



LUND UNIVERSITY

Reorganizing Life: A Qualitative Study of Fathers' Lived Experience in the 3Years Subsequent to the Very Preterm Birth of Their Child.

Lundqvist, Pia; Hellström-Westas, Lena; Hallström, Inger

Published in:

Journal of Pediatric Nursing: Nursing Care of Children and Families

DOI:

[10.1016/j.pedn.2013.10.008](https://doi.org/10.1016/j.pedn.2013.10.008)

2014

[Link to publication](#)

Citation for published version (APA):

Lundqvist, P., Hellström-Westas, L., & Hallström, I. (2014). Reorganizing Life: A Qualitative Study of Fathers' Lived Experience in the 3Years Subsequent to the Very Preterm Birth of Their Child. *Journal of Pediatric Nursing: Nursing Care of Children and Families*, 29(2), 124-131. <https://doi.org/10.1016/j.pedn.2013.10.008>

Total number of authors:

3

General rights

Unless other specific re-use rights are stated the following general rights apply:

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal

Read more about Creative commons licenses: <https://creativecommons.org/licenses/>

Take down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

LUND UNIVERSITY

PO Box 117
221 00 Lund
+46 46-222 00 00

Reorganizing life: A qualitative study of fathers' lived experience in the three years subsequent to the very preterm birth of their child

Pia Lundqvist^{1§}, Lena Hellström-Westas², Inger Hallström³,

¹ PhD, RSCN, Department of Health Sciences, Lund University, Lund, Sweden

² Professor, MD, Department of Women's and Children's Health, Uppsala University, Uppsala, Sweden

³ Professor, RSCN, Department of Health Sciences/The Swedish Institute for Health Sciences, Lund University, Lund, Sweden

§Corresponding author

Pia Lundqvist

Department of Health Sciences

P.O. Box 157

Lund University

SE-221 85 Lund

Sweden

Phone. +46 46 222 1828

Fax. +46 46 222 1808

Pia.Lundqvist@med.lu.se

ABSTRACT

This is the second part of a study that is following eight Swedish fathers of very preterm children using qualitative interviews. The aim was to illuminate fathers' lived experience of the three years since the birth of their very preterm child using a hermeneutic phenomenological method. The fathers described their lived experience as a process of reorganizing life, which constituted the overarching theme. They described a journey from the past to the present in which they adapted ordinary family life. The sub-themes identified were: struggling to endure, experiencing empowerment, and building a secure base. The results may serve as a basis for neonatal staff to optimize care for both fathers and mothers during the child's hospitalisation, as well as subsequent to their discharge.

Keywords: Father, preterm infant, experiences, longitudinal study, qualitative interviews

BACKGROUND

As an increasing number of preterm infants are surviving thanks to life-saving neonatal care, more parents are living through the neonatal intensive care unit (NICU) experience (Fellman et al., 2009; Wilson-Costello, Friedman, Minich, Fanaroff, & Hack, 2005). Several researchers have investigated the experiences of mothers of preterm infants (Aagaard & Hall, 2008; Davis, Edwards, Mohay, & Wollin, 2003; Hall & Brinchmann, 2009; Holditch-Davis & Miles, 2000). There is currently a lack of studies that have focused exclusively on the father's experiences in connection with the birth of a preterm infant and longitudinally, but this situation is slowly improving (Lundqvist & Jakobsson, 2003; Lundqvist, Westas, & Hallstrom, 2007; Pohlman, 2005, 2009; Sloan, Rowe, & Jones, 2008). It has been shown that caring for a preterm infant in a NICU is stressful for fathers; they have reported feelings of worry related to their infant's preterm birth, concern for their partner and difficulties in prioritizing their roles as partner, father and breadwinner (Arockiasamy, Holsti, & Albersheim, 2008; Lundqvist et al., 2007). Lundqvist et al. (2007) investigated the experiences of Swedish fathers when caring for a preterm infant and found that the fathers prioritized their own needs lower than those of the mother and the newborn child.

The majority of NICUs in Sweden practice family-focused care (Shields, Pratt, & Hunter, 2006) and the father is generally considered to be as important as the mother in parent-child interaction, not only in early infancy, but also throughout the rest of childhood (Hallberg, Lindbladh, Petersson, Rastam, & Hakansson, 2005). Sweden is also one of the few countries in the world with a legislative and social insurance system that provides paid parental leave to both parents, allowing them to stay with their child throughout the period the child is hospitalized (SFS 2010:110, Chapter 13, Articles 8-13).

It is well known that the child-parent attachment has an impact on the attainment of parental identity (Bowlby, 1997). In Sweden, men's parental identity has changed over the course of recent decades, from being purely the breadwinner, to being an involved father (Hallberg et al., 2005). In order to develop a close relation to the child, the father needs to be engaged with and actively involved in the child's life (Dubowitz et al., 2001). The American Academy of Pediatrics (AAP) has stated that it is an important goal of pediatric care to actively enhance men's roles in their child's care and development (Coleman & Garfield, 2004).

