Voices of experience: insights from Dutch parents on periviability guidelines and personalisation

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ABSTRACT

Objective To investigate the perspectives of experienced parents regarding guidelines and personalisation for managing imminent extremely premature births (22–26 weeks gestational age (GA)) . The study examined four scenarios: no guideline, a guideline based on GA, a guideline based on GA plus other factors and a guideline based on a calculated prognosis.

Design Nineteen semistructured qualitative interviews were conducted with Dutch parents who experienced (imminent) extremely premature births between 23+5 and 26+2 weeks of gestation. Diversity was aimed for through purposive sampling from a database created prior to this study. Four of the parents opted for palliative care. Among the parents who chose intensive care, in nine cases the infant(s) survived.

Results All participants acknowledged the necessity of having a periviability guideline because it would provide valuable decision-making support, and counterbalance decisions solely based on parental instincts to save their infant. Parents preferred guidelines that considered multiple prognostic factors beyond GA alone, without overwhelming parents with information, because more information would not necessarily make the decision easier for parents. Personalisation was defined by parents mainly as 'being seen and heard' and associated with building relationships with healthcare professionals and effective communication between them and professionals.

Conclusions The results underscore the importance of having a periviability guideline including multiple prognostic factors to assist parents in making decisions at the limit of viability, and the importance of a personalised care approach to meet parental needs in the context of imminent extremely preterm birth.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Internationally, guidelines for extremely preterm birth vary. Different types of guidelines can be distinguished: guidelines based solely on gestational age, gestational age and other factors or an estimated prognosis. Also, the importance of personalisation in the periviability context is emphasised.

WHAT THIS STUDY ADDS

⇒ This study gives insight into the parental wish to have a periviable guideline and their preference for a guideline considering multiple prognostic factors to assist decision-making. It elaborates on their perspective on personalisation, linking it to relationships with healthcare professionals.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ This study underscores the critical need for a periviable guideline, preferably one that takes into account multiple prognostic factors. However, careful consideration is required regarding which factors should be included, necessitating consensus among stakeholders in perinatal care. The current Dutch gestational-based guideline may be perceived as overly simplistic by parents, suggesting that it may be time for a review to incorporate more nuanced considerations. Additionally, the considerable international heterogeneity in guidelines suggests a potential benefit in exploring ways to achieve greater uniformity among countries. Moreover, the study's findings emphasise the importance of training in communication skills to enhance the quality of care and support provided to parents during periviable situations.

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BACKGROUND

Guidelines for management of imminent extremely premature birth serve as a framework for decision-making at the limit of viability. These periviable guidelines vary significantly across countries.[1] While the Dutch guideline primarily considers gestational age (GA) with a lower treatment limit at 24 weeks and a grey zone between 24 and 26 weeks of gestation,[2] many other countries adopt a limit lower than 24 weeks GA, such as Canada and Japan providing intensive care at 22 weeks GA.[1 3] Furthermore, guidelines exist that consider multiple prognostic factors instead of solely GA.[3 4] The British and Canadian guidelines incorporate prognostic factors such as birth weight, sex and the administration of corticosteroids.[5 6]

At the limit of viability, the necessity for personalisation is emphasised.[7 8] Generally, personalisation is defined as adapting care and communication to meet parents' unique needs.[9] Periviability personalisation, however, may encompass different dimensions. Although a considerable amount of research on extremely premature birth already involves perspectives of healthcare professionals (HCPs) and experienced parents,[10 11] their perspective on treatment limits, type of guidelines and a systematic exploration of personalisation in the context of

