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FROM DISTANCE TOWARDS PROXIMITY

Fathers' lived experience of caring for their preterm infants

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ABSTRACT

Open interviews with thirteen fathers were performed, using a hermeneutic phenomenological method, to illuminate their lived experience of caring for their preterm born infant. Their lived experience was expressed as a process moving from initial feelings of distance towards feelings of proximity. The process was described as a pendulum that was easily disturbed. Feelings of distance included experiences of living beside reality, becoming an outsider and living with worry. Feeling proximity included experiences of returning to reality, becoming a family and facing the future. Illumination of the father–infant interaction add the family centered body of knowledge in neonatal nursing.

INTRODUCTION

Family-centered care (FCC), based on the close and continuous involvement of the newborn infant's family, is a widely used concept in neonatal care (Harrison, 1993; van Riper, 2001). A majority of Neonatal Intensive Care Units (NICU) in Sweden practice FCC, and the father is generally considered to be as important as the mother in the parent–infant interaction (Hallberg et al., 2005). However, neonatal care traditionally pays attention to the mother–infant attachment and the woman's transition to motherhood. Most studies on parental experiences in the NICU focus on mothers (Wereszczak, Miles & Holditch-Davis, 1997; Holditch-Davis & Miles, 2000; Holditch-Davis et al., 2003;) or both parents' experiences examined at the same time (Miles, 1989; Young Seideman et al., 1997; Doering, Dracup & Moser, 1999; Doering, Moser & Dracup, 2000; Jackson, Ternstedt & Schollin 2003), without considering possible differences in parental roles. The Swedish social insurance system allows both mothers and fathers to stay at the hospital and participate in the care of their infant while receiving compensation for loss of work (Law, SFS 1962: 381). Yet, little research, whether in Sweden or worldwide, has focused on the fathers' lived experience of caring for their preterm infants.

BACKGROUND

A key element in FCC is that the family is the constant in the infants' life whereas service system and personnel in those systems vary (Bruce & Ritchie, 1997). The American Academy of Pediatrics (AAP) provides a definition of FCC, which states that the family is the infants' primary source of strength and support (AAP, 2003). Als (1986) developed a theoretical framework for family-centered, developmental and supportive care of preterm infants, NIDCAP (Newborn Individualized Developmental Care and Assessment Program).

Parents of infants staying in the NICUs face many obstacles that can affect their parental roles. Such obstacles include the infants' medical condition, the interruption of normal parental responsibilities, being physically separated from the infant and the NICU environment (Young Seideman et al., 1997; Jackson, Ternstedt & Schollin, 2003). These obstacles do not promote optimal parent-infant interaction and can affect the attachment process and the transition to parenthood (Miles, Funk & Kasper, 1992; Young Seideman et al., 1997).

A Swedish interview study showed that fathers want to be involved in their prematurely born infants' basic care but they want this to happen through negotiation with the nursing staff. (Lundqvist & Jakobsson, 2003). Jackson, Ternstedt and Schollin (2003) showed that Swedish mothers expressed a need to be an active participant in their preterm infants' care but that they felt uncertain about what was expected from them in the NICU. This is in line with other research, investigating parents' experiences when a child is hospitalized after the neonatal period (Coyne, 1995; Hallström, Runesson & Elander, 2002). Jackson, Ternstedt & Schollin (2003) also showed that fathers did not express any need to be in control of their infants' care. They described that they felt confident in the competence of the staff. As pointed out by Neill (1996), it is important to be aware that parents may participate in care procedures mainly because they perceive that this is what the staff expects. Kristensson-Hallstrom and Elander (1997) investigated parents' experience when their infants were hospitalized in a pediatric surgery unit. They showed that parental attitudes and level of participation corresponded to the strategy parents used in their effort to minimize uncertainty and gain control in an unfamiliar environment.