Very preterm birth (born before 32 weeks gestation) often involves a long period of hospitalization for the infant, and an increased risk of medical complications (Fanaroff et al., 2007). Even though many NICUs have become more family-focused, becoming the parent of a preterm infant still implies coming face-to-face with the unfamiliar technical environment of the NICU, as well as the challenges of assuming the parental role (Aagaard & Hall, 2008; Lundqvist et al., 2007). Parents who begin their parenthood at a NICU are at risk of developing stress that is related to the loss of the expected parental role which includes negative feelings of being separated from their infant, ambivalence about their parenthood and helplessness with regard to how to support and protect the infant (Aagaard & Hall, 2008; Jackson, Ternestedt, & Schollin, 2003; Lundqvist et al., 2007; Turan, Basbakkal, & Ozbek, 2008). It is also well-documented that, aside from the environmental factors within the NICU itself, worries about the child's survival and their risk of future disability are other sources of stress for parents (Jackson et al., 2003; Lundqvist et al., 2007).

The findings of longitudinal studies examining the experiences of parents of preterm infants point to the increased risk for stress disorders resulting from the initial hospitalization of the child (Feeley, Gottlieb, & Zelkowitz, 2007; Holditch-Davis, Bartlett, Blickman, & Miles, 2003; Lefkowitz, Baxt, & Evans, 2010). Shaw et al. (2006) investigated the prevalence of acute stress disorder (ASD), a precursor to post-traumatic stress disorder, in a cohort of 37 mothers and 26 fathers whose infant had been cared for in a NICU. After 2-4 weeks, the severity of ASD symptoms was significantly greater among mothers than fathers, and none of the fathers met all of the criteria for ASD. However, the sample size was small and the proportion of mothers was higher than that of fathers. Lefkowitz et al. (2010) identified post-traumatic stress symptoms in parents of infants being treated in a NICU at 4 weeks post-admission. In contrast to Shaw and colleagues (2006), they also found that both fathers and mothers met the full criteria for ASD a few days after their infant's admission. Some studies have shown contradictory results regarding the long term risk for parental stress reactions. Tommiska, Ostberg, and Fellman (2002) reported that, even if the birth of a preterm infant was stressful for the parents, most parents seemed to have recovered well by the time the child had reached the age of 2 years. In a nine-month follow up study, Carter, Mulder, Frampton, and Darlow (2007) showed that increased levels of anxiety symptoms were evident in parents following their preterm infant's birth, but that this did not result in continuing psychological distress.

In order to optimize the quality of care for both parents and other family members, it is important to obtain increased knowledge about fathers' lived experience in the years following the very preterm birth of their child. Such information could form a basis for the development of encouraging interventions that can take place during the child's hospitalization, as well as once they have been discharged. Furthermore, knowledge arising from nursing research needs to be focused on implementation in order to be of future benefit to patients and relatives. Therefore, the aim of this study was to illuminate fathers' lived experience in the three years subsequent to the very preterm birth of their child.

METHODS

Study design

This is the second data collection point in a longitudinal study following fathers of very preterm infants through the use of qualitative interviews. The first interview was conducted 1 to 3 months after their child's birth (Lundqvist et al., 2007) and this second interview was performed approximately 3 years later. An inductive design with a hermeneutic phenomenological approach inspired by van Manen (van Manen, 1997) was chosen as the purpose was to illuminate and interpret the meaning of the experience as it was lived by the fathers'. According to van Manen (1997), the lifeworld is unique for everyone but shared with others. In this study the lifeworld of the fathers' was the center of attention.

Participants

Thirteen Swedish fathers of very preterm children, who had neither a chromosomal anomaly nor other congenital defects, participated in the first interview (Lundqvist et al.,

2007). The fathers were informed that a second interview would be performed when their child was approximately 3 years old. Each of the fathers was subsequently contacted again and asked to participate in the second interview. Of the 13 fathers, 1 had moved without providing new contact information, 3 did not respond and contact was lost with 1 father subsequent to the agreement to participate. The remaining eight fathers were interviewed.

The age of the fathers was between 31 and 48 years. At the time of the interview, all eight of the fathers were living with the child's mother and two of the families had had one more baby. For five of the eight fathers, the very preterm infant was their first child, for two of them their second and for one father the third. Two of the fathers lived in a town and six in the countryside. Five of the fathers had a university education and the other three had a high school education. The fathers were all working outside of the home. The children whose fathers participated in the study had a gestational age at birth between 25 and 32 weeks and their birth weight ranged from 875 to 2130 grams. Five of the children were female. None of them had ongoing medical complications at discharge and all of the children were healthy at the time of the second interview.

