

*Becoming a parent of a premature infant:
experiences and needs*

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ABSTRACT

Title: Becoming a parent of a premature infant: experiences and needs

Background: The admission of 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 parental stress is associated with a higher risk of stress disorders. Preterm birth is usually unforeseen, but it can also be preceded by the hospitalisation of the pregnant woman. This period opens an opportunity to prepare parents for their parental role. Little is known about parents' experiences in this preparation phase.

Aim: The aim was to obtain a deeper understanding of the experiences of parents in preparing for their role as a parent of a premature infant.

Method: A generic qualitative study using semi-structured interviews was conducted among parents who have a premature infant admitted at a NICU in the Netherlands. A thematic analysis was performed.

Results: Twelve parents of eight infants between 26–34 weeks gestational age were included. Four themes emerged: *hoping for a good outcome*, *coping with information*, *need for personalised information*, and *bonding through involvement*. The emphasis was initially on hope, and parents had limited expectations regarding their parental role. After NICU admission, personalised information and closeness with their premature infant became important.

Conclusion: Parents in a high-risk pregnancy want to be informed about their role as parents of a premature infant. Appropriate timing and personalisation of information are essential.

Recommendations: A tool for personalising information about parenting a premature infant and NICU environment should be developed. Further research is needed to determine if the effects of family-centred care are enhanced when parents are prenatally informed about the benefits of their involvement in their infant's care.

Keywords: Neonatal intensive care units, Parents, Premature birth, Preparation, Qualitative research

SAMENVATTING

Titel: De voorbereiding op de ouderrol van een prematuur kind: ervaringen en behoeften

Achtergrond: De opname van een kind op een neonatale intensive care unit (NICU) is stressvol voor ouders. Het verlies van hun gewenste ouderrol is een grote bron van stress. Deze stress wordt geassocieerd met een hoger risico op stressstoornissen. Een vroeggeboorte is vaak onverwacht, maar kan worden voorafgegaan door een ziekenhuisopname van de zwangere vrouw. Deze opnameperiode geeft de mogelijkheid om ouders voor te bereiden op de ouderrol van een prematuur kind. Er is weinig bekend over de ervaringen van ouders in deze voorbereidingsfase.

Doel: Het verkrijgen van een dieper inzicht in de ervaringen van ouders ter voorbereiding op hun rol als ouder van een prematuur kind.

Methode: Een generiek kwalitatief onderzoek met semigestructureerde interviews werd uitgevoerd onder ouders van premature kinderen op een NICU in Nederland. Een thematische analyse werd verricht.

Resultaten: Twaalf ouders van acht premature kinderen tussen 26–34 weken zwangerschapsduur werden geïncludeerd. Vier thema's: *hoop op goede uitkomst, omgaan met informatie, gepersonaliseerde informatie* en *hechting door betrokkenheid* kwamen voort uit de data. Aanvankelijk lag de nadruk op hoop en hadden ouders beperkte verwachtingen van hun ouderlijke rol. Na de opname op de NICU werden gepersonaliseerde informatie en de nabijheid bij hun kind belangrijk.

Conclusie: Ouders met een dreigende vroeggeboorte willen geïnformeerd worden over de ouderrol van een prematuur kind. De juiste timing en personaliseren van de informatie zijn van belang.

Aanbevelingen: Een instrument zou ontwikkeld moeten worden, waar informatie over de ouderrol en de NICU gepersonaliseerd kan worden. Toekomstig onderzoek is nodig om te bepalen of de effecten van familie gerichte zorg worden versterkt als ouders vóór de geboorte al geïnformeerd worden over de voordelen van betrokkenheid in de zorg van hun premature kind.

Trefwoorden: Kwalitatief onderzoek, Neonatale intensive care units, Ouders, Voorbereiding, Vroeggeboorte.

