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ORIGINAL ARTICLE

Getting a grip in the middle of chaos: Preparing for preterm parenthood during a high-risk pregnancy – Parental experiences and needs

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Abstract

Aim: Admitting an infant to a neonatal intensive care unit (NICU) is stressful for parents. A great source of stress is the loss of their desired parental role. This study explores parents' experiences and needs during a high-risk pregnancy in preparation for their role as parents of a preterm infant.

Methods: An exploratory qualitative study was conducted among parents with a preterm infant admitted to two level-III NICUs in the Netherlands. A thematic analysis was performed.

Results: Nineteen interviews were conducted with parents of preterm infants (26–34 weeks gestational age). *Getting a grip in the middle of chaos* was identified as the central theme. In the pre-admission phase, *coping with potential preterm parenthood* was a theme, with coping strategies as subthemes that changed over time from *avoidance* to being *ready* to parent a preterm infant. The theme *envisioning the NICU* emerged in the NICU admission phase, with subthemes *preterm care journey* and opportunities for involvement fostering *parental empowerment*.

Conclusion: Timing and content of information about a parental role in the NICU should be tailored to the individual expectant parent. A customisable intervention bundle may provide a vision of the NICU and the parents' active role in care.

KEYWORDS
neonatal intensive care units, parents, premature birth, preparation, qualitative research

1 | INTRODUCTION

The admission of a very preterm infant (i.e., born earlier than 32 weeks gestational age [GA])[1] to a neonatal intensive care unit (NICU) is stressful and potentially a traumatic event for parents.[2,3] In addition to their infant's medical condition and potential loss, the infant's appearance—attached to tubes and surrounded by technological equipment and unknown alarms—is also a parental stressor.[2,3] Moreover, a recent meta-analysis concluded that one of the most significant sources of stress cited by NICU parents is losing their desired parental role.[3] Physical and emotional barriers prevent parents from holding, feeding, protecting, and caring for their

Abbreviations: FIC, family-integrated care; GA, gestational age; NICU, neonatal intensive care unit; UMC, university medical centre.

infant,[4] leading to symptoms of depression, anxiety, and posttraumatic stress disorder.[2,5] Furthermore, prolonged postnatal distress can negatively affect parent–infant interactions, the parents' long-term mental health, and the infant's development.[6,7]

Because of the impact of these parental stressors, family-integrated care (FIC) is increasingly emphasised during NICU admission.[8] FIC is an approach that empowers parents to become core members of the NICU team in caring for their infant and fulfilling their parenting roles.[9] This approach includes education programmes, parents' involvement in medical rounds, and environmental changes to support parents' presence in the NICU.[10] Recent studies have shown that FIC interventions have significant positive effects on infants and parents (e.g., improved infant weight gain and decreased parental stress).[11]

However, little is known about familiarising parents with the role of parent of a preterm infant before admission to the NICU. Preterm birth is usually unexpected, but it can be preceded by a prolonged hospitalisation of a high-risk pregnant woman. This period opens an opportunity to prepare these women and their partners for the parenting role in the NICU. Knowing what to expect in the NICU enables parents to cope more effectively with stress and improves bonding with their infant.[12] A neonatologist generally informs high-risk pregnant women and their partners about prematurity survival rates and medical complications during prenatal counselling.[13] However, studies have revealed that women with high-risk pregnancies also need information about the NICU environment and parental role.[14,15] Nevertheless, there are limited resources in the literature and few practical methods available to prepare parents for this role. Although prenatal tours of the NICU,[16] smartphone applications,[17] and nurse-led orientation programmes[18] are sometimes practised, empirical studies of the effectiveness of these methods are scarce.

In the Netherlands, there is no standard method of preparing parents to 'become parents' in a NICU environment. Moreover, little is known about parents' experiences in this preparation phase. Therefore, this study aims to obtain greater insight into parents' experiences and needs during a high-risk pregnancy to prepare for their role as parents of a preterm infant in the NICU. Understanding these experiences is valuable to identify theories and future evidence-based interventions[19] to empower parents in this critical early parenting phase.

Key Notes

- Expectant parents with high-risk pregnancies use different coping strategies to handle the stress of potential preterm parenthood; these coping strategies can change from avoidance to being ready for preparation.
- Expectant parents need information regarding the preterm care journey and their increasing parental role.
- A customised intervention bundle about parenting a preterm infant in a NICU environment should be developed.