Data collection

The first author (PL) conducted open individual interviews with each father. Before starting, the fathers were informed that the interview three years ago had contained narratives about their experience of caring for their very preterm infant (Lundqvist et al., 2007). The fathers were then asked to narrate, in their own words, their experience subsequent to the child's discharge from the hospital. In an interview situation, there is always a risk that the respondents describe their experiences in a way that they believe will please the researcher (van Manen, 1997). In an attempt to minimize this risk, the researcher strove to talk in a way that felt natural and to keep the interview conversational so that the fathers would feel comfortable divulging their lived experience. To give fathers the opportunity to expand on their personal experiences, questions that were more probing or that sought clarification were asked such as "Can you tell me more?" When necessary, the interviewer asked the fathers to clarify their experiences and then summarized and asked the fathers if it was understood correctly. Following each interview, field notes were transcribed by the interviewer in order to contextualize the interview. This field notes were then used during the analysis process to recreate the interview situation.

The dates and places for the interviews were decided in accordance with the fathers' wishes, to allow them to feel comfortable during the interview. Six of the fathers preferred to be in their own homes and two of the fathers chose to be interviewed in a room outside the neonatal unit where their child had been treated three years ago, combining the interview with family business in town. The interviews lasted between 40 and 75 minutes; they were tape-recorded and later transcribed verbatim by the interviewer (PL).

Analysis

The first author began the analysis during the interviews by actively listening and reflecting upon what the fathers were saying. The first author then listened back to the recording of each interview before transcribing it verbatim. During this process, the field notes written up after each interview were reflected upon. Each of the transcripts was then

carefully read and re-read by two of the authors (PL& IH) in order to obtain a sense of the whole of each transcribed interview. After this, the first author re-read the interviews and looked at every single sentence, asking what it revealed about the fathers' lived experience – a *line-by-line approach* according to van Manen's method (van Manen, 1997). The fathers' experiences were then organized into structures of experience that reflected the lived experience they revealed. These structures of experiences were compared to the text as a whole according to the hermeneutical circle (van Manen, 1997), and then, based on their differences and similarities, organized into three sub-themes and one overarching theme. Two of the authors (PL & IH) discussed the sub-themes and theme in an ongoing process, and the text was written and rewritten following several collaborative discussions that aimed to deepen the insights of the fathers' specific lived experience. The third author (LHW) read the interviews and the analysis schedule and actively discussed the result with the other two authors; minor changes were then made to the text. The findings were evaluated in terms of trustworthiness (Lincoln & Guba, 1985). In accordance with van Manen's guidelines, the findings were presented at research seminars where pediatric nurses and midwives gave valuable comments and confirmed the findings (van Manen, 1997). Quotes from the interviews were used to elucidate the fathers' lived experiences.

Ethical considerations

Each of the fathers provided their written consent to participate. They received written and verbal information about the study, about their right to withdraw without giving any reason, about the guarantee of confidentiality, and that no findings could be associated with anyone specific. The Ethics Committee at the University of Lund (LU 173-2006) approved the study.

RESULT

The overarching theme for the fathers' lived experiences in the 3 years following their child's very preterm birth was described as a process of *reorganizing life*, starting on the day the child was discharged from hospital. The process was described as a journey from the past to the present. The fathers started their story by looking back over the last 3 years and being in the past was associated with the sub-theme *struggling to endure*. As time went by, the fathers started *experiencing empowerment*, forming the second sub-theme, and finally, being in the present was associated with *building a secure base*, which formed the third sub-theme.

Reorganizing life

Struggling to endure

The first time at home with the child was described as hard, and they had difficulty dealing with the situation of living as a family with a very preterm infant. The fathers felt that they were prepared for the child's discharge from the NICU but not prepared for what this actually implied. The tiredness they experienced while their child was hospitalized was intensified and they described being physically and mentally exhausted over the course of this initial period following discharge. One father expressed it as "*being a huge trial*" (4, p. 5). The alteration

to “normal” family life was initially experienced as turbulent and the fathers expressed a guilty conscience about not being able to fully cope with the situation.

And when I got home I had a bad conscience because I couldn't manage it, at first I was very tired, then came a time when we had a lot of rows, then it calmed down. It was like that the whole time (11, p.7).

Being at home was enjoyable, but was also associated with new demands as they now had complete responsibility for the child both day and night. The day-to-day care of the child sometimes felt to be laborious. One father described his doubt about being given the responsibility of putting a nasogastric feeding tube into his own child. He described that it gave them, as a family, the opportunity to be in their own home, but it was something a parent should not have to do with their own child: *“It was necessary, so it was just a matter of grin and bear it. But it's no fun”* (8, p. 3).