INTRODUCTION

Every year, about 12,000 (7.2%) infants in the Netherlands are born premature (i.e. before 37 weeks of gestation).¹ Infants born between 24 and 32 weeks gestational age (GA) or dysmature infants weighing less than 1,500 grams are admitted to a neonatal intensive care unit (NICU).² The admission of an infant to the NICU is a stressful time for parents.^{3,4} This parental stress has ramifications: It interferes with initial bonding, and it is correlated with a higher risk of acute stress disorder (ASD),^{3,4} 'a trauma- and stressor-related disorder during the first month after a potentially traumatic event.'⁵ Four studies found that 23–28% of parents reported symptoms of ASD after the admission of their preterm or dysmature infant (henceforth: premature infant) to the NICU.^{3,4,6,7} The most trauma-related symptoms reported by parents are hyperarousal, flashbacks of their infants' admission, and avoidance of the NICU.³ In addition to the medical condition of their infant, the greatest source of stress cited by parents is the loss of their desired parental role.^{8,9} The infant's appearance, being hooked up to tubes, and surrounded by technological equipment with unknown alarms, is a stressor as well.⁸

When symptoms of ASD persist for at least one month, they may develop into a posttraumatic stress disorder (PTSD).⁸ PTSD can negatively affect the interaction between parent and infant, the long-term mental health of parents, and the development of the infant.⁸ Yildiz et al. revealed that the prevalence of PTSD is 18.5% among mothers with a low-birthweight infant, preterm infant, or traumatic birth and is 4.0% among mothers without these risk factors.¹⁰ Aside from the psychological burden, PTSD is a major source of lost human capital. The World Health Organisation reported PTSD accounts for an average of 42.7 'days out of role a year (i.e. days a person is unable to work or perform activities)'.¹¹

Because of the impact of these stressors, family-centred interventions are increasingly emphasised during admission at a NICU.^{12,13} Family-centred care (FCC) or family integrated care (FIC) are approaches that empower parents to become the core members of the NICU team in caring for their infant.^{13,14} Recent studies have shown these methods have significant positive effects for infants and parents, such as decreasing parental stress.^{14–16} O'Brien et al. found significantly lower mean stress scores among parents in the FIC group than those in the standard care group after 21 days.¹⁴ Conversely, little is known about how to familiarise parents with their role as parents of a premature infant before admission to the NICU. Preterm birth is usually unexpected, but it can also be preceded by a prolonged hospitalisation of a high-risk pregnant woman.¹⁷ This period opens an opportunity to prepare parents. Knowing what to expect in the NICU enables parents to cope more effectively with stress and improves parents' bonding with their infant.^{18,19}

The consultation with a neonatologist is an example of an intervention in which parents are informed about survival rates outcomes of prematurity.^{20,21} However, studies and current practice reveal parents expect more than essential statistical facts from the neonatologist.^{22,23} Yee et al. affirmed parents request more information about 'being parents', such as holding, feeding, understanding the NICU environment, and caring for their premature infant.²⁴ There are limited resources in the literature and few methods available in practice to prepare parents for their future parental role. Giving a prenatal tour of the NICU,^{25,26} smartphone applications,^{27,28} and nurse-led orientation programmes^{29,30} are sometimes applied in practice. The evidence on the effectiveness of these methods is scarce. In the Netherlands, there is no standard method to prepare parents to 'become parents' in a NICU environment.

Moreover, little is known about parents' experiences in this preparation phase. It is important to have a better understanding of the experiences of parents with a possible pending premature delivery and NICU admission to improve their preparation and reduce their stress. Understanding these parents' experiences is a valuable step in identifying theories and developing future evidence-based interventions.³¹

AIM

This study aimed to obtain a deeper understanding of the experiences of parents and the meanings they attach to their experiences of preparing for their role as parents of a premature infant cared for in a NICU.