2 | METHODS

2.1 | Population and setting

An exploratory qualitative study was conducted with parents who have experienced preterm birth and whose infant was admitted to a NICU. Parents were eligible for participation when (a) they had an infant born between 26–32 GA or ≥32 GA and weighed <1,500 g, (b) the mother had been hospitalised for at least 24 h in a university medical centre (UMC) obstetric ward before birth, and (c) they spoke Dutch. A threshold of 26-week GA was set because this study does not focus on decision-making at the margins of viability. Participants were recruited through purposive sampling until data reached saturation. The study was conducted in two Dutch level-III[1] NICUs with open bay units of 18–24 beds and an average of 400 admissions per participating NICU. Staff neonatologists, neonatology fellows, and physician assistants performed antenatal consultations in both hospitals.

2.2 | Procedures

The researcher KR has worked for 19 years as a neonatal nurse at one of the study sites and did not invite participants herself to ensure their freedom to participate. Instead, eligible participants were invited by independent nurses trained in the study protocol. After 24 h, KR personally approached interested participants for informed consent, and 23 of 33 agreed to participate; 19 were included in the study. Reasons for not participating were (a) wanting to spend all their time with their infant ($n = 8$), (b) having their infant transferred to a Level-II nursery before the interview ($n = 4$), and (c) having no interest in the study ($n = 2$). See Appendix S1 for a description of the study's reflexivity process.

2.3 | Data collection

Semi-structured, face-to-face interviews were conducted between January 2020 and January 2021. The interview guide was developed based on relevant literature and input from two researchers (AH, KR). Two questions were discarded after two pilot interviews because they did not answer the research question. Data from the pilot interviews were used in the analysis. See Appendix S2 for the interview guide.

Participants were interviewed with a median of 12 days (5–42 days) after their infant's initial admission. Couples were interviewed as individuals because research has shown that fathers often do not want to increase their partner's stress by discussing concerns.[20] KR conducted and audio-recorded all interviews in a private hospital room. The median duration of the interviews was 39 min (21–60 min).

2.4 | Data analysis

An exploratory qualitative approach was used to investigate this little-understood topic to develop new knowledge to improve expectant parents' preparation.[21] With limited literature on the topic, an inductive approach (i.e., allowing the data to determine the themes) was chosen. The six phases of Braun and Clarke's thematic analysis were applied iteratively: '(a) familiarising with data, (b) generating initial codes, (c) searching for themes, (d) reviewing themes, (e) defining and naming themes, and (f) producing the report.'[22] The study's trustworthiness and reliability were enhanced in each phase.

In the first phase, KR single-handedly transcribed verbatim and summarised each interview. A transcript summary was returned to the participants for a member check. Thirteen (68%) participants replied, and they all agreed with the summary's content. Three researchers (AH, JW, KR) independently assigned codes to meaningful fragments in the second and third phases. After a thorough discussion, initial codes were transformed into themes. A constant comparison approach was used between new data and the previously established codes and themes.

In the fourth phase, saturation was reached after 19 interviews. One participant was considered a deviant case because, compared with other participants, she had more knowledge and experience with preterm infants and NICU wards because of her occupation. Analysis of this deviant case was used to refine the emerging patterns from the data analysis. In the fifth phase, a peer debriefing was conducted by an independent psychologist (TB) who works with NICU parents. In the final phase, the report was written following the consolidated criteria for reporting qualitative research (COREQ) guidelines.[23]

The first two phases from the figure 'Healthcare Trajectory NICU' was used to visualise and order themes. This trajectory is organised into pre-admission, admission, and post-discharge phases.[24] The themes in the pre-admission phase originated from participants' experiences in preparing for a parental role during a high-risk pregnancy, whereas admission-phase themes arose from their experiences when admitting their infant to the NICU. Parents expressed what they would have needed pre-admission during this phase.

2.5 | Ethical issues

The Medical Research Ethics Committee of the VUmc Amsterdam approved the study (No. 2019–675).

3 | RESULTS

3.1 | Participants

In total, 19 interviews were conducted with eight fathers and 11 mothers, including eight couples. Before birth, mothers were hospitalised in five different university hospital obstetric wards, with a median of 9 days (3–49 days). The GA of the 12 infants ranged between 26 and 34 weeks. Tables 1 and 2 contain detailed characteristics of parents and infants.