Over the course of this initial period at home, the fathers were afraid of pushing the child's siblings into the background, and tried to find time for them. They also experienced a threat to the relationship with their partner as they did not find enough time or energy to support each other. The mother and father were both focusing on the newborn child and on satisfying the needs of this child and any siblings, and they missed the closeness to one another as a result. The fathers found the quarrelling, which occurred more often than before, devastating. One father said, *“Me and M's relationship has had to take a back seat and that has been a very hard strain. ... and many's the time you wonder if you should carry on with this [relationship]”* (7, p. 5). At the same time, the fathers were observant of their partner's state of well-being and tried their very best to show consideration for her. One father described it in the following way: *“I tried to do all the heavy things so she didn't have to, I tried to do as much as possible so as not to put any pressure on her”* (8, p. 5).

Having a very preterm child implied that obstacles were encountered. The fathers described how they had to expend a lot of energy on their contacts with insensitive friends, as well as with insurance companies and the social insurance office. They experienced their child being branded as a “premature”, and they described the inability of other people to see their child as an individual.

It's also a question of integrity, because then you're clearly registered as a premature birth. Papers like that have irritated me, I haven't even been able to get insurance (8, p. 18).

They still had concerns for their child's well-being, but the focus of the fathers' attention was on the child's future development. The fathers compared their child's development with that of other children of the same age. They described needing to do this, but they were well aware of the insecurity in the comparison.

It's really difficult not to compare with others who are the same age. Although everybody says you shouldn't compare, that everyone is different, you can't help doing it, you want what's best for your children and you want things to go well for them (1, p. 7).

Experiencing empowerment

Re-establishing their normal social life with family and friends was described as encouraging to the fathers. One father felt he had been isolated from social interaction during his child's hospitalization and described his pleasure when relatives and friends were able to visit the family at home as usual, with family life then becoming more positive and enjoyable as a result. Life started to normalize and the fathers were gaining strength through being able to manage their lives again as they had done before.

The fathers described their child's positive development as a source of relief and they said that they were thinking less about their child's risk for developmental problems. They found the continuing support from the neonatal outpatient clinic valuable and important. One father said, "*It has been a security, even though you think yourself that he's growing and getting bigger, you still wonder if everything is normal and if he's developing as he should*" (6, p. 7).

The fathers felt they had gradually matured in their parental role. They described how essential it was for them to be a manifest and important person in their infant's life. They felt happiness when they realized that their child needed them. "*It's about this feeling that B [the child] feels there's a father there. That he feels secure in that*" (3, p. 5). The fathers became confident and expressed the pride they felt for their child.

The fathers tried to support their partner by sharing the child's care, both day and night. They also tried to provide opportunities for their partner to have her own leisure time. This was sometimes hard for the fathers since they mostly worked full-time, but they said it gave them a natural closeness to their child which they found encouraging. Being at home caring for their child confirmed their role as parent. One of the fathers described his six months of parental leave as "*... the best thing I've ever done in my life, being at home on parental leave. Well, the best thing was to have them [the child] in the first place*" (7, p. 12).

Building a secure base

The fathers described how they had lived through the experience of having a child who was born very preterm and had adapted to ordinary family life. However, the initial exhausting period at home when they were struggling to manage family life with a very preterm infant was not forgotten, but this was now an experience they had left behind them. The fathers described how they had grown stronger from having lived through this time. "*I mean, if you can manage that, you can manage much more*" (4, p. 5). They were satisfied as their child was well and had no complications as a result of the preterm birth. It had helped them to find harmony and come to terms with their situation.

The fathers had fully re-established their normal social life and they described satisfaction, derived both from being at home with their family and from spending time with friends. They felt they were tied up in a positive way and they described a strong effort to engage their child in interactions such as play. They felt that there was a mutual exchange in their relation with their child.

We do a lot of things together. Watch drag racing and things like that, he's really interested in cars (5, p. 2).

Adapting to family life involved in some way that the fathers' lifeworld changed. They described how their focus had moved from being part of a couple to being part of a couple *and* a parent. They now had to respond to the changing needs of their growing child and that this was as it should be, but they described how they sometimes missed how it was before they became a parent when they were able to live their day-to-day life without planning for tomorrow.

It's a responsibility to become a parent, so in that way it changes your life. You can't do exactly what you did before. It makes a difference the older the child gets. They make more demands, they demand more, quite simply (3, p. 3).

