place of interview	
Home	11
Hospital	2
Online	6
Interview with	
Mother	12
Mother and father	7
Total parents interviewed	26
Highest education of the interviewed parents	
Secondary school	1
Secondary vocational education	10
Higher professional education	10
University education	5
Religion	
No religion	20
Christian	6

Table 1 Continued

Characteristics of interviewed parents	
Experience with extreme premature birth between gestational age (GA) 24+0-26+0 weeks (n = 21)	
>1 extremely premature birth between GA 24+0-26+0	
Yes	2
No	17
Year of experience with extreme premature birth(s)	
2009-2013	6
2014-2018	8
2019-2023	7
GA at which extremely premature birth first threatened	
<23+0	2
23+0 – 23+5	5
24+0 – 24+6	8
25+0 – 25+6	4
>26+0 – <28+0	2
Birth between GA 24+0-26+0	
Yes	14
No, beyond 26+0	6
Other (extremely premature birth at GA 23+6)	1
Multiple birth	
Yes (twin)	7
No, singleton birth	14
Initial treatment decision between GA 24+0-26+0	
Intensive care treatment	17
Palliative comfort care	4
Outcome of the premature birth*	
Survivor(s) (incl gemelli)	10
Deceased	7
Both outcomes (twin)	4
Self-reported consequences of extremely premature birth	
None	
Any (retinopathy of prematurity, bronchopulmonary dysplasia, hearing loss, short bowel (Necrotizing Enterocolitis), complex sensory processing, social-emotional problems, language development problems, tube feeding, motor developmental delay)	10
	4

** The outcome of premature births is categorized as survivor, deceased, or both, accounting for both singleton and multiple births. For instance, the survivor(s) outcome encompasses singletons who survived or multiple births where both children survived.*

Parental considerations and values at the limit of viability

Several considerations and underlying values were described related to parental decision making. In general, parents struggled with the uncertainty of their infant's prognosis; "one moment you decide to go left, two days later you decide to go right" [19, PCC]. Themes that emerged were 'the future of the infant', 'family-life', 'everything done', 'to give a chance', 'trust', 'existing knowledge and experience', 'desire to have children, and 'hope'.

Future of the infant

An important theme was the infant's future, encompassing (I) statistics about chances, (II) the long-term consequences, and (III) long-term QoL.

Some parents expressed the importance of the statistics on survival and the chance of a potential disability. They questioned how far they were willing to go for their infant to survive. As for other parents, the role of statistics about future chances was very limited, because at that moment "that means nothing to you".

The infant's future QoL was also considered important by multiple parents, describing this as "enjoyment", "happiness", or the ability 'to be and act like others', such as "play sports", "have relationships" "eat by yourself", and "live independently".

Box 1: Quotes 'Future of the infant'

"What you actually want to hear is if [your child] is going to make it or not? And, what [disabilities] she will have?" - Interview 16 (Early intensive care treatment)

"*I imagined children in bed boxes and wheelchairs with tube feeding. And I thought: you would love them equally, but if you don't have to, you don't have to. She didn't have to survive at all costs"* - Interview 13 (Early intensive care treatment)

"*He doesn't need to be the best at school, but he needs a place in society*"

- Interview 14 (Early intensive care treatment)

Family life

The potential impact of an extremely premature birth on the family was also mentioned by parents. They thought about the implications for their own lives and their own happiness. In case of siblings in the family, they considered the impact of having an extremely premature infant on these siblings. As part of family life, practical factors like housing were discussed in terms of the possibility of adjustment to the house.

Box 2: Quotes 'Family life'

"There were two things that played a role: our child's happiness and our own happiness."

- Interview 7 (Early intensive care treatment)

"*[When we heard all the chances], we also thought: we have a two-and-a-half year old child. (...) I want my baby, but I also have a family"* - Interview 17 (Palliative comfort care)

Everything done

Multiple parents were inclined to do everything possible to fight, often more driven by emotions than by rational arguments. However, one couple changed their reaction from 'do everything' to PCC after learning about the statistics:

Box 3: Quotes 'Everything done'

"*We will do everything we can*" changed to "*If we were to reach week 25+3, we would want to consider administering the lung maturation injections.*" - Interview 1 (Palliative comfort care)

To give a chance

Some parents wanted to give their child a chance and 'go for it', meaning a chance to have a normal life or the chance to survive. Parents found it acceptable to give their infant a chance when they were assured there would be no unnecessary suffering, but they indicated they might reconsider this if the treatment became disproportionate.