METHOD

Design

A generic qualitative study was conducted with parents who have experienced premature birth and whose infant was admitted to a NICU. A qualitative design with an in-depth nature is most appropriate to obtain a deeper understanding of the experiences of parents and the meanings they attach to their experiences of preparing to become a parent of a premature infant.³²

Population and setting

The target population were parents who had an infant cared for in a NICU in the Netherlands. Purposive sampling³³ was applied for this study. Parents were eligible for participation when (a) they had an infant born between 26–32 GA or ≥ 32 GA and weighed $< 1,500$ grams,² (b) the mother had been hospitalised for at least 24 hours in an obstetric ward before birth, and (c) they speak Dutch. The threshold of 26 weeks GA was set because this study does not focus on the process of decision-making at the margins of viability. Furthermore, participants were asked for the study after their infant's third day of life because mothers needed to recover from childbirth, and parents needed time to experience the NICU. Participants shared their experiences about how they have been prepared and, in hindsight, what they would have wanted to know regarding their parental role in the NICU. The study was initially planned to be conducted in two Level III NICUs;² however, due to the COVID-19 pandemic, the study was limited to one NICU.³⁴

Procedures

Recruitment took place at the NICU of one university medical centre (UMC) in the Netherlands. The researcher K. Ruhe (KR) who worked as a neonatal nurse at the study site did not invite participants to ensure they were free to choose whether to participate or not.³⁵ Eligible participants were screened using the inclusion criteria; they were asked to participate by independent neonatal nurses trained in the study protocol. If interested, participants received an information leaflet, a participant information letter, and an informed consent form (ICF). After 24 hours, KR personally approached interested participants for informed consent and provided them the opportunity to ask questions. After agreeing to participate in the study and signing the ICF, an interview date was scheduled. Of the 23 participants asked, 17 agreed to participate, of which 12 were included. Five participants dropped out after agreeing because their infant was transferred to a general hospital before the interview. Other reasons for not participating were (a) wanting to spend all their time with their infant ($n = 4$) and (b) having no interest in the study ($n = 2$).

Data collection

Semi-structured, face-to-face interviews with open-ended questions were conducted between January and May 2020. Qualitative interviews were chosen to obtain a deeper understanding of the parents' personal experiences.³² The interview guide was developed based on relevant literature and input from the research team of A. van den Hoogen (AH) and KR.^{36–42} After two pilot interviews; two questions were discarded because they did not answer the research question. Data from the pilot interviews were used in the analysis. Appendix A contains the interview guide.

Participants were interviewed once, with a median of 8 days (min = 5, max = 40) after their infant's admission. Couples were interviewed separately since research has shown fathers often do not want to increase their partner's stress by discussing their worries.^{8,43,44} All interviews were conducted by novice researcher KR, who is trained in qualitative research through her master's education and has 19 years of experience as a neonatal nurse. The interviews were conducted in a private room in the hospital. The interviews were audio-recorded, and the duration had a median of 38 minutes (min = 21, max = 60).³² KR wrote field notes for unrecordable items, such as emotions and the environment.³²

The sample size was considered sufficient when saturation was reached, meaning the participants did not provide any additional insights.^{33,45} The baseline characteristics of the participants were collected by KR, while the characteristics of their infants were obtained from patient files.

Data analysis

Since there was limited literature on this topic, an inductive approach (i.e. allowing the data to determine the themes) was chosen.^{33,46} The six phases of the thematic analysis of Braun and Clarke were applied iteratively^{33,47} (i.e. the analysis moved back and forward between the phases): '(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.'⁴⁷ The trustworthiness and reliability of the study were enhanced during each phase of the analysis.⁴⁸

In the first phase, KR transcribed verbatim, summarised, and repeatedly read each interview to familiarise herself with the data.^{33,47} A summary of the transcript was returned to the participants for a member check.^{32,48} Eight (67%) participants replied, and all agreed to the content of the summary. In the second and third phases, researchers' (AH, KR) triangulation was used to independently assign codes to meaningful fragments.^{47,48} The research team then discussed and transformed the initial codes into themes. The qualitative data software NVivo12 was used to organise codes and themes.^{48,49} In the fourth phase, saturation was reached after eleven interviews as a result of discussions and cross-checking of data within the research team.^{32,33} A twelfth participant was added to the sample because compared with other