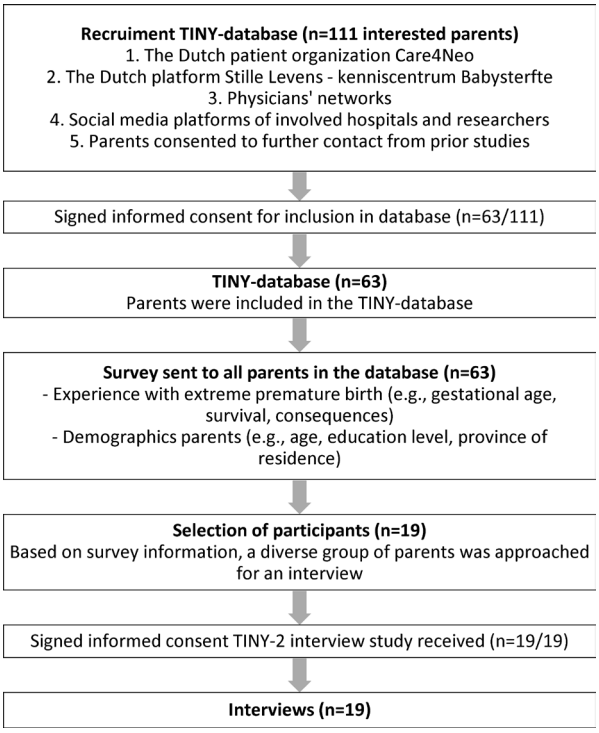

Figure 1 The process of recruitment of parents who experienced an (imminent) extremely premature birth for the TINY database, followed by the process of selection and inclusion of parents for the interview study (TINY-2). TINY, Towards INdividualized care for the Youngest.

extremely preterm birth has not been investigated much. Therefore, this study aims to explore their perspectives on the need and preferred type of guideline and on personalisation in the context of imminent extremely premature birth. These insights may contribute to the ongoing discussion about periviable guidelines and optimising counselling and care at the limit of viability.

METHODS

This qualitative interview study is part of the Dutch research project Towards INdividualized care for the Youngest (TINY). The TINY project explores perspectives of HCPs (TINY-0),[12 13] adults born prematurely (TINY-1)[14 15] and experienced parents (TINY-2). This article focuses on parental perspectives regarding guidelines and personalisation.

Prior to this study, a Castor database was created. Parents could be included when they experienced an imminent or actual extremely premature birth between 23 and 26 weeks GA after 2010. After inclusion in the database, an online questionnaire was completed by all parents to provide demographic information for purposive sampling, ensuring a diverse group of participants. The recruitment and inclusion process is recorded in figure 1.

A semistructured interview guide was developed. Two researchers conducted interviews until saturation was reached. Interviews were recorded and transcribed verbatim. Data analysis involved thematic content analysis following Braun and Clarke's guidelines, independently performed by researchers. Results are supported by quotes along with the corresponding interview number.

A comprehensive description of the methods, along with the Consolidated Criteria for Reporting Qualitative Research checklist, is provided in online supplemental appendix I. The codebook is reported in online supplemental appendix II.

RESULTS

Nineteen out of 63 parents from the TINY database were selected to participate. Semistructured interviews were conducted with these 19 parents between September 2022 and April 2023. 12 interviews involved only the mother, while seven interviews included both parents. Among the participants, two pairs of parents experienced extremely premature births twice. In four cases, palliative care was chosen, while intensive care treatment was initiated in the remaining cases. Further demographic information is documented in table 1.

First, we delve into the parental perspectives regarding the necessity of a guideline and their preferred type of guideline (table 2). Then, their views on personalisation are discussed.

Do we need a periviability guideline?

The consensus among the study participants was that a periviability guideline is necessary. Parents argued that guidelines offer support to both HCPs and parents in making difficult decisions at the limit of viability. They also expressed that guidelines serve a protective function emphasising parents might be inclined to pursue treatment regardless of the infant's GA without the direction of a guideline.

> Without a guideline, the danger would be for people to quickly say 'treat anyway'. [6]

Concerns were raised about the potential danger of making decisions based solely on parental instincts without considering the long-term perspectives for the infants.

> Without a guideline […], I think you would always want to go for it, but also would overlook many important future perspectives for your infant. [12]

Additional reasons provided for the necessity of a guideline are recorded in table 3.