Box 4: Quotes 'To give a chance'

"*I think that they really had a chance at a normal life, also because you heard about babies born at 25 weeks that did quite well. I would never forgive myself if I did not even try.*"

- Interview 3 (Early intensive care treatment)

"*[We wanted to give] a chance for survival. That ultimately, you can bring one or two girls home alive*" - Interview 4 (Early intensive care treatment)

Trust

Parents also based their decision on trust in the doctor and in science. One father felt uncertain as the birth approached, but his uncertainty dissipated upon the arrival of physicians with *"the expertise"*. Another couple mentioned they had trust in a good outcome.

Box 5: Quotes 'Existing knowledge

"*I work with children who have a disability, so I knew what could go wrong*"

- Interview 8 (Early intensive care treatment)

"We already had a lot of information from our firstborn. That makes things more concrete, you know what can happen, what trajectory you're entering and about the daily fears during your stay [at the NICU]. That made things easier for us." - Interview 17 (Palliative comfort care)

Existing knowledge and experience

Some participants already had knowledge about extremely prematurity and its consequences, since they worked in healthcare (n=7) or had prior experience (n=3). The information about consequences was more concrete to them, which could make decision-making more difficult for parents, but also easier.

Desire to have children

The intrinsic desire to have children was discussed as important in the decision. Among our participants, some parents did not conceive naturally, or the pregnancy was unexpected, because they thought to be infertile. This history played a role in both decisions to initiate EIC or to opt for PCC.

Box 6: Quotes 'Desire to have children'

"*Because we had a pretty tough time with the IVF process, (...) it was a real rollercoaster. And once you've come so far, we just felt like we wanted to take the chance even though that chance is so incredibly small*" - Interview 11 (Early intensive care treatment)

"*We got pregnant through IVF. So, for the second pregnancy, we thought about how far we wanted to go, knowing the risk of premature birth. (...) Nobody can guarantee you that everything is going to be okay*" - Interview 17 (Palliative comfort care)

Hope

Lastly, hope that it would go well for their infant was mentioned by some parents. One father described it to be natural to draw hope from everything and to keep searching for some certainty that it would turn out well for your infant.

Intuition and rational

The majority of the parents experienced their decision-making as intuitive with a lot of feelings involved; "*You can provide statistics and chances, but I think most parents make the decision based on their feeling"[4, EIC].* Some parents experienced the decision as a combination of rational and intuition. They had some time to reflect on the information and balance their feelings and values. However, participants acknowledged that feelings and intuition might take over when there is no time to decide: "*You had to decide very quickly, so you could not turn your feelings off"[7, EIC].* Mainly the fathers indicated that they experienced the decision as rationally made: "*It was a risk, but a calculated risk"[7, EIC],* or mothers indicated that their partners approached the decision more rationally: "*I'm actually quite a sensitive person myself. My husband is a bit more rational"[18, PCC]*. Furthermore, parents who opted for PCC often expressed their decision as rational. Participants mentioned that it is essential for HCPs to look at individual's needs; to explicitly clarify values or listen to intuition and feelings.

Value clarification experiences

VC may help in aligning decisions with values that are important to parents. However, many participants could not recall whether they discussed their values and considerations during counselling with the physician: *"Perhaps [having no memories of those moments is] simply because you were truly overwhelmed."[10, EIC].* Although parents would have liked to discuss their values and considerations during counselling, they felt it would not have changed their decision as they believed they had all the necessary information. However, it may provide them with a sense of making a more informed and carefully considered decision.