participants, she has more knowledge and experience with premature infants and NICU wards due to her occupation. Analysis of this deviant case was used to refine the patterns emerged from the data analysis.³² In the fifth phase, a peer debriefing was conducted by an independent psychologist who works with parents whose infant is cared for in a NICU.^{32,48} One theme and two subthemes were renamed as a result of this peer debriefing. In the final phase, the report was done according to the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines.⁵⁰ To minimise bias, a professional translator and native speaker translated the quotations from Dutch to English. To visualise and order themes, the Healthcare Trajectory of Corbin and Strauss⁵¹, edited for the NICU by Rouck,^{38,52} was used. This trajectory is classified into the pre-admission phase, admission phase, and post-discharge phase. The quantitative analysis was performed using SPSS Statistics, version 24.⁵³

Ethical issues

The study was conducted according to the principles of the Declaration of Helsinki 2013.³⁵ Personal data was handled following the General Data Protection Regulation Act.⁵⁴ The participants cannot be identified in the qualitative and quantitative data. A subject identification code list was used to link the data to the subject and was kept securely separate from the data. The study was approved and declared a non-WMO (Medical Research Involving Human Subjects Act)⁵⁵ study by the Medical Research Ethics Committee of VUmc Amsterdam and UMC Utrecht. Participating in the study did not cause any risks or provide any benefits to the participants.

RESULTS

Participants

This study included twelve parents (i.e. five fathers and seven mothers), including five couples. The couples were interviewed separately. The median age of the parents was 33.5 years (min = 29, max = 39). Ten (84%) parents have a higher education level,⁵⁶ and four (33%) were foreign-born. All of the parents were in a heterosexual relationship and were first-time parents. Before birth, mothers were hospitalised in five different obstetric wards, with a median of 9.5 days (min = 3, max = 42).

The GA of the eight infants ranged from 26 to 34 weeks (median = 27.5). All infants had an Apgar-score⁵⁷ of 8 or higher, 5 minutes after birth. Tables 1 and 2 contain more detailed characteristics.

Insert Table 1

Insert Table 2

Main results

The (sub)themes regarding the parent's experiences in preparing for their role as parents of a premature infant are presented in the following sections. Figure 1 visualises the parents' healthcare trajectory. In the pre-admission phase, parents were confronted with the unanticipated reality of the NICU when the pregnancy became high risk. Two key themes emerged from this high-risk phase: *hoping for a good outcome* and *coping with information*. In this phase, the twelfth participant had similar experiences as the other parents.

Two themes emerged from the admission phase – *need for personalised information* and *bonding through involvement* – as parents experienced the NICU and reminisced the pre-admission phase. The experiences from the twelfth participant differed in one subtheme; *information about the NICU*. The quotations presented were annotated with mother or father, and a participation number.

Insert Figure 1

PRE-ADMISSION PHASE

Theme: Hoping for a good outcome

Hope for the continuation of pregnancy: All parents hoped they could continue the pregnancy. Many spoke about how they tried to stay positive and how they distracted themselves from the stress of a possible preterm birth. Reaching a milestone in the GA or weight of the infant was an important achievement for half of the parents. Parents handled their anxiety by getting by from one day to the next or, from '24 weeks, then 25 weeks' and so on.

Yes, 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 can take another ten weeks. [Father, P02]

Need for positive stories: Positive stories about other preterm infants provided nine parents with hope for a more positive outcome for their infant. Most parents searched for stories about infants with a similar GA or weight. These stories came from internet resources or were based on the experiences of their social context, the neonatologist, or other patients in the obstetric wards. These stories counter 'the worst-case scenarios' regarding infant survival and future health problems. According to the parents, these stories provided them 'relief', 'hope', and 'trust'.