Guideline preferences

Most of the participants expressed criticism of a guideline relying solely on GA, like the current Dutch guideline. This type of guideline was described as 'too black and white' and 'shortsighted'. Parents stated that GA is an estimated factor and may not always be accurate in their specific situations.

> There was much discussion about the estimated gestational age in my situation… it still would have been around 24 or 25 weeks GA, but what if we had counted it differently, it might have been 24+6. [7]

Some parents referred to stories about infants born before 24 weeks GA who have a good quality of life, as criticism of GA-based guidelines.

> You can't make a treatment decision based solely on gestational age. There are success stories these days of babies who were born under the current treatment limit. [2]

Furthermore, participants mentioned the variation in treatment limits across different countries. They were aware that neighbouring countries had lower treatment limits. Some found it remarkable that a drive across the border would result in their infant receiving treatment, whereas in the Netherlands, the infant might not be eligible for treatment at that same GA:

> When I drive five kilometers, they would receive treatment. [You should] have good reasons to go with that: why can

Table 1 Demographic information of the participants (interviews: n=19)

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
Experience with extremely premature birth (n=21)	
>1 extremely premature birth between GA 24+0 and 25+6	
Yes	2
No	17
Years of experience with extremely premature birth(s)	
2009–2013	6
2014–2018	8
2019–2023	7
GA when extremely premature birth first threatened	
<23+0	2
23+0 to 23+6	5
24+0 to 24+6	8
25+0 to 25+6	4
>26+0 to <28+0	2
Birth between GA 24+0 and 25+6	
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 and 25+6	
Intensive care treatment	17
Palliative comfort care	4
Outcome of the premature birth*	
Survivor(s) (including gemelli)	10
Deceased	7
Both outcomes (twin)	4
Self-reported consequences of extremely premature birth	
None	10
Any (retinopathy of prematurity, bronchopulmonary dysplasia, hearing loss, short bowel (necrotising enterocolitis), complex sensory processing, social-emotional problems, language development problems, tube feeding, motor developmental delay)	4

*The outcome of premature births is categorised 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.
GA, gestational age.

they offer care at 23 weeks in Belgium and Germany? And what makes the Dutch policy different? [10]

As a result, some parents expressed a preference for 'European guidelines'.

One of the participants shared the experience of their baby being born abroad. They mentioned that if they had been in the Netherlands at that time, initiating treatment would not have been possible due to the treatment limit.

Table 2 Explanation of the different types of guidelines

Type of guideline	Explanation of guideline
No guideline	Treatment decisions are made on a case-by-case basis without a specific cut-off for offering intensive care treatment and/or accepting palliative comfort care.
Gestational age-based guideline	Relies solely on gestational age to determine the cut-offs for providing intensive care treatment and/or accepting palliative comfort care.
Gestational age-based-plus guideline	Considers gestational age along with other prognostic factors like birth weight or sex to fine-tune individual prognosis and make a risk assessment. This type of guideline allows for a less strict cut-off point for offering intensive care treatment and/or accepting palliative comfort care.
Prognosis-based guideline	A guideline that incorporates multiple prognostic factors and uses a prediction model to calculate the prognosis. The cut-off points to determine whether intensive care treatment should be offered and/or accepting palliative comfort care are based on this expected prognosis—the chance of a 'good' or 'poor' outcome. Yet, no consensus is reached about the value-laden definition of what a 'poor outcome' entails. Also, it is difficult to find consensus about prognostic cut-off points. Moreover, it is difficult to determine the correct prognostic figures, there is currently no internationally validated model, and the prognostic figures vary greatly between centres, countries and cultures. So, no countries are known to employ a prognosis-based guideline.