Parents with preterm infants are at greater risk of stress related to the infants' physical appearance and/or condition and difficulties with their parental role (Miles, 1989; Young Seideman et al., 1997; Wereszczak, Miles & Holditch-Davis, 1997; Holditch-Davis & Miles, 2000; Jackson, Ternestedt & Schollin 2003). However, there is little understanding of fathers' experience as the focus has usually been on the mother, or on both parents. When fathers are included in study sample their experiences are sometimes grouped together with those of mothers (Miles, 1989; Young Seideman et al., 1997; Doering, Moser & Dracup, 2000) and the percentage of mothers is often higher (Miles, 1989; Hughes, McCollum, Sheftel & Sanchez, 1994; Miles, Carlson & Funk, 1996; Young Seideman., et al., 1997). Some studies comparing mothers' and fathers' experiences have reported gender differences in the level of stress. Mothers usually report more stress than fathers (Miles, Funk & Kasper, 1992; Doering, Dracup & Moser, 1999; Pinelli, 2000; Tommiska, Östberg & Fellman, 2002). Few researchers have focused exclusively on fathers of preterm infants (Sullivan, 1999; Lundqvist & Jacobsson, 2003; Pohlman, 2005).

To promote positive interaction between parents and staff, and thereby improve the quality of care for the family, it is important to illuminate fathers' lived experience when an infant is born preterm.

AIM

The aim of this study was to illuminate fathers' lived experience of caring for their preterm infant.

METHOD

Design

This study is the first part of a longitudinal project aiming to follow fathers with interviews during the first two years after the birth of their preterm infant. An inductive design with a hermeneutic phenomenological approach based on van Manen was chosen (van Manen, 1997). Phenomenology is a description of the lived experience of people (Husserl, 1931) while hermeneutics is the philosophy of understanding through interpretation (Heidegger, 1998/1927). According to van Manen (1997) the object of hermeneutic phenomenological research is to “borrow” another person’s experience, in other words, to illuminate and interpret human experience in the way informants themselves describe them – to uncover the meaning of lived experience to a certain degree of depth and richness. Hermeneutic phenomenology is in a way retrospective since a person must have lived through the experience before he can reflect upon lived experience.

Setting/Sample

The study was conducted at a Level II NICU at a hospital in the south of Sweden. The catchment area includes about 228 000 inhabitants (SCB 2003) and approximately 260 infants are admitted to the NICU each year. The NICU has two rooms and 10 beds and there are three family rooms close to the wardroom. Parents, siblings and other close relatives are allowed to visit the newborn infant at any time.

A consecutive series of 14 fathers of preterm infants who, during a nine-month period in 2003, had a preterm infant, and who spoke and understood Swedish, were invited to participate in the study. Fathers of infants with chromosomal anomalies or other congenital defects were not approached. Thirteen of the fathers agreed to participate in the study.

The paternal age ranged between 27 and 45 years. At the time of the interview, nine of the fathers were supported by the parental insurance system, which enabled them to be away from work. For eight of the 13 fathers this was the first child, for three the second child and for two fathers it was the third child. One of the fathers had an earlier experience of a stillborn infant. All fathers lived together with the infants' mother.

Five of the babies were females, the gestational ages ranged between 25 and 32 weeks and birth weights ranged from 875 to 2625 gm. The infant's Apgar score at five minutes ranged from 4 to 10. All infants required initial incubator care. The most frequent diagnoses were respiratory distress syndrome and hyperbilirubinemia. Twelve infants needed initial respiratory support with mechanical ventilation and/or continuous positive airway pressure (CPAP). Seven of the infants were born by cesarean section, four of these were emergency cesarean sections when fathers were not admitted to the delivery room.

Procedure

A designated nurse gave fathers information about the study when the infant was stable, usually at 2 to 4 weeks after birth. Fathers gave written consent for their names to be forwarded to the investigator (PL), who gave extended information and obtained informed written consent. The participants were informed that their participation was voluntary and that they had the right to interrupt their participation whenever they wanted. They were also informed that all data were kept confidential and that data was not forwarded to the staff.

Data collection

The first author (PL) conducted open individual interviews with the fathers, one to three months after the baby was born. Dates and places for the interviews were decided in

accordance with the fathers' wishes. Eight fathers chose to be interviewed in a room outside the neonatal unit, and five fathers preferred to be in their homes. All the participants were asked to narrate their experiences about caring for their preterm born infant, starting from the time of delivery. During the interviews, questions for clarification such as: What did you feel? Can you describe? What happened next? were posed by the interviewer. The interviews, which lasted between 45 and 90 minutes, were tape-recorded and later transcribed verbatim.