I was here [in the obstetrics department] for quite some time, so I saw quite a number of women who had had early deliveries. Some had their water break at 30 weeks, and everything went fine... with no problems at all, nothing... [and] that helped me to have a bit more faith. [Mother, P03]

Theme: Coping with information

Medical information is a priority: All parents described medical information concerning their infant's survival and future health problems as their initial priority. There was a need for 'numbers' and 'percentages' regarding 'complications', and 'chances of survival'. Parents valued these medical facts above information about parenting a premature infant. All parents were satisfied with the prenatal counselling they received. However, most of the parents described the medical information as 'a lot of information' is sometimes 'difficult to remember' or 'stressful'.

At that point, I was more focused on what the consequences would be... of being born at 26 weeks. What are the risks? (...) We were more concerned with the survival and not really with parenting. [Mother, P01]

Protecting oneself from information: After acquiring medical information, most parents spoke about a 'quiet time' when they needed to 'protect themselves' from information. They talked about deliberately not searching the internet about prematurity, and they looked for distraction. The majority of parents discussed the need for psychological and physical rest. Specific information about the NICU and about parenting a premature infant were also considered by most as 'not wanted.' Parents did not find 'it relevant at that time', or they 'did not want to think about the reality of the NICU'.

I consciously chose not to [accept an invitation to tour the NICU] because I had the feeling that I needed to stay calm and relaxed. I was very afraid that this would lead to negative tension... And that was true despite the fact that I had reached the point that I wanted to know everything I could.

[Mother, P05]

Expectations about parenting in a NICU: Most parents stated the need for information about their parental role became relevant when the birth was forthcoming. The majority of parents revealed they did not receive information about becoming a parent in the NICU. Two participants asked about their parental role in the NICU, and they described this information as 'hard to imagine' but recognisable when their infant was admitted.

Ten parents expressed their expectations about a restricted parental role with their premature infant in the NICU. Most of them were not able to provide a reason for these expectations. Some parents thought their infant was 'too fragile', it was 'too difficult with all these wires and tubes', or it was 'not hygienic'.

I had painted a picture, you know. I'm going to stare at an incubator for a few weeks. [Mother, P07]

ADMISSION PHASE

Theme: Need for personalised information

Information about the NICU: The majority of parents expressed a need for a pathway regarding 'what to expect' in the NICU. However, the fulfilment of this pathway varied considerably between parents and even between couples. Some wanted to know about the admission day, some about the appearance and common problems of premature infants. Others focused on the NICU environment and the stressful events in the NICU. Concerning their parental role, some parents want to know what the NICU-staff expected from them. Fathers emphasised the importance of taking care of their partners. Half of the parents wanted to tour the NICU in the pre-admission phase; the other half were concerned about the additional stress this would give them. The twelfth participant explained her prior knowledge about premature children and the NICU environment provided her 'a protective factor', as not everything was new.

To know in advance that your baby may stop breathing [apneas]. No big deal. That happens, that is a part of being premature. [Mother, P01]

No, no, no, no. Because I think you can be very worried about that. (Response to 'Did you want to know in advance about these apneas?') [Mother, P07]

Manageable pieces: All parents cited the value of personalised information to prepare themselves for a parental role. Information gave them 'clarity', 'grip', 'control', 'feeling prepared' and 'lifelines' in an uncertain period. Preferences on how this information is delivered varied between parents. Prenatal consultation with a NICU nurse, a booklet, reliable internet sites, a video, a (virtual) tour of the NICU, and an information application were given as suggestions. Notably, almost all of the parents emphasised this information must be delivered in 'not too detailed, manageable pieces'.

Just give brief bits of information, and then leave. And not everyone all at once because we were living in a bubble since this had happened. But actually, I am not sure when the right time is to try to help. I'm not sure... Just ask. And, of course, don't talk too long. [Father, P08]

Theme: Bonding through involvement

Unexpected closeness: Ten parents were surprised about the level of closeness they had experienced with their infant in the NICU. They did not expect to touch and hold their infant so frequently. Most parents were not told about this level of closeness in the pre-admission phase. One mother who was told during prenatal counselling about holding her infant. Nevertheless, she was 'surprised' about the level of contact she had with their infant on the ward. This closeness provided many parents with a feeling of 'bonding' and 'a realisation of being parents'. The majority of parents mentioned they would have liked to be told about this level of closeness during the pre-admission phase.