> It's bizarre, such big differences… So we made a plan for ourselves when I was pregnant with our second infant: if this happens again … we will drive to [country]. [6]

Among the participants, a strong desire for a periviability guideline to consider multiple prognostic factors exists. The GA-based-plus guideline considering individualised factors beyond solely GA was particularly favoured. Parents appreciated that several factors involved in the situation of the mother and the infant would be considered:

> [The GA-based plus guideline] focusses more on the infant: what are the chances for that infant and which factors are important here? This really appeals to me. [6]

However, there appeared to be more hesitation regarding a prognosis-based guideline that relies on a calculated prognosis as treatment limits. Parents expressed concerns about reducing the decision to a number, as they believed it failed to capture the complexity of the situation and the uniqueness of each case. Moreover, it was emphasised that the decision is too complex and emotional to be made based on a calculated percentage.

> I am also very much into data and such. […] But, at the same time, I'm not sure whether it would be correct to attach a specific percentage to it, because it is, of course, a very emotional thing. [18]

In context of a guideline considering multiple prognostic factors, parents shared the view that an abundance of information about prognostic factors could potentially make the decision more challenging, leading to doubts and regrets afterwards. Some parents stressed the need to respect the preferences of parents who may not want detailed prognostic information.

> I think the more factors there are, the more you have to think about it and discuss it. [1]

Table 3 The discussed pros and cons per type of guideline by parents

No guideline	
Pro	(+) Gives the opportunity to personalise based on various factors per case, family and situation. (+) Gives everyone the chance to make a choice that suits them.
Contra (in other words, why a guideline is considered necessary)	(–) A guideline protects against arbitrary actions by healthcare providers, it supports uniformity in healthcare professionals' decision-making. (–) A guideline protects parents against the 'save at any gestational age', 'doing everything', 'giving a chance' and 'fighting for your child'. (–) A guideline gives support, is something to fall back on, supports both healthcare providers and parents. (–) A guideline protects against mistakes made by doctors, minimises the chances of medical errors. (–) A guideline protects against a slippery slope. (–) A guideline facilitates communication between healthcare providers and parents by providing a common reference point.
GA-based guideline	
Pro	(+) Some sort of limit is desirable.
Contra	(–) Too black and white, too rigid. (–) GA alone is very limited, chances are underestimated, influencing factors on survival and long-term consequences are not taken into account. (–) GA is measured with a margin of error. (–) Less room to give a child a chance.
GA-based-plus guideline	
Pro	(+) Not so black and white, multiple factors are taken into account. (+) Better representation of the situation. (+) More room to consider the situation of parents (such as what they find important in life). (+) More room for discussion between parents and healthcare providers, for giving an infant a chance of survival. (+) It is an 'in-between option'; not too rigid, but still providing some decision support.
Contra	(–) Difficult for parents to comprehend all of the factors and how to take this into account in their decision.
Prognosis-based guideline	
Pro	(+) Personalised prediction for the individual child, a prognosis-based guideline 'looks' at the child. (+) If the predictions would be really correct, this would be the best option. (+) Most scientific.
Contra	(–) Is the calculated prognosis really reliable? (–) What is a good outcome and how to translate that in treatment limits? How strict should this limit be? (–) At the moment, the algorithms are not yet good enough. (–) Which factors will be taken into account? (–) Slippery slope of the limit of viability, for example, to discuss early intensive care treatment in case of a baby at 22 weeks GA with a good enough outcome. (–) No room for feelings involved, emotionally challenging.

GA, gestational age.

If more prognostic factors would be discussed during counselling, parents emphasised the need for sensible communication. Anecdotes were shared highlighting the importance of how to communicate certain prognostic factors:

> If they had been girls, they would have had a better chance. Well… We don't have girls, but these boys will make it too! [14]
>
> […] discussing socioeconomic status with parents during such a challenging time might make the conversation even more difficult. It could potentially add another layer of stress. [18]

Parents expressed a preference for a GA-based-plus guideline. Some parents mentioned that they felt they had already received counselling aligned with the GA-based-plus approach instead of a GA-based guideline.