Preunderstanding

According to van Manen (1997) a problem of phenomenological inquiry may be that we know too much about the phenomenon that we want to investigate. The preunderstanding may predispose researchers to interpret the lived experience before arriving at the specific descriptions of the phenomenological question. Therefore the first author considered her preunderstanding as having been a neonatal nurse for more than 20 years. The second author (LW) is a neonatologist with extensive experience from 20 years in clinical neonatology. The third author (IH) became a pediatric nurse 25 years ago, she has a doctorate in medical science and is experienced in the use of the hermeneutic phenomenological method. The authors' preunderstanding was discussed and reflected upon to minimize the risk of influencing the interpretation in a biased way (van Manen 1997).

Analysis

Each interview was carefully read by two of the authors (PL, IH) to obtain a sense of the whole of each interview. After this the first author re-read each interview and looked at every single sentence, asking what it revealed about the fathers' lived experience – a detailed line-by-line approach (van Manen, 1997). The fathers' experiences were organized in structures of experience according to the lived experience they revealed. These structures were compared

to the text as a whole according to the hermeneutical circle (Kvale, 1997), and then organized in subthemes and themes, which according to van Manen (1997) should be the skeleton around which the phenomenological description will be woven. All authors discussed the subthemes and themes several times until agreement was reached. Quotes from the interviews are used to elucidate the themes and subthemes.

Ethical consideration

The interviews were performed when the fathers were in a vulnerable life situation. This entails carefully performed interviews showing psychological and emotional respect in order not to violate the fathers' integrity. Any infringement of integrity may be compensated for by the opportunity for the fathers to formulate and express their experiences. The Ethics Committee at the University of Lund (LU 139-03) approved the study.

RESULT

The fathers' lived experience of caring for their preterm infants was described as a process starting with a feeling of distance towards a feeling of proximity. Shortly after delivery, a feeling of distance dominated the fathers' lives. The fathers gave themselves and their own needs the lowest priority, as compared to the mother and the newborn infant. The mother's condition and his feeling of her transition to motherhood was a starting point for the father's transition towards a feeling of proximity. During the NICU period the fathers experienced an increasing sense of proximity. The process was described as a pendulum that was easily disturbed. Unexpected events that were outside the fathers' control, such as deterioration in their partners' and/or their infants' medical condition, or transfer of the infant to another hospital, affected and postponed their transition towards proximity. Essential themes, themes and subthemes are described in table 1.

Insert Table 1.

Feeling distance

Living beside reality

When the preterm baby was born fathers described how their normal life vanished and how they felt that they were living beside reality and in an emotional turmoil. They were overwhelmed by the infant's need for acute medical treatment and had difficulties in comprehending what was happening around them. Even if the staff informed them about the infant's condition and treatment, they felt incapable of taking in such information. Their situation was dominated by feelings of unreality. One father described it as being "inside a bubble".

The fathers understood that the infant needed incubator care, but at the same time they experienced the incubator as a barrier between them and their infant. This barrier and the fact that their preterm infant was less responsive to social interaction made it difficult for them to feel that they had become a father and to experience their infant as a "real infant".

You couldn't take him out and have him with you the whole time ...Essentially he's still in the womb and he just has to grow (10, p. 16).

The fathers more or less lived at the hospital and after a while they felt as if they lost all sense of time and space. Their usual weekday routines disappeared and they felt they were dependent upon people they did not know. Their life became bizarre and they lost their foothold in life. One father described it thus: *The first week, it felt as if you never went out, couldn't get out, you went out for maybe five minutes and then back in again, you know. You became like the monkeys at the zoo nearly, wandering back and forward (2, p. 11).*

Becoming an outsider

The fathers felt they were physically present but emotionally absent and described how they became an outsider and were acting, more or less, like a member of the staff. It was important to be present at the NICU but they felt they were standing beside, like a spectator, watching what was happening to their infant. One father felt loneliness but as he experienced the staff as to busy he did not want to disturb and talk to them. The NICU environment did not offer any privacy, and the fathers sometimes found the environment too feminine. One father felt it was like being “a rooster in a hen yard”. The fathers had a sense of being in-between because wherever they were they felt they ought to be somewhere else. However, as long as they sensed the mothers’ inability to handle the situation they felt she needed them the most.

...but at those moments you felt like you wanted to be in both places. That was the way you thought about the matter, B (the infant) could handle it well, and M (the mother) maybe needed support (6, p. 5).