To help parents formulate and discuss their values, they suggested to have a conversation with questions like: '*Let's see what you find important in life, or what you want for you child"[1, PCC]*, and help them with their values: *"Ask the parents a couple of questions which will give parents an idea of values to consider/think about"[5, EIC]*. Parents expressed concerns that this should not feel like '*an interview*' or '*the need to defend yourself*''. A more multidisciplinary approach was most frequently suggested. They suggested to include nurses,

psychologists, or social workers because parents thought physicians were not necessarily trained to talk about values. Support should be offered for making a decision, without aiming in a certain direction. In *Table 2*, all strategies suggested by parents are recorded.

Table 2 What parents teach us about how to help them to explore and formulate values

Suggested strategies to explore and formulate values
Personalization: Personalize, address parents' needs, adapt the conversation to those needs. Take into account that there will be parents who do not feel the need to discuss their values or what they consider important in the decision at the limit of viability. *"How can I help you to make this decision?"*
Examine: Assess whether parents understood everything about what will happen and what is ahead of them when their child is born extremely premature.
Questions: Ask parents questions after an introduction with information about considering values in this decision. Examples mentioned: "*What are values that you consider important in life?"* "*What do you consider important in life?"* "*What do you consider important for your child?"*
Examples: Discuss examples of values that parents could consider in their decision at the limit of viability.
Decision aid: A decision aid designed to explore values or preferences for their infant's future should be designed and/or incorporated into existing decision aids. It should contain questions and examples to assist parents in exploring and articulating their values.
Potential later decision moments: Inform parents that additional decision-moments may follow later. Explain to parents that in case of future complications, intensive care treatment may not be in the best interest of their child anymore, and treatment can be withdrawn.
Prepare during (high risk) pregnancy: Preparation during regular checks by the midwife/ gynecologist, especially for the group of pregnant persons with a high-risk pregnancy. Not in an overwhelming manner, but for example with a brochure. So, if you prefer not to read about the possibility of extremely premature birth and the decision at the limit of viability, that would be an option. The choice would be up to the person.
Suggested conditions to facilitate the exploration and formulation of values
Communication/give unbiased information · Create the environment for an open and honest conversation · Take parents seriously · Information provision in a friendly manner · Information provision in clear, understandable language
Decision-making · Ensure that the pregnant person is with another person to hear all the information · Give the parent(s) some time to think about it, adjusted to each individual situation · If possible, a second or third counselling's session
Make it multidisciplinary with the right professionals · The presence of a NICU-nurse · The presence of a psychologist · The presence of a social worker

Discussion

This study aimed to explore parental values during treatment decisions at the limit of viability, the role of intuition, and suggestions to help parents formulate values. Several notable findings emerged from our results.

Considerations and values of included parents mostly revolved around the infants' future and the impact on their family, consistent with prior studies.[17,18] Unlike international literature, religion and spirituality were not mentioned by our participants, potentially reflecting differing cultural values.[19] A recent review about common values considered important at the limit of viability showed the complexity and multi-layered nature of values. Some values reflect on process preferences, such as the desire to do everything possible, while other values reflect on feelings or intuitions.[8] Our findings demonstrate that probing parents about their considerations could specify the meaning of underlying values and their impact on decisions. For example, by exploring various personal interpretations of QoL, we uncovered what parents aspired for their child's QoL, and how this can shape their decision. Additionally, values should be explored without assumptions or biases. Among our participants, the desire to have children supported both EIC- and PCC-decisions. This emphasizes the variability in how a certain value can lead to different decisions, highlighting the importance of avoiding assumptions about an eventual decision. HCPs should explore parental values further to understand and align parental values into value-congruent decisions.

Participants acknowledged both the intuitive and rational aspects of decision making, with more emphasis on intuition and gut-feeling. This emphasis was even more pronounced when time was limited. However, particularly fathers and parents who opted for PCC emphasized the rational aspect of the decision-making process. Existing literature discusses that individuals can differ in their approach to decision-making, with some leaning towards a rational approach, analysing data and considering pros and cons, while others embrace an intuitive decision-making style, relying on gut feelings and instincts.[20] Intuitive and rational decisions at the limit of viability have not been described explicitly yet. Some research suggests that decisions are best made through analytical reasoning, and feelings interfere with good, rational decision-making.[21] Other research suggests that intuition may be surprisingly accurate by integrating existing values into decisions, because it can be based on an implicit integration of a large amount of information and may play a pivotal role in shaping preferences.[21,22] Our participants perceived their decision to opt for PCC as rational, a perception that may imply a sense of counter intuitiveness associated with palliative care decisions, because it goes against what parents instinctively want: a living child. Our results further underscore that intuition and rationality can co-exist or even be intertwined and dependent on each other. Rationality can be used to gather and analyse information, while intuition helps with judgement and interpretation of this information.[23] Yet, gently challenging the initial preference to check whether it is stable or not, may improve how parents feel about the decision in the long run.[14]

