

ORIGINAL ARTICLE

# EXPERIENCES OF HAVING A PREMATURELY BORN INFANT FROM THE PERSPECTIVE OF MOTHERS IN NORTHERN SWEDEN

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## ABSTRACT

**Objectives.** The aim of this study was to describe the mothers' experience of having a prematurely born infant, with the focus on the birth itself and during the time immediately following the birth.

**Study design.** A qualitative design was chosen to achieve the aim of this study.

**Methods.** Six mothers, whose infants were born prematurely and thereby needed care on a neonatal intensive care unit (NICU), participated in the study. Narrative interviews were conducted and the mothers were encouraged to freely narrate their experiences of having an infant born preterm. A qualitative content analysis was used to analyse the interviews.

**Results.** The results show that mothers were not prepared for having prematurely born infants and that initially they had difficulties feeling like a mother. Having an infant born preterm was dominated by feelings of anxiety. Feeling closeness to the child was important, and separation from the child was a very stressful experience. Family life was affected, but mothers felt they were able to handle the situation if they received support from their partner and hospital staff, and if they were equipped with knowledge regarding the birth and care of a premature infant. Furthermore, it was important for the mothers to be involved in their infants' care.

**Conclusions.** Support and knowledge made it possible for mothers to handle having a premature infant. Mothers' situations could be facilitated if nurses had increased knowledge and understanding about how mothers experience this situation.

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**Keywords:** preterm infant, premature, mothers' experiences, neonatal nursing care, qualitative content analysis

## INTRODUCTION

The experience of having a prematurely born infant can have a long term impact on the parents' experiences of having a baby and on the parent–infant relationship. When an infant is premature, the normal parental process and the mental preparation of parenthood are interrupted (1). Parents are not prepared psychologically, physically and emotionally for this event. Becoming a parent is hard to understand, because everything happens so quickly and unexpectedly (2–4). Having a preterm infant can be a shock; feelings of sorrow and loss are sometimes so intense that it can be difficult to handle the situation (5). Parents experience many stressful situations in connection with a preterm birth, which affects the possibility of them noticing their child's signals and their ability to interact with the infant (6). If parents do not experience early moments together with their child, they may have feelings of not having a normal connection to their child or believe that something might be missing in their future relationship (7).

Mothers of preterm infants often experience strain and depression in the early stages following the birth of the infants (8–11). At the same time, feelings of disappointment (12) and failure are often experienced, based on the fact that the mothers were unable to complete the pregnancy (6). Most of the mothers of high-risk premature infants experienced emotional responses similar to post-traumatic stress disorder 6 months after their child's expected birth date (13). Transition to motherhood is a normal developmental process, but mothers of preterm infants can have difficulties keeping these

normal processes under control (11). Mothers of preterm infants experience a process of bonding similar to full-term mothers, except for the fact that the identity recognition of their newborn is relatively delayed (14).

Neonatal nurses have a pivotal role in facilitating the early mother–infant relationship, (15) and it is of great importance for nurses to consider the mothers' individual needs, as these are essential to their sense of well-being (16). As an important part of that process, parents should be actively involved in the care of their child. They must be supported and encouraged to take an active part in the care of the child from the start, with the goal of eventually taking full responsibility (1,17,18).

According to Jackson (4), most of the research with a focus on parents' experiences of having a prematurely born infant has been done in the U.S., and there is a lack of research with a Scandinavian perspective. The social security system in Sweden allows parents to obtain a leave of absence from their job, with policies stipulating that parents can receive compensation equivalent to 80% of their income while they are taking care of a sick child (19). This makes it possible for both parents to stay at the neonatal intensive care unit (NICU) with their infant, which creates a certain framework for mothers and fathers in Sweden to deal with having a prematurely born infant together. Therefore, existing research is not always transferable to conditions in Sweden, so further research is needed. However, it would be of interest to know whether the parents being together at the NICU might influence the mothers' experiences of having an infant born preterm.

## MATERIAL AND METHODS

A descriptive qualitative method was chosen for the study. The study took the form of interviews with qualitative content analysis.