We had not expected to be able to touch her, to hold her. That is beautiful (...) especially the kangaroo care. That is best of all. Holding, touching, holding hands, and just enjoying. Talking to her. Just telling her what is going on. That everything will be all right. That daddy is here... [Father,P06]

Growing in care: All parents highlighted the value of being increasingly involved in the care of their infant. All parents appreciated being shown how to change a diaper a clean their infant's mouth with mother's milk; some parents also mentioned cleaning the incubator themselves. Performing parental duties gave them 'a feeling of participation', as they 'get to know their infant' and 'connect with their infant.' Nine parents indicated they would have liked to know this 'growing in care' during the pre-admission phase. Notably, three parents mentioned they would have preferred to receive this information at the start of the admission phase because they received enough information during the pre-admission phase.

You [as parents] will get an increasingly important role in the care. Well, I think that kind [of information] could be a little more concrete (...) The strength will lie in getting the things into the limelight that are obvious to you [staff NICU] because they are not self-evident to us. [Mother, P12]

DISCUSSION

This qualitative study identified themes reflecting the experiences and needs of parents preparing for their parental role of a premature infant in a NICU. When parents entered the high-risk pregnancy phase, *hoping for a good outcome* and *coping with information* became key themes. The emphasis was initially on hope and medical information. In case birth was forthcoming, parents had limited expectations regarding their parental role in the NICU. After NICU admission, a *need for personalised information* and *bonding through involvement* emerged. Parents considered personalised information essential. Moreover, missed topics in their preparation for their parental role were holding and caring for their premature infant.

The theme *hoping for a good outcome* in the current study confirmed the findings of previous qualitative studies.^{58–63} Carter et al. found the theme ‘coping with uncertainty’ in women who experienced threatening preterm labour.⁶¹ Coping strategies, such as trying to stay calm, setting themselves markers to reach, and maintaining the pregnancy, resonate with present findings. Participants in previous studies were predominantly women. The present study found fathers use the same coping strategies.

Coping with information was another important finding in the high-risk pregnancy phase. This study revealed different stages parents go through while dealing with information about their parental role in the NICU. Although the primary need for medical information has been discussed in previous studies,^{38,63,64} the present study provide a clearer pathway as to when parents are ready to receive information about their parental role. A systematic review found information at ‘an unsuitable moment triggers anxiety in expected parents while too little information can equally induce fear’.³⁸ Appropriate timing of information is, therefore, essential to reduce stress.

The *need for personalised information* is in line with the current literature regarding prenatal counselling.^{63,65–69} Geurtzen et al. recently showed there are various parental preferences in counselling regarding extreme prematurity (i.e. 24–26 weeks GA).^{65–67} They subsequently developed a decision aid whose content can be personalised for parents facing an extreme premature birth.⁷⁰ The current study revealed parents in a high risk-pregnancy of 26–34 weeks GA also want personalisable information about a parenting in a NICU environment. Furthermore, the deviant case strengthened the results that information about a NICU before admission could lead to less stress upon admission.

Moreover, this study demonstrated parents want to be told about the level of closeness and their participation in the care of their premature infant. These experiences contrasted the minor expectations regarding parenting in the pre-admission phase. Informing expectant parents aligns with the principles of family-centred care, enabling parents to play an active role in caring for their premature infant.^{12,13}

This study has some limitations. First, the transferability of the findings is limited by the fact the study took place in one NICU instead of multiple centred due to the COVID-19 pandemic. Second, mothers were mainly prenatally hospitalised at one obstetric ward. A sample from various hospitals could lead to different results due to differences in preparation methods. Third, the whole sample consisted of first-time parents, relatively older, and mainly white, highly educated parents. A more heterogeneous sample could lead to different results.

A strength of this study was that it was conducted at the admission phase; hence, parents had time to reflect on their experiences and express what they would have needed in the pre-admission phase. Moreover, the trustworthiness of the study was enhanced by researchers' triangulation, member checking, use of a professional translator, and peer debriefing. In addition, the sampling of a deviant participant strengthened the results of this study.