Lastly, our study offers beneficial suggestions to help explore values during prenatal decision making. By exploring values, a treatment decision can be aligned with personal goals and circumstances.[23] Despite its acknowledged importance, several studies show this is not always practiced.[13] Our results underscore this trend, with parents expressing a lack of recall regarding discussing their values during counselling. Generally, parents in this study acknowledged both the importance and challenges associated with exploring their values, expressing the wish for an active role for themselves in this process. They emphasized the need for HCPs to assist in articulating and constructing values for making decisions congruent with their values, as other experts suggested.[24,25] Although participants stressed the importance of an unbiased neutral approach, achieving this is challenging. Formulating values and preferences can be influenced by parents' and HCPs' prior knowledge, bias, and emotions.[24,26,27] HCPs might, inadvertently, influence the process by framing information due to their own values or bias.[24,28] Therefore, addressing those challenges is essential.

Some of the participants' suggestions align with literature about VC-strategies, including unbiased information, building a trustful patient-counsellor relationship, allowing extra time for parents to let them absorb information, and promoting participation by empowering parents.[28-31] Newly suggested practical recommendations how to initiate the conversation and conditions to facilitate the exploration of values are provided, such as adopting a multidisciplinary approach or preparing parents during pregnancy. Furthermore, literature suggests talking to a significant other or utilizing value-clarification exercices.[7,32] Not all parents may perceive the necessity of clarifying values in general, choosing not to engage in this process or do this independently. Therefore, HCPs should explore preferences in formulating values during SDM.

Strengths and limitations

This study has several strengths offering a unique perspective of experienced parents on the SDM-process and explores beyond the existing literature in this topic area. Purposive sampling was used to select a diverse group of participants ensuring variations in experience with extremely premature birth and personal backgrounds. We achieved a broad selection of participants, increasing the external validity. Furthermore, the interdisciplinary nature of the research team contributes to the study's strength.

This study also has limitations. First, some findings of this study may be specific to the Dutch context and its societal values, which may limit their generalizability to other countries or healthcare systems. However, the overarching principles, such as the complexity of values, the need for probing deeper with follow-up questions and the role of intuition, derived from the study can still provide valuable guidance in diverse cultural contexts. Secondly, despite our efforts with purposive sampling, we faced challenges in recruiting parents with various religious and cultural backgrounds, members of the LGBTQIA+-community and parents who opted for PCC. However, a described Dutch cohort shows the decision for PCC occurs much less frequently than active care (8% vs. 92%).[33] Third, the

results may be limited by recall bias worsened by the emotionally overwhelming situation that parents faced at that time.

Conclusion

Parents experienced a significant role of overwhelming emotions and a gut-feeling in their decision, yet they acknowledge the importance of discussing values during counselling. However, exploring and formulating these values is challenging for them, underscoring the need for assistance. Improving skills to help parents formulate their values and create conditions facilitating this process could lead to better understanding parental values.