Personalisation

Parents discussed personalisation in terms of: 'considering the story behind the person', 'being seen and heard', 'engaging in dialogue with parents', 'being taken seriously', 'providing support to cope with the situation', 'being humane', 'taking the time', 'thinking together with parents', 'showing empathy', 'focusing on parental needs', 'adapting to the situation', 'recognizing the uniqueness of each situation', 'providing one-on-one interactions' and 'involving parents in the care process'.

Parents primarily associated personalisation with building relationships with HCPs and having empathetic and sensitive communication. They shared anecdotes about 'information in everyday language' and 'making decisions as a team'. Personalisation was also about the way it is said:

> There's a difference between the compassionate communication of the nursing staff and that one doctor telling us, '[Your son] is making a mess of things'. There's not much gentleness in that. [10]

When discussing personalisation in relation to guidelines, parents expressed concerns about the challenges of incorporating personalisation within a guideline that has a rigid cut-off limit for treatment.

DISCUSSION

This qualitative study aimed to explore parental perspectives on periviability guidelines and personalisation. Several notable findings emerged from the analysis.

First, all participants agreed on the necessity of having a guideline to support decision-making and to counterbalance decisions solely based on parental instincts, such as 'do everything' or 'save at any gestational age'. These findings align with the perspectives of HCPs and adults born extremely premature.[12 13 15–17] This last group believed that guidelines are crucial to prevent arbitrary treatment decisions and counter physician bias.[15] Earlier research shows only 13.4% of HCPs supported the absence of guidelines, indicating a widespread recognition among Dutch stakeholders involved in extremely premature care that guidelines can offer support and protection.[13]

Second, none of the participants agreed with the current guideline based solely on GA. For several years, a more personalised approach has been advocated for internationally and is now also confirmed by Dutch parents.[4 18 19] Therefore, policymakers should reflect on current guidelines with a relatively rigid, high GA-based lower limit.[2] Furthermore, parents recognised the significance of considering multiple prognostic factors, as in the GA-based-plus guideline; however, they did not necessarily believe that increasing the number of factors would simplify the decision-making process. In fact, complex information presented within a short timeframe could further complicate the decision. Other studies support this conclusion, suggesting that additional information may complicate decisions for parents, particularly during the challenging event of imminent extremely premature birth.[20–22]

A study among Dutch physicians (2017) expressed similar sentiments regarding the challenges of decision-making and the need for personalisation in cases of extremely premature birth.[23] These physicians acknowledged the difficulties in involving parents in decision-making, particularly when there is an overload of information. They emphasised the importance of personalising the provided information, as not all parents can effectively process a large amount of information.[23]

Third, our findings indicate that parents associate personalisation mainly with relationship building and communication between parents and HCPs. Our findings align with existing literature on prenatal counselling for extreme prematurity, highlighting the significance of sensible communication, individualising the approach to parental circumstances and tailoring information based on parental preferences.[8 9 24 25] Our participant's examples underscore the value of small gestures that demonstrate empathy and sensitivity. These examples are reminiscent of what has been referred to as 'Mangomoments' in the *Lancet*.[26] The authors describe the profound impact of unexpected small acts or gestures on the care experience for patients, families and HCPs: 'These micro-moments of positive resonance can foster stronger connections and contribute to the fabric of our communities,' the authors explain.[26 27]

Based on our findings, it can be concluded that personalisation and a one-size-does-not-fit-all approach are highly valued in the context of extremely premature birth. The study highlights the importance of recognising and addressing the unique needs and circumstances of individual parents, rather than reducing them to mere statistical figures. However, these results should not be interpreted as a dismissal of research on prognostic factors and individualised predictions. Rather, they emphasise the need for a thoughtful approach in using prognostic knowledge within the framework of prenatal counselling. Completely relying on numerical data may not be beneficial during prenatal counselling, but individualised predictions can provide valuable information and help parents prepare for the potential future they may face.[28 29] It is essential to focus on effectively incorporating and communicating those individualised predictions into prenatal counselling. This requires a balanced approach recognising the significance of personalisation, while ensuring that parents receive necessary information and support to make decisions. Tools such as decision aids can have additional value.[30 31] Additionally, the ethical implications of certain prognostic factors in predictions should be considered thoughtfully, for example, socioeconomic status or ethnicity.[32]