In the beginning the fathers described a one-way communication with the staff. They were informed about decisions concerning their infant but they did not feel that they were involved in the decision-making process concerning their child’s care. They did not know how to interact with their infant but felt that the staff invited them and gave them permission to care for their infant. Even so, one father described how initially he did not understand that it was all right for him to spend as much time as he wanted together with his infant. It was difficult to understand their importance as a father as they felt the staff were much more competent in providing care for their infant.

... of course, they’re much better at it than me, well, not better, I just mean it goes faster when they change (11, p. 5).

Living with worry

The fathers experienced an immediate threat related to their preterm infant's chances of survival and lived with a sense of worry. The fathers were concerned for their partner and they felt that the situation was more difficult for her. They assisted her transition to motherhood, and felt that they needed to have a positive attitude in order to support her.

The fathers felt a threat of complications due to their infants' prematurity and this threat followed them for a long time. It was frightening for them to watch the baby inside the incubator, connected to and dependent on technical equipment. They were well aware that their infant required the technology, but they felt they were not able to protect their infant as a parent normally does, and they felt they were not fulfilling their parental role.

... it was like, you rather not touch him 'cause you thought then I'll rip off this or that tube or something like that. So it was a bit, it was hard.

The fathers watched the staff and were sensitive to their behavior. The fathers become worried if the interpreted behavior seemed to be related to uncertainty. A lot of energy went into observing the staff. When the infant was transferred to another hospital it affected the fathers. They became worried as they felt that the staff were no longer the experts on their infant.

We as parents trust the staff because we know the staff. Then we came to a new hospital and were forced to establish new relationships and that was really hard (13, p. 12)

Feeling proximity

Returning to reality

When the fathers felt that they were able to comprehend what was happening around them, that is, a semblance of reality has returned, they felt that they were standing on firm ground again. They became more receptive to information from the staff and they appreciated the time the staff spent helping them to understand and cope with their chaotic feelings. They described the importance of being supported, not only by friends and family, but also by the staff. They felt the staff's engagement and encouragement important in their striving to live in the present.

... It's whole-hearted, they really encouraged you to be here and take part in this. Because it is your own child (2, p. 10).

When holding or having eye contact with their infant for the first time, a feeling of realness was established. The fathers described it as the moment when they realized that the infant was real and their child. One father said it was a wonderful moment when his infant grasped his finger and the emotional barrier between them disappeared. As soon as the infant was able to be cared for outside the incubator the fathers felt their situation returned to reality.

... yes, when we could take him out, when we could change him and feed him outside the incubator, then it felt more normal (3, p. 12).

Becoming a family

The fathers increasingly matured in their parental role. They felt they behaved like a parent and felt they were becoming a family. They were enthusiastic about spending time together with their infant, alone, or together with their partner as a family. One father described the infant as a part of him and he felt a need to give attention to his infant. They felt confirmed as a father when they were able to care for their infant. All fathers planned their days in a way that made it possible for them to be by their infants' side. Being able to stay at the NICU overnight increased their feelings of being a family.

When the fathers felt their own importance as a parent they became more active in their infants' care. During the hospitalization they learned about the infants' medical condition and appearance and they gradually felt competent and familiar with the infant's needs. Their responsibilities for the infant's care increased and they found themselves taking their own initiatives, which in turn strengthened their role as a parent. One father said he knew what was best for his daughter and he felt it was all right to tell the staff his point of view.

there's been a good compromise between the professionalism of the staff, we know that they know what they have to do, but still they listen to the knowledge and prior experience that I bring along about her development, her experiences (13, p. 4).

Facing the future

The fathers felt security when the infant's condition was stable and the immediate threat to the infant's survival decreased. They felt proximity and happiness and started to believe in the future.