### Context

This study was conducted in collaboration with a neonatal intensive care unit (NICU) in the county of Norrbotten, the largest and most northerly county in Sweden. Norrbotten covers one-quarter (98,249 km<sup>2</sup>) of the country's surface area. The county is sparsely settled, with most of the population of 250,000 living near the coast (20). The study included mothers of preterm infants who had been cared of in a Level 3 NICU. A Level 3 unit cares for infants born as early as 28 weeks in the gestation period, and can provide sustained life support with conventional mechanical ventilation. Minor surgical procedures may also be performed, such as the placement of central venous catheters. A total of 14 infants can be cared for in the unit, which includes intensive care space for 4 infants. The NICU runs a Newborn Individualized Developmental Care and Assessment Programme (NIDCAP), based on the idea that premature infants need a great deal of support and a specially designed environment in order to thrive and develop as normally as possible. The rooms in the unit are designed to provide peaceful surroundings. Parents are involved in their infants care at an early stage (21). However, it is not possible for all parents to stay at the unit overnight, as there are only a few family rooms, with a total of 6 beds.

### Participants and procedure

A purposive sample of 6 mothers of preterm infants participated in the study. The criteria

for inclusion were twofold: the participant had to be a mother of a premature infant born before gestation week 36, and the infant must have been cared for at a NICU approximately 3 years ago, as the intention was to acquire the mothers' reflected experiences. The participants who fulfilled the criteria were selected from documents by the head nurse at the NICU. There were no exclusion criteria. The mothers were between 25 and 35 years of age. All of the mothers lived with the child's father when the infant was born, but at time of the interviews one of the mothers was divorced. Four of the mothers were primiparae and two were multiparae. The children were born at gestational ages between 28 and 34 weeks and had been cared for at the NICU for at least one week, but most of the children had been at the NICU for several weeks. The children had developed normally up until their preterm birth; however, it is not possible to speculate if the preterm births will influence the children's development in any way as they continue to grow. The head nurse at the NICU contacted the participants by phone and provided some information about the study. It was made clear that participation in the study was entirely voluntary and that participants could withdraw from the study at any time. Mothers who were interested in participating were sent written information, outlining the study in greater detail. The first author (BL) contacted the mothers by phone about a week after they received the written information and provided more information about the nature of the study. At this point, appointments for the interviews were made. The participants were also guaranteed confidentiality and anonymity in the presentation of the results. The Ethics Committee at Luleå University of Technology approved the study.

**Data collection**

Narrative interviews (22) were conducted with the mothers three years after the children’s birth. The intention was to have the mothers describe the experience of having a preterm infant from the time of the birth to the period immediately following it. The first author (BL) performed all the interviews. The interview started with the question: “Please tell me about your experience of having a prematurely born infant with the focus at the birth and initially after the infant’s birth?” The narration was supported by questions such as, “How did you feel then?” “Can you explain more?” “What did you think then?” The mothers were encouraged to talk freely about their experiences of being the mother of a prematurely born infant. The interviews took the form of a conversation, and the interviewer used active listening skills in the process (23). The time and place for the interviews was chosen by the mothers. All of the interviews were conducted in a quiet room, five in the mothers’ home, and one in the first authors’ office. Each interview lasted approximately 25 to 50 minutes. The interviews were tape recorded, transcribed verbatim and the transcriptions were reviewed for accuracy by the first author (BL).

**Data analysis**

A qualitative content analysis inspired by Burnard (24,25) was used to analyse the interviews, described as follows. All texts from the interviews were included in the analysis. Each interview was read through several times to gain a sense of the content. The whole text was then read to identify meaning units guided by the aim of the study. Before the material was revised further, the second author (KÖ) read parts to judge the credibility of the

revisions. The first analysis was made by creating a memorandum to bring out the character of the text as a help to do the analysis. Consensus was reached about the fundamental qualities of the material by the two authors. The meaning units were condensed and thereafter grouped into categories. The analysis progressed by reducing the number of categories through a process of combining similar categories into broader categories. Finally, the meaning units were reread and compared with the categories. The two authors independently checked and reached agreement on the categories. Quotations were chosen from the complete text to increase the credibility of our conclusions.

**RESULTS**

The analysis resulted in 5 categories (Table I), which are presented in the text below and illustrated with quotations from the interview texts.

**Table I.** Categories (n=5) of mothers’ experiences of having a prematurely born infant, with the focus on the birth and the period initially following.