References

1. Singh J, Fanaroff J, Andrews B, Caldarelli L, Lagatta J, Plesha-Troyke S, et al. Resuscitation in the "gray zone" of viability: determining physician preferences and predicting infant outcomes. Pediatrics. 2007;120(3):519-26.
2. de Laat MW, Wiegerinck MM, Walther FJ, Boluyt N, Mol BW, van der Post JA, et al. [Practice guideline 'Perinatal management of extremely preterm delivery']. Ned Tijdschr Geneeskd. 2010;154:A2701.
3. Myrhaug HT, Brurberg KG, Hov L, Markestad T. Survival and Impairment of Extremely Premature Infants: A Meta-analysis. Pediatrics. 2019;143(2).
4. Ding S, Bijelić V, Daboval T, Dunn S, Lemyre B, Barrowman N, Moore GP. Assessing shared decision making during antenatal consultations regarding extreme prematurity. J Perinatol. 2023;43(1):29-33.
5. Stiggelbout AM, Pieterse AH, De Haes JC. Shared decision making: Concepts, evidence, and practice. Patient Educ Couns. 2015;98(10):1172-9.
6. Kukora SK, Boss RD. Values-based shared decision-making in the antenatal period. Semin Fetal Neonatal Med. 2018;23(1):17-24.
7. Tucker Edmonds B, Hoffman SM, Laitano T, Bhamidipalli SS, Jeffries E, Fadel W, Kavanaugh K. Values clarification: Eliciting the values that inform and influence parents' treatment decisions for periviable birth. Paediatr Perinat Epidemiol. 2020;34(5):556-64.
8. de Boer A, de Vries M, Berken DJ, van Dam H, Verweij EJ, Hogeveen M, Geurtzen R. A scoping review of parental values during prenatal decisions about treatment options after extremely premature birth. Acta Paediatr. 2023.
9. Boss RD, Hutton N, Sulpar LJ, West AM, Donohue PK. Values parents apply to decision-making regarding delivery room resuscitation for high-risk newborns. Pediatrics. 2008;122(3):583-9.
10. de Vries M, Holland RW, Witteman CLM. Fitting decisions: Mood and intuitive versus deliberative decision strategies. Cognition and Emotion. 2008;22(5):931-43.
11. de Vries M, Fagerlin A, Witteman HO, Scherer LD. Combining deliberation and intuition in patient decision support. Patient Educ Couns. 2013;91(2):154-60.
12. Gallagher K, Shaw C, Parisaei M, Marlow N, Aladangady N. Attitudes About Extremely Preterm Birth Among Obstetric and Neonatal Health Care Professionals in England: A Qualitative Study. JAMA Netw Open. 2022;5(11):e2241802.
13. Tucker Edmonds B, McKenzie F, Panoch JE, Wocial LD, Barnato AE, Frankel RM. "Doctor, what would you do?": physicians' responses to patient inquiries about periviable delivery. Patient Educ Couns. 2015;98(1):49-54.
14. Geurtzen R, Wilkinson DJC. Incorporating parental values in complex paediatric and perinatal decisions. Lancet Child Adolesc Health. 2024.
15. Haward MF, Gaucher N, Payot A, Robson K, Janvier A. Personalized Decision Making: Practical Recommendations for Antenatal Counseling for Fragile Neonates. Clin Perinatol. 2017;44(2):429-45.
16. Geurtzen R, van Heijst AFJ, Draaisma JMT, Kuijpers L, Woiski M, Scheepers HCJ, et al. Development of Nationwide Recommendations to Support Prenatal Counseling in Extreme Prematurity. Pediatrics. 2019;143(6).
17. Young E, Tsai E, O'Riordan A. A qualitative study of predelivery counselling for extreme prematurity. Paediatr Child Health. 2012;17(8):432-6.
18. de Boer A, De Proost L, de Vries M, Hogeveen M, Verweij E, Geurtzen R. Perspectives of extremely prematurely born adults on what to consider in prenatal decision-making: a qualitative focus group study. Arch Dis Child Fetal Neonatal Ed. 2023.
19. De Proost L, Verweij EJT, Ismaili M'hamdi H, Reiss IKM, Steegers EAP, Geurtzen R, Verhagen AAE. The Edge of Perinatal Viability: Understanding the Dutch Position. Front Pediatr. 2021;9:634290.
20. Webster DM, Kruglanski AW. Individual differences in need for cognitive closure. J Pers Soc Psychol. 1994;67(6):1049-62.