Generally, this study provides further evidence of the critical role of effective communication skills for HCPs in the context of extremely premature birth contributing to personalised care. A recent study revealed that many parents do not understand the language commonly used during prenatal counselling.[33] Other recent studies emphasise the significance of integrating a variety of training methods and programmes to equip HCPs with the necessary skills for effective communication during periviability discussions.[34–38] The findings of our study underscore how training communication skills should be prioritised to enhance the support offered to parents. It is essential to recognise that effective communication extends beyond the content of information but also encompasses the way it is conveyed.

Strengths and limitations

This study possesses several notable strengths. First, it emphasises the importance of parents' perspectives in the development and implementation of periviability guidelines. Second, purposive sampling is also a strength of this study. By purposefully selecting participants with diverse backgrounds, the study captures a wide range of parental perspectives ensuring saturation. This diversity enhances the generalisability and applicability of the study's findings. Furthermore, the interdisciplinary nature of the research team contributes to the study's strength.

This study is also subject to limitations. An important note is that parents' perspectives on guidelines may contain misinterpretations or inconsistencies: an example, the opportunity for shared decision-making in a grey zone might not inherently be broader in a GA-based guideline compared with others—it could vary widely based solely on GA. Another example is the dual sentiment expressed by parents: the desire for guidelines to help manage emotions and parental instincts, while also emphasising that guidelines should not be too rigid and eliminate emotional considerations. This may seem contradictory, but it reflects the complex nature of decision-making in highly emotional contexts. Moreover, the results show that parents find guidelines necessary mainly for establishing a lower limit, to prevent them from requesting interventions that are not feasible or beneficial in the long term. However, it was not discussed whether it is important to have an upper treatment limit. Further, the findings of this study are specific to the Dutch context, which may limit their generalisability. The Dutch periviability guidelines are shaped by the sociocultural context of the Netherlands, so perspectives may differ in other cultural or geographical settings.[1 39] Lastly, it is important to acknowledge that despite our efforts to ensure a diverse participant population, we faced challenges in recruiting parents from various religious backgrounds, members of the LGBTQIA+ community, individuals with various ethnicities and parents who opted for comfort care.

CONCLUSION

Parents in this study highlight the importance of having a guideline to provide decision-making support. A guideline may also counterbalance decisions solely based on parental instincts to not simply default to doing everything to save their baby. Parents expressed a preference for a guideline that considers multiple prognostic factors. Personalisation was defined by participants as 'being seen and heard', emphasising the significance of sensible communication and building relationships with HCPs. This study emphasises the development of empathetic and sensitive communication skills should be prioritised to deliver personalised care in periviability situations.

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who have a baby that needs to be placed in an incubator and the infant itself. We also thank Stille Levens | Kenniscentrum Babysterfte for their assistance in recruiting participants for this study. They support bereaved parents and others who are affected by the death of a baby to promote the best possible care, raise awareness and promote collaboration for the prevention of stillbirth and death of newborns. This article is an adaptation of research presented in the author's (LDP) doctoral thesis, titled 'Navigating periviability: On the ethics of personalization at the limit of viability', submitted to the Erasmus Medical Center.

Contributors LDP took part in designing the study, collected the data through focus group interviews, carried out the initial analyses of the data and wrote the initial draft of the manuscript. AdB designed the study, collected the data, carried out the initial analyses together with LDP and reviewed and revised the manuscript. EV and MH made a substantial contribution to the analyses and interpretation of the data by participating in the discussions about the data, and critically reviewed and revised the manuscript in multiple rounds of feedback. J(E)JTV and RG conceptualised and designed the study, contributed to and supervised the analyses of the collected data, and critically reviewed and revised the manuscript. LDP is the guarantor of the overall content. All authors approved the final manuscript as submitted and agreed to be accountable for all aspects of the work.

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