Categories
Being a mother without being prepared
Being in a situation filled with anxiety
Struggling to feel close to the infant
Effects on family life
Being able to handle the situation

**Being a mother without being prepared**

All the mothers described having an infant born prematurely as a shocking experience. They were not prepared for the birth of the child so early, and having a tiny infant was experienced as a very special situation. To realize that the infant was born and to fully accept that they had become mothers took several days, but even after the initial shock,

they described having lingering feelings of detachment, a sense of not being the infant's mother. At the time of the birth, when motherhood normally begins, all experienced difficulty feeling like a mother. They also described a sense of unpreparedness for having an infant who was ill or underdeveloped.

*She was born on a Thursday and I remember that on both Friday and Saturday, I spoke with the child's father and I said to him, I might as well go home from the hospital; it was just as nothing has happened, it was as if it was so unreal...*

The women all had expectations about becoming a mother, but motherhood did not turn out to be what they had expected. All of the mothers missed the initial sense of happiness of having a baby. They also reflected on "why only they" had to have a preterm infant. After their infants' birth, they initially avoided meeting mothers whose infants were born full term. Feelings of being "robbed" emerged constantly in the days following the birth, as well as feelings of disappointment and sadness because they had not been able to complete preparations before the birth of the infant. During the pregnancy, the mothers had created an image in their minds of how the baby would look upon arrival, which did not match the real infant. When they saw their child, their first impression was that the baby was so tiny. Mothers described a sense of incomprehension regarding the information given about the infant and how to care for him/her because of the situation. Their opinion was that the information was likely adequate but that it was given at the wrong point in time. Nevertheless, all believed that it was important to have the information.

### **Being in a situation filled with anxiety**

For the women in the study, having a preterm infant was dominated by feelings of anxiety. All the mothers feared the infant might be ill or injured, or that it would not survive. They were also worried that the infant might have a defect, or would be affected for life because he/she was born premature. As one mother said: "Yes, the fact that the child might not survive and just like...Even though they do survive they might have injuries...most of all I was afraid of that she not might survive..."

To realize that the infant was weak and underdeveloped and to have the impression that the infant might be ill were factors that created an unwanted stressful situation. Once their infant's condition was stabilized and the mothers were able to see him/her, their anxiety decreased. It was hard to believe that the infant was in good health because the anxiety was so strong. They described the worry of not being present if something happened. Mothers also feared hurting the infant when they handled or held her/him.

### **Struggling to feel close to the infant**

Mothers described a need to be with the infant as much as possible. Spending time with and being close to the infant made "feelings of motherhood" grow. All the mothers found that not being able to hold the infant was hard, and they described a longing to hold their infant. They could also feel close by being near the infant and touching him/her.

*I thought that it was really great the first time I could touch her you know...I tried to have her with me as much as possible and when she came from the incubator I wanted to stay with her by myself without being disturbed...*

Being separated from the infant was emotionally stressful, and was described as the most stressful part of having a preterm baby. Mothers wanted to stay close by, which was not always possible when the infant was in the NICU. Being able to see or hold the infant for a brief moment after the delivery was important, even if it was only for a few seconds. Seeing the infant as soon as possible was of great importance, and it was also valuable for the mother to have a picture of the infant, especially when her condition made it impossible for her to go to the NICU. Kangaroo care, where parents are permitted to hold the infant using skin-to-skin contact, was also described as very important. When they could breastfeed their infant, a sense of closeness was experienced. Mothers also wanted to take care of the infant as much as possible. Feelings were soothed by being close by and spending time with the infant.

### **Effects on family life**

Family life was affected in many different ways by having an infant born preterm. Families could not spend time together, which resulted in mothers longing for the rest of the family and experiencing a sense of loneliness. When the whole family was at the NICU and the infant's condition was stable, it was important for the family to be together without being disturbed by staff or others. The mothers who had children at home described a longing for their older children, stating that it was hard to be away from them. They wanted to be at home yet at the same time they wanted to be with the infant at the NICU. It was especially difficult for mothers when their other children could not understand why their mum could not be at home.