21. Scherer LD, de Vries M, Zikmund-Fisher BJ, Witteman HO, Fagerlin A. Trust in deliberation: The consequences of deliberative decision strategies for medical decisions. Health Psychol. 2015;34(11):1090-9.
22. Usher M, Russo Z, Weyers M, Brauner R, Zakay D. The Impact of the Mode of Thought in Complex Decisions: Intuitive Decisions are Better. Front Psychol. 2011;2:37.
23. Fagerlin A, Pignone M, Abhyankar P, Col N, Feldman-Stewart D, Gavaruzzi T, et al. Clarifying values: an updated review. BMC Med Inform Decis Mak. 2013;13 Suppl 2(Suppl 2):S8.
24. Epstein RM, Peters E. Beyond information: exploring patients' preferences. Jama. 2009;302(2):195-7.
25. Gillick MR. Re-engineering shared decision-making. J Med Ethics. 2015;41(9):785-8.
26. Lantos JD. Ethical Problems in Decision Making in the Neonatal ICU. N Engl J Med. 2018;379(19):1851-60.
27. Fischhoff B, Barnato AE. Value Awareness: A New Goal for End-of-life Decision Making. MDM Policy Pract. 2019;4(1):2381468318817523.
28. Parish O, Williams D, Odd D, Joseph-Williams N. Barriers and facilitators to shared decision-making in neonatal medicine: A systematic review and thematic synthesis of parental perceptions. Patient Educ Couns. 2022;105(5):1101-14.
29. Boland L, Graham ID, Légaré F, Lewis K, Jull J, Shephard A, et al. Barriers and facilitators of pediatric shared decision-making: a systematic review. Implement Sci. 2019;14(1):7.
30. Entwistle VA, Watt IS. Broad versus narrow shared decision making: Patients' involvement in real world contexts. Shared Decision Making in Health Care. 3 ed. Oxford: Oxford University Press; 2016.
31. Strick M, Papies EK. A Brief Mindfulness Exercise Promotes the Correspondence Between the Implicit Affiliation Motive and Goal Setting. Pers Soc Psychol Bull. 2017;43(5):623-37.
32. Epstein RM, Gramling RE. What is shared in shared decision making? Complex decisions when the evidence is unclear. Med Care Res Rev. 2013;70(1 Suppl):94s-112s.
33. de Kluiver E, Offringa M, Walther FJ, Duvekot JJ, de Laat MW. [Perinatal policy in cases of extreme prematurity; an investigation into the implementation of the guidelines]. Ned Tijdschr Geneeskd. 2013;157(38):A6362.

Appendix I: detailed description methods

Study setting and design

The current Dutch guideline on care for extremely premature infants born <26 weeks gestational age (GA) dates from 2010.[1] In the Netherlands, the 24-to-26-week GA period is considered the gray zone allowing both EIC-treatment and PCC.[2] We performed a qualitative interview study among Dutch parents who experienced an imminent or actual extremely premature birth in this gray zone post-2010. Ethical approval was obtained from the Medical Ethics Committee Leiden-Den Haag-Delft, the Netherlands, in November 2021.

TINY-study

This research is part of the Dutch study called Toward INdividualized care for the Youngest (TINY), initiated from three perinatal centers in the Netherlands: Erasmus MC Rotterdam, LUMC Leiden, and Radboudumc Nijmegen. As part of the TINY-studies, we conducted qualitative research with extremely premature born adults (TINY-1)[3,4] and with experienced parents (TINY-2) to explore periviability guidelines, personalization, and parental values. This article presents the TINY-2 results on parental values in prenatal decision-making.

A Castor-database was developed for this study. Parents were included if they had either experienced an imminent extremely premature birth <26 weeks GA but gave birth beyond 26 weeks, or if they were parents of an extremely prematurely born infant.

Parents were approached through the Dutch patient organization Care4Neo for parents who have a baby that need to be placed in an incubator and the infant itself, the Dutch platform Stille Levens - kenniscentrum Babysterfte for parents who supports bereaved parents and others who are affected by the death of a baby, physicians' networks of patients, social media platforms, e.g. Instagram and Linkedin of the NICU-departments of the involved hospitals and researchers, or through parents of previous studies (PreCo study[5], CODA-study) who gave permission to be contacted again.