TABLE 1 Characteristics of parents ($n = 19$)

Characteristics	*n*(%) or Median (Min – Max)
Gender male, *n* (%)	8 (42)
Age years, (median)	33 (29–39)
Education level, *n* (%)	
Lower education	1 (5)
Middle education	3 (16)
Higher education	15 (79)
Family composition, *n* (%)	
First child (ren)	16 (84)
Second child	3 (16)
Prenatal medical counselling yes, *n* (%)	17 (90)
Prenatal tour of NICU, *n* (%)	
Yes	3 (16)
Offered, not conducted	5 (26)
Not offered	11 (58)

Note: Education level =classification Statistic Netherlands.
Abbreviations: Min, Max; minimal, maximal.

3.2 | Main results

*Getting a grip in the middle of chaos*was the central theme during pre-admission and NICU admission, reflecting overall parental experiences and needs. Expectant parents use coping strategies to deal with information and must envision the NICU to 'get a grip' on the unexpected reality of becoming a preterm infant's parent.

The experiences of the outlying participant only differed during the admission phase. The quotations presented were annotated with mother or father and a participation number. Figure 1 presents the healthcare trajectory and themes.

3.3 | Theme pre-admission phase: Coping with potental preterm parenthood

During pre-admission, parents were confronted with the possibility of becoming a parent of a preterm infant when the pregnancy became high risk. The theme *coping with potential preterm parenthood* emerged from the participants' experiences. This theme contains four coping mechanisms as subthemes used over time: *avoidance*, *counterbalancing*, *self-protection*, and *readiness*.

3.3.1 | Avoidance

Most parents initially expressed their hope to continue the pregnancy. They did not want to face the possibility of becoming a parent

to a preterm infant in a NICU. Reaching a milestone in the GA or weight of their unborn infant was an important achievement for parents. At this early stage, receiving information about their potential parental role in a NICU was considered irrelevant or stressful:

> Her water broke, yet even then, I still thought it could be anything. I just always assumed everything would be all right. I thought this could take another ten weeks.
>
> *[Father, P02]*

3.3.2 | Counterbalancing

All parents considered medical information about their infant's survival and future health problems as their initial priority, desiring statistics about complications and survival rates. Thus, they sought information from prenatal counselling, internet resources, and social contacts. All parents valued medical facts above the parenting information, although most described medical statistics as 'a lot of information' or 'stressful'. Almost all parents searched for positive stories about other preterm infants with a similar GA or weight to counter 'the worst-case scenarios', hoping for a more positive outcome:

> You read stories of children born around 30 weeks. They are in the hospital for weeks, but with the proper care, they are all right. That gives hope.
>
> *[Father, P08]*

TABLE 2 Characteristics of infants ($n = 12$)

Characteristics	*n*(%) or Median (Min – Max)
Gender male, *n* (%)	6 (50)
Gestation in weeks (median)	28 (26–34)
(Multiple)birth, *n* (%)	
Singleton	10 (83)
Twins	1 (17)
Birthweight in grams (median)	1063 (605–1,365)
Most prevalent morbidities until interview, *n* (%)	
RDS in newborns	9 (75)
LOS	5 (42)
NEC	3 (25)

Abbreviations: LOS, late-onset sepsis; Min, Max; minimal, maximal; NEC, necrotising enterocolitis; RDS, respiratory distress syndrome.

3.3.3 | Self-protection

After acquiring medical information, parents reported needing 'quiet time' to protect themselves from information about preterm infants and the NICU. They deliberately stopped searching the internet for information about prematurity and looked for distractions. The majority of parents affirmed the need for psychological and physical rest. Furthermore, mothers' medical conditions often reduced the need for more information because they were sometimes too sick to process or remember detailed information:

> I consciously chose not to [tour the NICU] because I had the feeling that I needed to stay calm and relaxed. I was terrified that this would lead to negative stress.
>
> *[Mother, P05]*

3.3.4 | Readiness

Nearly all parents stated that the need for information about their roles in the NICU became relevant when their child's birth was forthcoming. Expectant parents were ready to receive or search for information when they felt their infant's NICU stay was unavoidable. Many participants searched for or seized various opportunities to learn about the parental role in the NICU environment, some of which were frightening or hard to imagine. Nevertheless, parents stated that this preparation helped them *get a grip in the middle of the chaos*:

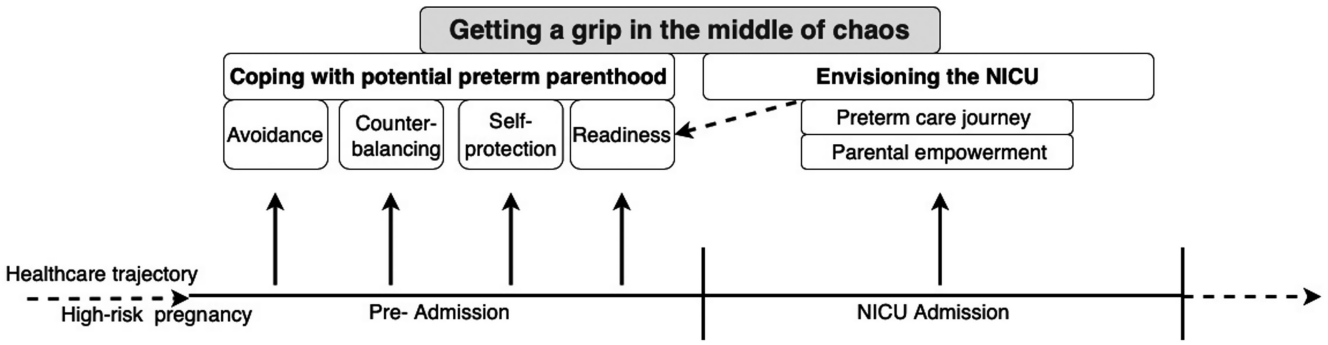

FIGURE 1 The themes regarding parents' experiences and needs in preparation for their role as parents of a preterm infant in a NICU. Based on the two first phases of Healthcare Trajectory NICU by Rouck[24]

> Interviewer: When did you want to know information about the NICU? Mother, P07: After that Friday, I was having abdominal pains, (…) maybe I'm going into labour. Indeed, at that moment. What can we expect there [NICU]?

3.4 | Theme NICU admission phase: Envisioning the NICU

The theme *envisioning the NICU* emerged when parents experienced the NICU and reminisced on what they would have needed during pre-admission. In hindsight, parents wanted to receive personalised information about the preterm care journey and how they could have been empowered to care for their preterm infant. Hence, *the preterm care journey* and *parental empowerment* emerged as subthemes.

3.4.1 | Preterm care journey

All parents expressed the need for information about the preterm care journey: 'what to expect' in the NICU. The fulfilment and details of this journey varied considerably between parents and couples. Nevertheless, they all wanted general information about the admission day, issues with preterm infants, NICU environment, expectations and possibilities concerning the parental role, and transferring to a Level-II nursery. Many parents emphasised that this information must be manageable and not too detailed. Parents desired personalised information associated with the GA of their infant and their preferences. The deviant participant explained that her prior knowledge about preterm infants and the NICU provided her 'a protective factor', as not everything was new.

> Of course, it differs with every child, but maybe you could give the general course of a preterm child. (…) That's very relevant because then, as a parent, you have a little bit more resistance.
>
> *[Mother, P18].*

3.4.2 | Parental empowerment

The majority of parents reported being surprised about the level of closeness they experienced with their preterm infant in the NICU. They did not expect to touch and hold their infant so frequently. However, most did not provide reasons for these expectations. Some thought their infant would be 'too fragile' or touching would 'not be hygienic'. However, all participants valued their increasing involvement in caring for their preterm infant (e.g., changing a diaper, comfort-holding, skin-to-skin care, providing mother milk, and cleaning the incubator).

Most parents indicated they would have appreciated learning about this level of closeness and involvement during the pre-admission phase, whereas some participants preferred receiving such information at the start of the admission phase. Although the outlying participant knew about parental involvement beforehand, she affirmed that this information should be emphasised more explicitly at the beginning of the admission:

> I didn't understand that I was allowed to have my hands in the incubator (…) that I was allowed to help with changing and care. I did not know that. In hindsight, if I knew that a little more or had a little more explanation, I would be more reassured (…) It's still my kid. I can touch her. I can do things, not just wait.
>
> *[Mother, P17].*

4 | DISCUSSION

This study identified *getting a grip in the middle of chaos* as the central theme reflecting parental experiences and needs during a high-risk pregnancy phase to prepare for their role as parents of a preterm infant.