Conclusion

This study demonstrated that parents in a high-risk pregnancy want to be informed about how to bond and care for a premature infant. Empowering and informing parents beforehand is a necessary step that supports them in internalising their parental role sooner. Appropriate timing and tailored information about their parental role and NICU-environment are essential.

The practical implications of these findings are as follows: First, parents should be provided with concise information about the importance of their parental role and their increasing involvement in the care of their infant at a NICU. Second, a personalisable and retrievable information tool about parenting a premature infant and the NICU environment included should be developed. Third, further research is needed to determine whether the effects of FCC can be enhanced when parents are prenatally informed about the benefits of being involved in their infant's care. Concluding, parents should be empowered before the birth of their preterm infant and not only afterwards.

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TABLES and FIGURES

Table 1. Characteristics of parents (n = 12)

Characteristics	n (%) or M (min-max)
<i>Gender, male</i>	5 (42%)
<i>Age in years</i>	33.5 (29–39)
<i>Education level</i>	
Lower education	1 (8%)
Middle education	1 (8%)
Higher education	9 (84%)
<i>Marital status</i>	
Married or registered partnership	10 (83%)
Cohabiting	2 (17%)
<i>Ethnicity</i>	
Afro-Surinamese	1 (8%)
Arab-Berber	1 (8%)
Dutch	8 (67%)
Sinhalese	2 (17%)
<i>Religion</i>	
None	9 (75%)
Christian	2 (17%)
Islam	1 (8%)
<i>Family composition</i>	
First child(ren)	12 (100%)
<i>Prenatal medical counselling, yes</i>	10 (83%)
<i>Previous knowledge about premature infants, yes</i>	1 (8%)
<i>Prenatal admission of mother, days</i>	9.5 (3–42)
<i>Location of prenatal admission of mothers, total days</i>	
Hospital A	2 (2%)
Hospital B*	83 (80%)
Hospital C	5 (5%)
Hospital D	3 (3%)
Hospital E	10 (10%)
<i>Causes of prematurity or dysmaturity</i>	
Abruptio placentae	1 (14%)
Anatomic problems mother	2 (29%)
Genetic problems infant	1 (14%)
Pre-eclampsia	1 (14%)
PROM	2 (29%)

M = Median (minimal - maximal), Education level = classification Statistic Netherlands,⁵⁶
 PROM = Premature Rupture of Membranes, * = Study Site

Table 2. Characteristics of infants (n = 8)

Characteristics	n (%) or M (min-max)
Gender, male	5 (63%)
Gestation in weeks	27.5 (26–34)
Birth	
Vaginal	2 (25%)
Caesarian section	6 (75%)
(Multiple)birth	
Singleton	6 (86%)
Twins	1 (14%)
Birthweight in grams	1,160 (780–1,365)
Apgar at 5 minutes, 0–10	8.5 (8–9)
Morbidities until interview	
RDS in newborns	6 (75%)
BPD	1 (13%)
NEC	1 (13%)
IVH	1 (13%)
LOS	3 (38%)
ROP	1 (13%)

M = Median (minimal–maximal), Apgar = test newborn 1 and 5 minute(s) after birth; range 0–10, RDS = Respiratory Distress Syndrome, BPD = Bronchopulmonary Dysplasia, NEC = Necrotising Enterocolitis, IVH = Intraventricular Haemorrhage, LOS = Late Onset Sepsis, ROP = Retinopathy Of Prematurity