*Then I thought they (the staff) know how to take care of him much better than I, so I stayed with him four hours, that's enough for me, because I can't do any more. I was torn: when I was at home I wanted to be at the unit and when I was there I wanted to go home, and then I felt guilty. Oh God, he needs his mother.*

### **Being able to handle the situation**

When the infant needed care in the NICU it was, in the end, described as a positive experience. Mothers had to handle the situation, because they knew they had no other alternative. The realization that the infant might survive also gave them the strength to cope with the situation, which provided them with a feeling of personal growth. One factor that enabled mothers to handle the situation was having support from the hospital staff, the infant's father and other people of importance. It also was important to learn about preterm birth during the situation, as experience and knowledge of having a prematurely born infant born were limited prior to the early delivery. As one mother said: *"I had some knowledge because it wasn't my first child, which I was happy to have..."*

Feeling support from and having the opportunity to talk to the staff resulted in less worry. Being received by the staff with kindness was of great importance, and by receiving support from them, mothers felt that the infant was well taken care of. Mothers described it as important to receive information specific to their experience and related to their unique situations, which they didn't always have. A sense of disappointment was felt when nobody listened to their thoughts and desires. The mothers described that support could come

from the infant's father and by being able to talk about their experiences with other mothers. It was important to have support and assistance when caring for the infant and to have someone show and explain how to take care of him/her safely. It was also of great importance for mothers to decide how much they wished to be involved in the infant's care. When mothers had to ask for permission to participate in their own infant's care, it resulted in feelings that the infant belonged to the staff. Mothers expressed concerns about whether their role as a mother had been affected by their early experiences of having a preterm infant. Some mothers stated that it did not have any influence on the way they treated their infant, but some mothers were negatively influenced by having a preterm infant. As one mother said: "...but I thought, and so did some other people, that I was going to be an overprotecting mum because he was so tiny, but it isn't like that...". Mothers also stated that it had been a stressful start having a baby born prematurely and that might be a reason they were more worried and anxious.

## DISCUSSION

The results of this study show that mothers described having a preterm infant as a unique experience. They had not been able to complete normal preparations before the infant's birth, which made it difficult initially to feel like a mother after the infant's birth. Having a prematurely born infant meant the transition to parenthood was difficult, since the infant in the beginning was too weak to send strong signals and could not as clearly communicate his/her needs to the parents (26).

The results indicate that mothers had developed expectations about having a baby which did not correspond with reality. Mothers described expectations of the preparations they wanted to make before the infant's birth and also expectations about the initial time after the infant's birth. Unfulfilled expectations made mothers feel both disappointment and sadness. The clash between expectation and reality might be a factor that makes it more difficult for mothers to be filled by love for the infant (27). According to Sydnor-Greenberg, Dokken and Ahman, the birth of a preterm infant can be experienced as the loss of a perfect baby, because the ideal picture of the infant disappears (28). Mothers who participated in this study described the first sight of the infant and the infant's size as a shocking experience, which is similar to the results found in another study (29). In spite of that, it was of great importance for the mother to see the infant as soon as possible.

In the present study, mothers experienced difficulties understanding the given information, as they were in shock, which meant that they were not open to the information they received. Calam, Lambrenos, Cox and Weindling pointed out that it is not clearly understood how much information mothers of preterm infants can absorb at the time of the birth (30). More research is needed to fully comprehend the process of how the given information is understood, and to determine the best ways the information should be given.

The results of this study show that the mothers of preterm infants were in a situation filled with stress and anxiety. It also shows that mothers initially felt unhappiness about the outcome of the pregnancy, and were concerned for the infant's health and life. A great number

of mothers initially did not feel happy about their preterm infants; the first days were chaotic and memories are blurred (30). Mothers expressed worry about the infant being ill or injured and worried that it might not survive. Having a preterm infant prevents women from being confronted with the apprehension during the pregnancy that the infant is ill or not might survive, it is important that women during the pregnancy are confronted with this apprehension (27). However, this is complicated as the mothers of preterm infants are interrupted in their preparations and therefore do not get as far as going through the phase of anxiety over their unborn child's health during the pregnancy.

Separation from the infant was experienced as the most stressful part of having a preterm birth and mothers in this study wanted to be close to the infant as much as possible. Many studies (2,31–33) show that mothers experience frustration when separated from their newborn infant. When separation occurs, mothers and their infants have no opportunity to experience mutual bonding and recognition. There might be a delay in the process of maternal role identity, and this process must be initiated as soon as possible (34). Nurses' attitudes towards and treatment of mothers are found to be integral in the development of the relationship between mothers and their infants (35). It is interesting to note that mothers talked about the stress related to being separated from the child, but never mentioned the effect this may have on their partner. However, this is not in accordance with a study (36) about fathers of prematurely born infants. Fathers also find it stressful when they are unable to be with both the partner and the infant. Initially after the infant's birth, it is even more stressful to be separated from their partner.