*Coping with potential preterm parenthood*emerged as a theme when expectant parents entered the high-risk pregnancy phase. The emphasis was on strategies to handle the stress of an impending role as a preterm-infant parent, in which coping with information was vital. Over time, these coping strategies changed from avoidance to being ready. These strategies resonate with the coping styles of Lazarus and Folkman: emotion-focused and problem-focused coping.[25] Both coping types help relieve stress. However, problem-focused coping is needed to affect health outcomes positively over time.[25,26] First, emotion-focused coping focuses on reducing negative emotional responses through denial, positive reinterpretation, minimalising, and distraction from stressors aligned with this study's subthemes: *avoidance*, *counterbalancing*, and *self-protection*. The findings of previous qualitative studies confirm these strategies.[27,28] For instance, Carter et al.[27] identified emotion-focused coping strategies, such as staying calm, setting milestones, and hoping to maintain the pregnancy, in women who experience threatening preterm labour. However, while participants in these previous studies were predominantly women, our study also included fathers, finding they used the same coping strategies. Although the need for medical statistics regarding prematurity was previously discussed in several studies,[29,30] this study demonstrated parents' additional need for positive stories to counterbalance these medical scenarios.

Second, the subtheme of *readiness* is consistent with problem-focused coping. Problem-focused coping targets the causes of stress in practical ways, including planning and taking action.[25] In this study, when most expectant parents felt preterm birth was inevitable, they were receptive to preparation and took action to inform themselves about their parental role with a preterm child. Therefore,

determining the appropriate timing for giving information about parenting in a NICU is challenging for professionals because every expectant parent is in a different coping phase throughout their prenatal journey. The most appropriate time to provide information was discussed in a systematic review, which found that providing information at 'an unsuitable moment triggers anxiety in parents on a NICU, while too little information can equally induce fear'.[31] These findings underlined the importance of providing expectant parents with flexible information options during high-risk pregnancies.

Subsequently, *envisioning the NICU* emerged as a theme when the infant was admitted to the NICU. In retrospect, parents wanted to receive personalised information about the preterm care journey and their level of involvement in caring for their preterm infant. Notably, the need to envision the journey aligned with a recent focus on patient journey mapping in healthcare: 'a visual presentation of the complete route a patient follows during all stages of a care trajectory and the patients' emotional experience during this journey'.[32,33] Moreover, participants stated that besides this general journey, they needed personalised information correlating to their infant's GA and based on their preferences on how to access this information. This need for customised information confirmed current literature findings on prenatal counselling.[29,34] For example, Geurtzen et al.[34] discussed various parental preferences regarding extreme prematurity (i.e., 24–26-week GA). For example, the supportive visual information needs to be dynamic and personal. This current study revealed that parents with a high-risk pregnancy in a later phase (i.e., 26–32-week GA) also needed personalised information.

Finally, this study demonstrated that parents wanted to know about the level of participation in caring for their preterm infant. Informing expectant parents about the parental role aligns with the principles of FIC, enabling them to actively engage in caring for their preterm infant, reducing parental stress, and enhancing empowerment.[8,9,11,35] Therefore, an intervention bundle about the parental role in the NICU environment should be developed with dynamic and customisable options ideally constructed of two core topics: a preterm care journey and parental empowerment. This bundle (e.g., education application, a (virtual) NICU tour, relevant websites, counselling) should be developed with relevant stakeholders. This bundle can offer expectant parents a view of the future by describing a pathway of being a parent in the NICU, consequently lowering thresholds for the parental role (e.g., skin-to-skin contact, comfort-holding, family-centred rounds, feeding). Moreover, further research is needed to determine whether flexible access to relatable and personalised information about a parental role prenatally in the NICU can improve parental empowerment and relieve stress.

This study has limitations. First, the transferability of the findings is limited because the study was conducted in two Dutch NICUs. Thus, a sample from various (international) hospitals may lead to different results because of various preparation methods. Second, the sample consisted mainly of older, highly educated, first-time parents, so a more heterogeneous sample may result in different outcomes. Finally, the study was conducted during the COVID-19 pandemic, which likely increased parental stress levels because of reduced social support and worries about infection. A strength of this study is that it was conducted during NICU admission; hence, parents had time to reflect on their experiences and express what they needed during the pre-admission phase. Moreover, the researchers' triangulation, member-checking, and peer debriefing enhanced the study's trustworthiness. Furthermore, having an outlier participant with relevant NICU knowledge and including fathers as participants strengthened the study's findings.

5 | CONCLUSION

Preparing expectant parents for a parental role empowers them during their NICU stay. In this study, expectant parents revealed different coping strategies to handle the stress of an impending role as a preterm-infant parent. Therefore, timing and content of the information should be customised according to the parent's needs. Moreover, providing a vision of the NICU, including their active participation in care, can empower and enable parents *to get a grip in the middle of chaos*.

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CONFLICT OF INTEREST

The authors have no conflicts of interest to declare.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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