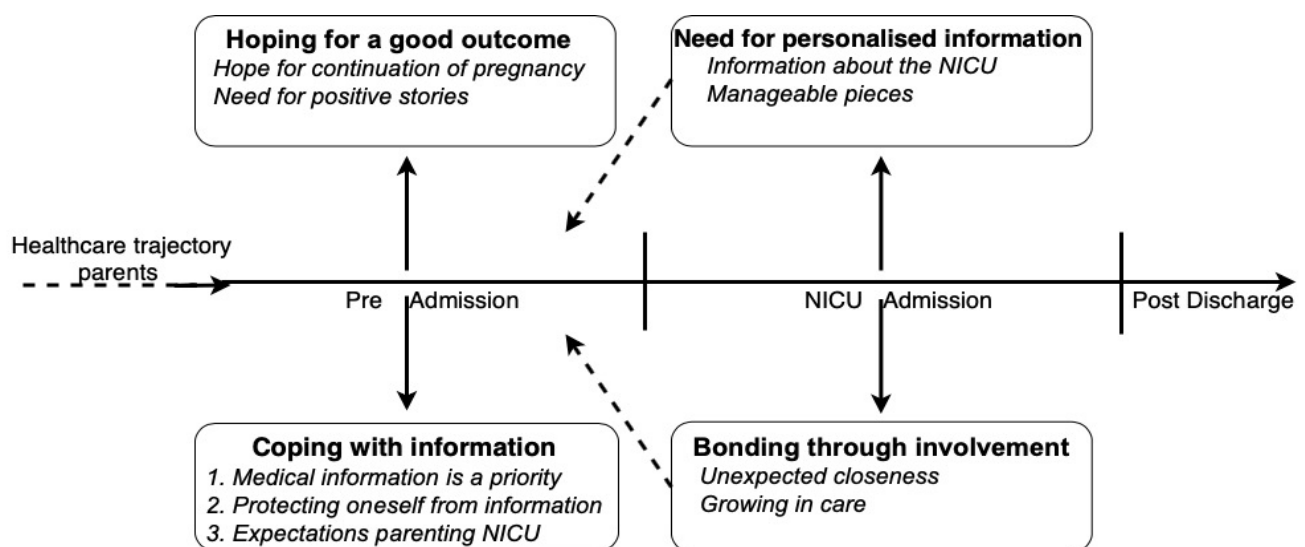


Figure 1: Themes based on the experiences of parents becoming a parent of a premature infant. Based on the Healthcare Trajectory by Corbin and Strauss⁵¹ and edited for the NICU by Rouck.^{38,52}

APPENDIX A

Interview guide

The interview guide is based on themes from relevant literature.³⁶⁻⁴² The guide consists of two phases (i.e. before and after birth) in becoming a parent of a premature child based on Gibbs.³⁶

Before birth: The (unexpected) reality of the NICU

1. *If you think back on the period before the birth of (child's name), how were you prepared to become the mother/ father of a premature child?*
 - 1a. *How did you think about this preparation? How did you feel about it?*
2. *Have you prepared yourself by searching for/asking about your role as parents of a premature child or about the NICU environment? Why (not)?*
 - 2a. *How did you think about this preparation? How did you feel about it?*

After birth: Adapting to the NICU environment

1. *You are now the father/ mother of a premature child in the neonatology department. What experiences would you have wanted to know in advance? Why?*

Topics from the literature (only when no answer is given)

- **Parental role:** feeding/ breastfeeding/ caring for/ holding / kangaroo care/ protecting the child
 - **Baby:** appearance of the baby/ tubes /pain/ behaviour/ medical condition of the baby
 - **NICU environment:** sounds/ equipment/ privacy/ other sick babies/ limited space/ department rules
 - **Staff:** barriers (conflicting ways of working and providing information); facilitating (supporting parents in their parental role/ getting to know the NICU)
 - **Practical:** mother and father's roles/ other children/ financial situation
 - **Stress:** being away from the child/ shame/ guilt/ loss of 'pink cloud'/ loss of control/ life crisis/ fear of the child dying / change in family dynamics
2. *You have shared many experiences. If I [as a neonatal nurse] go to the obstetrics department right now to talk to parents with preterm labour, what is the most important thing they need to know regarding a parental role on the NICU? Why?*
 3. *Think back of the time before the birth of (child's name). What were your expectations of motherhood/fatherhood in the first weeks of the baby's life? What would your parental role be?*