Finding stability in life gave the fathers the opportunity to look forward. They were still confronted with unprocessed experiences from the time at the NICU, but felt that it was possible to deal with these. One father said that he and his partner now had time to look back together and to talk things through which made life easier. The fathers described having mutually positive relationship with their partner and how they tried to find occasions, from time to time, to spend time together with just their partner. Over the course of the 3 years, there had been times of strain, times when they had not even had time to quarrel, where they were just trying to "keep their heads above water". However, the fathers were convinced that their relationship with their partner had been worth fighting for. This was expressed by one of the fathers as follows:

Well, now we're starting to feel as if, well, it's going in the right direction now. We've been together since I was 18, so it feels as if we shouldn't give up just because it's been difficult a while. Life just is hard work at times (7, p. 5)

DISCUSSION

According to van Manen (1997) every person has a temporal landscape consisting of the past, the present and the future. Experiences from the past exist in the present as bad or good memories. The fathers' experiences from three years ago were not forgotten; instead it seemed as if the fathers had a distinct recollection of these past experiences. Three years ago, they described their lived experience of caring for their very preterm infant as a process that took them from their initial feelings of distance, towards feelings of proximity. In connection with their infants birth they felt as if their normal life had vanished and they were living beside reality and in a state of emotional turmoil. However, when the fathers felt they were able to comprehend what was happening around them, they felt that they were standing on firm ground again and had returned to reality (Lundqvist et al., 2007). This memory of the past is congruent with the findings of earlier research that reported mothers' vivid memories of their experiences in the NICU (Holditch-Davis et al., 2003). In another Swedish study following mothers' and fathers' experiences of parenthood over time, Jackson et al. (2003) showed that when children were 18 months old their fathers described how they were living in the present and tried not to dwell on the past. In the same study by Jackson et al., five of the seven fathers were interviewed together with their partner while in the present study, as well as in the study three years ago (Lundqvist et al., 2007), only the fathers participated in the

interviews. When being interviewed in a father-mother dyad, there might be a risk that the father will try to protect the mother by withholding some of his inmost thoughts; this may be one reason for the differences in the results.

Fathers' lived experience from their child's first three years at home following discharge from the NICU were described as a process of reorganizing life. The fathers needed to reconstruct their lives in order to gain stability in their personal lives, as well as the function of their family. Three years ago, while their very preterm child's was hospitalized, the fathers lived more or less continuously at the hospital and they described how they felt as if they had lost all sense of time and space; their usual weekday routines having disappeared (Lundqvist et al., 2007). In the initial period at home following discharge, the fathers experienced increasing tiredness while they struggled to endure the alteration from hospital to family life. Coming home with an infant born preterm entails a changing lifeworld as it brings with it a lot of changes to family life (Fagerskiold, 2008). The initial period at home is demanding for all parents as they have to incorporate a new family member and new routines into their lives (Fagerskiold, 2008; Nystrom & Ohrling, 2004). Parenting a very preterm infant is probably more demanding than parenting other infants as the needs of a very preterm infant may be different as a result of their immaturity at birth (Ritchie, 2002). The fathers in the present study also have to find their way back to a changed, yet ordinary, family life.

While their child was hospitalized three years ago, the fathers prioritized their partner's needs and gave their own needs the lowest priority (Lundqvist et al., 2007). Following discharge, the fathers continued to support their partner which might be one reason for their increasing tiredness and experience of not being able to fully cope with the situation they encountered in the initial period at home. They experienced an initial strain in their relationship with their partner at this time, and they found the quarrelling, which occurred more often than before, devastating. The fathers expressed their initial difficulty in finding enough time to focus on their relationship with their partner and that may have impaired their relationship. However, prior research has indicated that this strain seems to be true, not only for the parents of preterm infants (Stjernqvist, 1992), but also for those of full-term infants (Ahlborg & Strandmark, 2001; Hall, 1995). Fagerskiold (2006) showed, in a Swedish study, that fathers of full-term infants had similar needs to mothers with regard to the support provided by healthcare nurses and it is to be assumed that the same is true for fathers of very preterm infants, not only after discharge, but also during the NICU period. If a link between the NICU and the child healthcare services is established at an early stage of a child's hospitalization, child healthcare nurses will have the opportunity to support both the father and the mother subsequent to their child's discharge, which has the potential to reduce the length of time the parents are under strain. In Sweden supporting parents is an important goal of the child healthcare services (Swedish Ministry of Health and Social Affairs, 2009).

The fathers felt they were prepared for the child's discharge from the hospital, but not for what this actually implied, namely having the full responsibility for the child. This feeling was present irrespective of the fathers' involvement in their infant's care while they were hospitalized (Lundqvist et al., 2007). The lack of preparedness may have increased their level of stress and contributed to the physical and mental tiredness they experienced in the initial period at home. Feeling unprepared might also be related to insufficient information having been provided to them by nurses during the NICU period. Nurses are almost certainly well