After the premature birth, mothers in this study struggled to feel close to the infant; being involved in the care of the infant and spending time with him/her made the sense of motherhood grow. Mothers wanted to get to know their babies by seeing, holding and touching them, but the process of getting to know the newborn baby was often interrupted because the infant was preterm (34). Mothers wanted to be close to the infant and hold him/her as soon as possible after the birth, and they explained that their desire to hold the infant came much earlier than the opportunity to do so. According to Neu, skin-to-skin contact (kangaroo-care) was experienced as positive, and parents expressed a longing to hold the infant as soon as possible (37).

Mothers experienced that the whole family was affected by the preterm birth. Mothers who already had children felt torn between being at home with their elder children and being at the NICU with the infant. According to studies (28,29,38,39), it is very important to create and develop neonatal family-centred care. The whole family should play a part in the infant's care (40), which was not the case for mothers in the present study.

The results show that having a preterm infant was experienced by mothers as especially strenuous, but most of the situation could be handled with support from the hospital staff, the infant's father and by obtaining knowledge about preterm born infants. "Small-talk" or "everyday-chat" is an important tool for nurses in the NICU to support mothers. Verbal communication between nurses and mothers helped the mothers feel confidence in the nurses and the care they were giving their infants (41). The results indicate that mothers felt positive support from the staff. According

to previous research (29,31), that sense of support is important in order for parents to handle the situation of having a preterm infant who needs care in a neonatal unit. When the infant's condition is stabilized, parents of a preterm infant have more time and psychological space for their own emotions. Some parents needed to meet professionals to receive help with their own feelings after the birth (42).

The results show that it was of great importance to participate in the infant's care. Being a mother means having the utmost responsibility to make decisions about the care of the infant, but mothers in this study felt a lack of that responsibility. Being involved in the infant's care contributed to the sense of being a mother (14). With the hospital staff providing support and aid, parents are empowered and know that they have the ability and competence to take care of their child independently. Empowerment is a process of helping people to assert control over the factors that affect their lives (43). Family empowerment can be a nursing intervention intended to optimize the power of the family, and increasing the skills of the parents to effectively care for the child and sustain family life (44).

### Conclusions

Mothers of preterm infants are not prepared for the infant's birth, which makes feeling like a mother initially difficult. Mothers experience a situation filled with stress and anxiety. Having a premature infant affects the whole family, and mothers feel strain when they cannot be with the rest of the family. This study shows how important it was for the mothers to be close to the infant and also to be involved in the infant's care. It is essential

for mothers to feel supported by the infant's father and the hospital staff, as well as being provided with the knowledge that facilitates and creates the necessary conditions for mothers to handle a prematurely born infant. The fact that the partner was mentioned as an important part of being able to handle having an infant born preterm, might be different from other studies where the partner was not specifically discussed (e.g., 45–47). It seems that mothers in this study could have experienced greater support if the partner had been present at the NICU, which could have more positively influenced their experiences of having a prematurely born infant. However, it is not possible to come to a specific conclusion. This study cannot provide an answer on whether both parents in Sweden staying at the unit influenced the mother's experience of having a prematurely born infant. Further research about this is needed.

The results of the study have implications for nurses caring for families with a child born prematurely. They must be willing to listen to the mothers' experiences of being a parent. It is essential to remember that the results state there are powerful memories of becoming a mother of a preterm infant, memories that almost certainly are going to last for a long time. The interviews were conducted approximately 3 years after the child's birth, yet despite this fact, all the mothers remembered and could clearly narrate their experiences, which indicates the importance of sharing their experiences of being a mother to a preterm infant. However, this finding could have influenced the results. Increased knowledge of parents' experiences of having a prematurely born infant entails a challenge to further develop and improve

nursing care, with the possibility of having to work on strengthening the relationship between parents and infants. Developing of parental support after having a prematurely born infant is of great importance. It is therefore of great interest to continue to follow and study parental support in neonatal care.

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