Participant selection

All parents were invited to fill out a brief online questionnaire, providing essential demographic details about themselves and their experience with extremely premature birth. This information was used to select parents from the database by purposive sampling to include a diverse group of participants for this research (e.g., both PCC- and EIC-decisions, both parents of survivors and non-survivors). Our aim was to include a group of parents with a wide variety in educational level, age, geographic regions within the Netherlands and different experiences with extremely premature birth based on the gestational age of the imminent extreme premature birth, the actual birth in the gray zone or not, the year of the extreme premature birth, the number of extremely premature births, the decision made at the limit of viability, the infant's survival or the potential longterm consequences of the infant.

Data collection

Based on literature and the research team's expertise (neonatologists, maternal-fetal-medicine specialist, psychologist, and ethicist), an interview guide was developed.[6] The interviews were conducted in the participants' homes, the hospital, or online using Microsoft Teams, based on the participant's preferences. A medical doctor (AB) and bioethicist (LP) conducted the interviews and were performed until saturation. Informed consent was obtained from all participants. Interviews were recorded and transcribed verbatim.

Data analysis

Two researchers (AB, LP) independently analyzed and coded the interviews using a thematic content analysis approach.[7] The codebook and analysis underwent several rounds of discussion and revision until all authors reached consensus. The manuscript followed the COnsolidated criteria for REporting Qualitative research (COREQ)-checklist to report methods and results.[8] In the results section, themes with subthemes are presented, supported by illustrative quotations in boxes and in the manuscript along with the corresponding interview number and treatment decision (EIC = early intensive care treatment, PCC = palliative comfort care).

References

1. de Laat MW, Wiegerinck MM, Walther FJ, Boluyt N, Mol BW, van der Post JA, et al. [Practice guideline 'Perinatal management of extremely preterm delivery']. Ned Tijdschr Geneeskd. 2010;154:A2701.
2. De Proost L, Verweij EJT, Ismaili M'hamdi H, Reiss IKM, Steegers EAP, Geurtzen R, Verhagen AAE. The Edge of Perinatal Viability: Understanding the Dutch Position. Front Pediatr. 2021;9:634290.
3. de Boer A, De Proost L, de Vries M, Hogeveen M, Verweij E, Geurtzen R. Perspectives of extremely prematurely born adults on what to consider in prenatal decision-making: a qualitative focus group study. Arch Dis Child Fetal Neonatal Ed. 2023.
4. De Proost L, de Boer A, Reiss IKM, Steegers EAP, Verhagen AAE, Hogeveen M, et al. Adults born prematurely prefer a periviability guideline that considers multiple prognostic factors beyond gestational age. Acta Paediatr. 2023;112(9):1926-35.
5. Geurtzen R, van Heijst A, Draaisma J, Ouwerkerk L, Scheepers H, Hogeveen M, Hermens R. Prenatal counseling in extreme prematurity - Insight into preferences from experienced parents. Patient Educ Couns. 2019;102(8):1541-9.
6. de Boer A, de Vries M, Berken DJ, van Dam H, Verweij EJ, Hogeveen M, Geurtzen R. A scoping review of parental values during prenatal decisions about treatment options after extremely premature birth. Acta Paediatr. 2023.
7. Braun V, Clarke V. What can "thematic analysis" offer health and wellbeing researchers? Int J Qual Stud Health Well-being. 2014;9:26152.
8. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care. 2007;19(6):349-57.

Appendix II: codebook

Theme / codes eng (nl)	Definition
Everything done 'Do everything' (er alles aan doen)	Parents wanted to "do everything" in the decision at the limit of viability
Give a chance 'Go for it' (ervoor gaan) 'Giving a chance' (een kans geven) // 'Try' (proberen) · A chance to have a life · A chance to survive	Parents wanted to go for it when their infant was born at the limit of viability Parents wanted to give their infant a chance when their child was born. On the question what chance they wanted to give their child, the following was answered: · They wanted to give their infant a chance to have a life · They wanted to give their infant a chance to survive
Hope 'Hope' (hoop) ● Hope that it will be okay	When making a decision at the limit of viability, hope played an important role in their decision. Parents said they had hope it would be okay in the end
Uncertainty in the decision 'Uncertainty' (onzekerheid)	Parents mentioned the uncertainty regarding the outcomes/prognosis in the decision
Trust 'Trust' (vertrouwen) · In the doctor/science · In a good outcome	Parents mentioned they based their decision on trust.. · .. in the doctor · .. in a good outcome
Existing knowledge and experience 'Background knowledge' (achtergrondkennis) · From work in healthcare · From earlier experience with premature birth	One of the parents or both parents had already (some) knowledge about extremely premature birth, and this played a role in their decision-making process. · Parent(s) had more knowledge because they work in healthcare · Parent(s) had more knowledge because they experienced an extremely premature birth before.