aware of parents' needs for information, but perhaps the information focused too much on care-related issues and not enough on the individual roles of parents and what the transition from hospital to home might imply. Loo, Espinosa, Tyler, and Howard (2003) found that parents need information and support to deal with the experience of caring for a preterm infant in the NICU. The information provided, however, must change over the course of the NICU stay to address the knowledge parents require in order to care for their child at home. This highlights the importance for neonatal nurses in providing sufficient support and information in a more structured and individualized way so fathers, as well as mothers, can feel confident when the infant is discharged from the NICU. One way to facilitate the transition to caring for the infant at home for fathers, as well as for mothers, may be to use some form of intervention program that aims to support them during the time on the NICU, but that also prepares them for the future discharge. In a Danish study, Broedsgaard and Wagner (2005) showed the positive effects of using an intervention program during the NICU period. The intervention described consisted of providing parents with the support and guidance of a specialist nurse, during the NICU stay, an early appointment with their prospective healthcare nurse, and a structured multi-disciplinary hospital discharge consultation in advance of the infants' discharge from the NICU. Because prior research has demonstrated that one great source of stress for the parents of preterm infants appeared to be the alteration in their parental roles, it is important to customize interventions that focusing on this issue. It is time to use the knowledge gained through nursing research concerning the experiences of both fathers and mothers and move forward towards implementation in practice. However, it should be noted that developing and implementing complex interventions is a challenge (Craig et al., 2008; Richards & Borglin, 2011).

Nevertheless, it seemed as if the fathers started to grow in their parental role after coming home with their very preterm infant, and the attachment between the children and their father seemed to have developed in the intervening years. Hammarstrand, Jönsson, and Hallström (2008), who evaluated a neonatal home care program, and Lindberg, Axelsson, and Ohrling (2008), describing fathers' adjustment to fatherhood, also found that coming home was associated with a sense of being a father. In the present study, the fathers felt that their child was healthy and they described this as having helped them to come to terms with the situation. Perhaps the result would have been different if any of the children had been suffering from some chronic health problems as there is evidence that chronic health problems associated with preterm birth have an impact on the daily lives of families in the form of increased stress among parents (Treyvaud et al., 2011).

When researching lived experience the credibility (Lincoln & Guba, 1985) is dependent on, among other things, the informants' ability and willingness to speak about their experiences in a way that results in rich descriptions (van Manen, 1997). The fathers in the present study were well aware of the phenomenon they described and they spoke openly about their experience over the course of the three-year period following the birth of their child. In order to ensure understanding, the interviewer sought clarification and also summarized then asked if it was understood correctly. To further improve credibility (Lincoln & Guba, 1985), the fathers were interviewed individually to minimize the influence of their partners' experiences. However, 5 of the 13 fathers participating in the first interview 3 years ago did not agreed to participate in the present study. It is unknown whether the experiences

of the missing informants differed from those fathers who were included in this study. To further strengthened trustworthiness, the authors had ongoing collaborative discussions during the analysis process with the aim of finding the most plausible interpretation and of ensuring that the interpretation was grounded in the text. The methodological descriptions and the analysis process are clearly described to make it possible for the reader to evaluate the confirmability (Lincoln & Guba, 1985). Quotes from the original narratives are used to confirm the result. NICUs nationally and internationally have different conditions and resources, as well as different intervention programs for parents. Therefore, this must be taken into consideration when discussing transferability.

There are other limitations in this study. One is the lack of ethnic and educational diversity among the fathers. It is possible that fathers with different ethnicity or education experienced the phenomenon differently. It is also possible that some of the participants may have had difficulties expressing their experiences; however, they spoke openly and said it was important for them to tell their story.

CONCLUSION AND CLINICAL IMPLICATION

Findings from this study reveal that fathers undergo a fragile process in the initial years following the birth of a very preterm child. An improved understanding of their experiences may serve as a basis for improvements in family-focused neonatal nursing care, both during the child's initial hospitalization and subsequent to the child's discharge from hospital.

The findings highlight that it is not only possible, but also necessary that guidelines and procedures that aim to optimize care for both the fathers and the mothers of very preterm infants are developed in neonatal nursing care. Implementation of supportive intervention programs that focus not only on the parental role, but also on the parents' relationship may be a way to support fathers. This could enable fathers to make the transition to full responsibility for their family more smoothly. Today, NICUs generally consider that they have become more family-focused; however, to be family-focused involves having a structured policy defining the concept of family-focused care. A definition might help to reduce restrictive NICU policies such as limited visiting hours for relatives and friends, which could be experienced as barriers for parents. However, from the time of admission, the goal should be to prepare the family as a whole for discharge.

AUTHORS' CONTRIBUTION

PL and IH designed the study. PL collected the data. PL and IH performed the data analysis, discussing the results with LHW through the process. LHW helped to draft the manuscript. All three authors read and approved the final manuscript.

REFERENCES

- Aagaard, H., & Hall, E. O. (2008). Mothers' experiences of having a preterm infant in the neonatal care unit: a meta-synthesis. *J Pediatr Nurs*, 23(3), e26-36. doi: 10.1016/j.pedn.2007.02.003
- Ahlborg, T., & Strandmark, M. (2001). The baby was the focus of attention - first-time parents' experiences of their intimate relationship. *Scand J Caring Sci*, 15(4), 318-325.
- Arockiasamy, V., Holsti, L., & Albersheim, S. (2008). Fathers' experiences in the neonatal intensive care unit: a search for control. *Pediatrics*, 121(2), e215-222. doi: 10.1542/peds.2007-1005
- Bowlby, J. (1997). *Attachment and loss: Attachment* (2nd ed ed.). London: Vintage.
- Broedsgaard, A., & Wagner, L. (2005). How to facilitate parents and their premature infant for the transition home. *Int Nurs Rev*, 52(3), 196-203. doi: 10.1111/j.1466-7657.2005.00414.x
- Carter, J. D., Mulder, R. T., Frampton, C. M., & Darlow, B. A. (2007). Infants admitted to a neonatal intensive care unit: parental psychological status at 9 months. *Acta Paediatr*, 96(9), 1286-1289. doi: 10.1111/j.1651-2227.2007.00425.x
- Coleman, W. L., & Garfield, C. (2004). Fathers and pediatricians: enhancing men's roles in the care and development of their children. *Pediatrics*, 113(5), 1406-1411.
- Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., & Petticrew, M. (2008). Developing and evaluating complex interventions: the new Medical Research Council guidance. *BMJ*, 337, a1655. doi: 10.1136/bmj.a1655
- Davis, L., Edwards, H., Mohay, H., & Wollin, J. (2003). The impact of very premature birth on the psychological health of mothers. *Early Hum Dev*, 73(1-2), 61-70.
- Dubowitz, H., Black, M. M., Cox, C. E., Kerr, M. A., Litrownik, A. J., Radhakrishna, A., . . . Runyan, D. K. (2001). Father involvement and children's functioning at age 6 years: a multisite study. *Child Maltreat*, 6(4), 300-309.
- Fagerskiold, A. (2006). Support of fathers of infants by the child health nurse. *Scand J Caring Sci*, 20(1), 79-85. doi: 10.1111/j.1471-6712.2006.00383.x
- Fagerskiold, A. (2008). A change in life as experienced by first-time fathers. *Scand J Caring Sci*, 22(1), 64-71. doi: 10.1111/j.1471-6712.2007.00585.x
- Fanaroff, A. A., Stoll, B. J., Wright, L. L., Carlo, W. A., Ehrenkranz, R. A., Stark, A. R., . . . Poole, W. K. (2007). Trends in neonatal morbidity and mortality for very low birthweight infants. *Am J Obstet Gynecol*, 196(2), 147 e141-148. doi: 10.1016/j.ajog.2006.09.014
- Feeley, N., Gottlieb, L., & Zelkowitz, P. (2007). Mothers and fathers of very low-birthweight infants: similarities and differences in the first year after birth. *J Obstet Gynecol Neonatal Nurs*, 36(6), 558-567. doi: 10.1111/j.1552-6909.2007.00186.x
- Fellman, V., Hellstrom-Westas, L., Norman, M., Westgren, M., Kallen, K., Lagercrantz, H., . . . Wennergren, M. (2009). One-year survival of extremely preterm infants after active perinatal care in Sweden. *JAMA*, 301(21), 2225-2233. doi: 10.1001/jama.2009.771
- Hall, E. O. (1995). From fun and excitement to joy and trouble--an explorative study of three Danish fathers' experiences around birth. *Scand J Caring Sci*, 9(3), 171-179.