Theme / codes eng (nl)	Definition
Future of the infant 'The chances for the child' (de kansen voor het kind) · Chances of survivial · Chances of a disability · At that moment chances mean nothing to you · Quality of life for the child' (kwaliteit van leven kind) · How happy can you be? · Living life, to be able to.. ..go on vacation ..play a sport ..have relationships ..run, swim, play ..be a child, to nurse, to crawl, to discover the world ..communicate, to live or share life with each other ..eat by yourself, live independently, be self-reliant ..participate in society 'Long-term outcomes for the child' (lange termijn gevolgen kind) · Handicaps	The chances for the child, told during counselling, were important for parents in making the decision regarding treatment after birth. · Parents mentioned specifically the chances of survival for their child · Parents mentioned specifically the chances of a disability for their child · During counselling the chances for the child were told, but at that moment it did not mean anything for the parents · Parents found quality of life for their child very important in their decision-making · In term of quality of life, parents questioned if you could be genuinely happy when their child had a chance to be limited in their functioning · When asked what quality of life meant for parents, they came with various examples what they wanted for their child. Parents considered the long-term outcomes for the child during their decision at the limit of viability. · Parents described the long-term outcomes in terms of potential handicaps.
Family-life 'Family' (gezin) 'Social factors (e.g., housing, financially, etc) (Sociale factor (vb. Huis, financieel, etc)) · Practical reasons · Maternal age 'Future suffering for the parents' (Toekomstig lijden van ouders)	Parents considered the burden/consequences of an extremely premature birth and infants on the rest of their family. Parents considered the burden/consequences of an extremely premature birth and infants on other social factors than their family. Parents considered the more practical reasons during the decision. Parents took into account the maternal age for their decision. · Parents considered their own potential suffering of having an extremely premature infant, that potentially could have an handicap
Desire to have children 'Wish to have a child' (kinderwens) 'IVF' (IVF)	The wish to have a child and the effort it took to get pregnant played a role in the parental decision at the limit of viability When parents mentioned IVF to get pregnant and as consideration in the decision.

Intuïtion vs. ratio

Theme / codes eng (nl)	Definition
Intuition vs. ratio · **Ratio** · **Intuition** · **Both**	When the question above was asked, parents answered with the following Parents found a the decision a rational decision Parents based their decision on feelings and intuition Parents made the decision based on both feelings and intuition and rational thinking about what was important to them.
Is that okay?	Do parents think that making the decision at the limit of viability based on feelings and intuition is okay?

Value clarification

Theme / codes eng (nl)	Definition
Value clarification during counselling · Did not · Did	Parents did not discuss their considerations with their physicians during counselling, but only received information about the chances for their child. Parents discussed their considerations with their physicians during counselling, after receiving information about the chances for their child.
Ways to clarify values **How to clarify values?** · Ask the question · Help with what sort of values are important to consider/asd question about those values **'VC multidisciplinary'** · Nurse · Psychology/MMW ***How not to clarify values?*** ● Defending their decision Not necessary at that moment	Parents discussed ways how to and how not to clarify values during counselling about the treatment of their infant at the limit of viability Parents discussed ways how they think physicians should clarify values during counselling Ask the question: what is important in your life and discuss this further with parents The HCP should help parents with what sort of values they can consider for this decision. The counselling should involve other disciplinaries. A nurse should be included in prenatal counselling A psychologist or social work should be included in prenatal counselling Parents discussed that when you explore parental values during counselling, the parents should not feel like they have to defend their decision