- Hall, E. O., & Brinchmann, B. S. (2009). Mothers of preterm infants: Experiences of space, tone and transfer in the neonatal care unit. *Journal of Neonatal Nursing, 15*, 8. doi: 10.1016/j.jnn.2009.05.001
- Hallberg, A. C., Lindbladh, E., Petersson, K., Rastam, L., & Hakansson, A. (2005). Swedish child health care in a changing society. *Scand J Caring Sci, 19*(3), 196-203. doi: 10.1111/j.1471-6712.2005.00339.x
- Hammarstrand, E., Jönsson, L., & Hallström, I. (2008). A neonatal home care program - an evaluation for the years 2002-2005. *Vård i Norden, 90*(4), 38-41.
- Holditch-Davis, D., Bartlett, T. R., Blickman, A. L., & Miles, M. S. (2003). Posttraumatic stress symptoms in mothers of premature infants. *J Obstet Gynecol Neonatal Nurs, 32*(2), 161-171.
- Holditch-Davis, D., & Miles, M. S. (2000). Mothers' stories about their experiences in the neonatal intensive care unit. *Neonatal Netw, 19*(3), 13-21.
- Jackson, K., Ternstedt, B. M., & Schollin, J. (2003). From alienation to familiarity: experiences of mothers and fathers of preterm infants. *J Adv Nurs, 43*(2), 120-129.
- Lefkowitz, D. S., Baxt, C., & Evans, J. R. (2010). Prevalence and correlates of posttraumatic stress and postpartum depression in parents of infants in the Neonatal Intensive Care Unit (NICU). *J Clin Psychol Med Settings, 17*(3), 230-237. doi: 10.1007/s10880-010-9202-7
- Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry*. Beverly Hills, California: Sage Publications.
- Lindberg, B., Axelsson, K., & Ohrling, K. (2008). Adjusting to being a father to an infant born prematurely: experiences from Swedish fathers. *Scand J Caring Sci, 22*(1), 79-85. doi: 10.1111/j.1471-6712.2007.00563.x
- Loo, K. K., Espinosa, M., Tyler, R., & Howard, J. (2003). Using knowledge to cope with stress in the NICU: how parents integrate learning to read the physiologic and behavioral cues of the infant. *Neonatal Netw, 22*(1), 31-37.
- Lundqvist, P., & Jakobsson, L. (2003). Swedish men's experiences of becoming fathers to their preterm infants. *Neonatal Netw, 22*(6), 25-31.
- Lundqvist, P., Westas, L. H., & Hallstrom, I. (2007). From distance toward proximity: fathers lived experience of caring for their preterm infants. *J Pediatr Nurs, 22*(6), 490-497. doi: 10.1016/j.pedn.2007.04.008
- Nystrom, K., & Ohrling, K. (2004). Parenthood experiences during the child's first year: literature review. *J Adv Nurs, 46*(3), 319-330. doi: 10.1111/j.1365-2648.2004.02991.x
- Pohlman, S. (2005). The primacy of work and fathering preterm infants: findings from an interpretive phenomenological study. *Adv Neonatal Care, 5*(4), 204-216. doi: 10.1016/j.adnc.2005.03.002
- Pohlman, S. (2009). Fathering premature infants and the technological imperative of the neonatal intensive care unit: an interpretive inquiry. *ANS Adv Nurs Sci, 32*(3), E1-16. doi: 10.1097/ANS.0b013e3181b0d68c
- Richards, D. A., & Borglin, G. (2011). Complex interventions and nursing: looking through a new lens at nursing research. *Int J Nurs Stud, 48*(5), 531-533. doi: 10.1016/j.ijnurstu.2011.02.013

- Ritchie, S. K. (2002). Primary care of the premature infant discharged from the neonatal intensive care unit. *MCN Am J Matern Child Nurs*, 27(2), 76-85.
- SFS 2010:110. *Socialförsäkringsbalken (Social insurance)*. Stockholm: Socialdepartementet (The Ministry of Health and Social Affairs). Retrieved from <https://lagen.nu/2010:110#K13>
- Shaw, R. J., Deblois, T., Ikuta, L., Ginzburg, K., Fleisher, B., & Koopman, C. (2006). Acute stress disorder among parents of infants in the neonatal intensive care nursery. *Psychosomatics*, 47(3), 206-212. doi: 10.1176/appi.psy.47.3.206
- Shields, L., Pratt, J., & Hunter, J. (2006). Family centred care: a review of qualitative studies. *J Clin Nurs*, 15(10), 1317-1323. doi: 10.1111/j.1365-2702.2006.01433.x
- Sloan, K., Rowe, J., & Jones, L. (2008). Stress and coping in fathers following the birth of a preterm infant. *Journal of neonatal nursing*, 14(4), 108-115.
- Socialdepartementet (The Ministry of Health and Social Affairs). (2013). *Nationell strategi för ett utvecklat föräldrastöd – en vinst för alla (A national strategy for improved parental support)*. Stockholm: Socialdepartementet. Retrieved from <http://www.regeringen.se/sb/d/16824/a/222846>
- Stjernqvist, K. M. (1992). Extremely low birth weight infants less than 901 g. Impact on the family during the first year. *Scand J Soc Med*, 20(4), 226-233.
- Tommiska, V., Ostberg, M., & Fellman, V. (2002). Parental stress in families of 2 year old extremely low birthweight infants. *Arch Dis Child Fetal Neonatal Ed*, 86(3), F161-164.
- Treyvaud, K., Doyle, L. W., Lee, K. J., Roberts, G., Cheong, J. L., Inder, T. E., & Anderson, P. J. (2011). Family functioning, burden and parenting stress 2 years after very preterm birth. *Early Hum Dev*, 87(6), 427-431. doi: 10.1016/j.earlhumdev.2011.03.008
- Turan, T., Basbakkal, Z., & Ozbek, S. (2008). Effect of nursing interventions on stressors of parents of premature infants in neonatal intensive care unit. *J Clin Nurs*, 17(21), 2856-2866. doi: 10.1111/j.1365-2702.2008.02307.x
- van Manen, M. (1997). *Researching lived experience: Human science for an action sensitive pedagogy*. Ontario: Althouse Press.
- Wilson-Costello, D., Friedman, H., Minich, N., Fanaroff, A. A., & Hack, M. (2005). Improved survival rates with increased neurodevelopmental disability for extremely low birth weight infants in the 1990s. *Pediatrics*, 115(4), 997-1003. doi: 10.1542/peds.2004-0221.