When they felt that the infant's need for hospitalization would come to an end it helped them to look forward and face the future. Coming home with their infant was wonderful and the fathers felt that at last it was exactly as it ought to be when you become a parent. One father said he could not describe his feelings: *Then I start to cry. It's like filling the house again after it's been empty (12, p. 15).*

DISCUSSION

This study highlights fathers' lived experience of caring for their preterm infants. In open interviews with thirteen fathers their lived experience was described as a transition from feeling distance to feeling proximity. Feelings of distance dominated at the beginning and the

fathers put their own needs aside to be supportive to their partner. Their initial mission was described as caring for their partner and helping her cope with the situation. Initially they expressed more concern for her than for the infant. This is in line with another Swedish study investigating experiences of becoming a father of a preterm infant (Lundqvist & Jakobsson, 2003) but also in line with research in which the mother identified her partner as the best source of support (Miles, Carlsson & Funk, 1996). Lundqvist & Jakobsson (2003) pointed out that, at the beginning of the infants' hospitalization, professionals should provide opportunities for the father to focus on his partner's need because it seemed to be one way for him to establish control in an unfamiliar situation. That might be so, but at the same time, it is important for professionals to be aware of whether, and how, the father's response to his partner's needs influences his attachment to the infant and supports the father–infant interaction.

The fathers in the present study said that they were “waiting for an invitation” from the professionals and that at the beginning their care was similar to nursing procedures. They also thought that the nurses were more competent to care for their infant than they themselves were. This may be a result of indistinct role distribution between professionals and parents (Hayes, Stainton & McNeil, 1993). Coyne (1995) showed that one problem in parental participation was non-negotiation of roles. As Affonso et al. (1992) pointed out, it is important for nurses to take time to evaluate how their interventions to encourage parenting affect the parent.

In the present study fathers described a need to take an active part in their infants' care and they took parental leave while their infant was at the NICU. This differs from the results of the study by Pohlman (2005) in which fathers returned to work soon after the birth. In their

study fathers gave priority to the financial security of their family and visited their infant after work. The differences in result may be due to the differences in parental insurance between Sweden and the United States. In Sweden fathers as well as mothers receive 80% of their salary to care for their sick infant (Law, SFS 1962:381). The cost of medical treatment also differs between the two countries. In Sweden the medical treatment of infants is free of charge. Fathers in the United States perhaps return to work as soon as possible due to the cost of medical treatment.

The fathers described their lived experience from feeling distance towards proximity as a pendulum that was easily disturbed. The transition from feeling distance was disturbed by several events such as deterioration in their partner's medical condition, her way of handling the situation, the infant's medical condition and how they experienced the teamwork with the professionals in the NICU. In our study feelings of proximity were related to fathers' feelings of becoming a family and therefore the professionals may be aware of these affecting factors in order to ease the transition towards a feeling of proximity. The transfer of the baby to another hospital or unit either slowed the movement of the pendulum towards proximity or made it swing back towards distance again. Infants sometimes have to be transferred to other hospitals or units but it is important for professionals to prepare parents in order to facilitate a positive transfer experience (McDonald Gibbins & Chapman, 1996).

The preterm delivery and fathers' difficulties in finding their parental role in the NICU seemed to delay fathers' transition to proximity and thereby also their feeling of becoming a family. The concept of attachment has been used to describe one aspect of the relationship between parents and their infants (Bowlby, 1974). The parent–infant attachment has an impact on the attainment of parental identity (Bowlby, 1974; Klaus & Kennel, 1976). Some

researchers have focused only on the mother–infant attachment (Klaus & Kennel, 1976; Rubin, 1977; Gottlieb, 1978). Other studies have shown that the infant has the ability to interact and attach to more than one person (Bowlby, 1974; Brazelton & Cramer, 1990). Paternal attachment behavior can begin during pregnancy (Harding Weaver & Cranley, 1983) and is an important forecaster of early postnatal attachment (Ferketich & Mercer, 1995). The father’s fetal attachment is also closely related to the quality of the marital relationship (Harding Weaver & Cranley, 1983).

When researching lived experience the credibility depends, among other things, on the quality of interviews and the informants’ ability and willingness to speak about their experience in a way that results in rich descriptions (Patton, 1990). In the present study the fathers were well aware of the phenomenon they described. They spoke openly, and for a long time, about their experience of caring for their preterm infant, and the interviews contained narrative life-world material that was rich in depth as well as in breadth. The methodological description and the analysis process is clearly described to give the reader the possibility to value its transferability (van Manen, 1997), The findings were presented at seminars where nursing colleagues, midwives and pediatric nurses, gave valuable comments and confirmed the findings.

CONCLUSION AND CLINICAL IMPLICATIONS

Illuminating fathers’ lived experience of caring for their preterm infant may help professionals in developing clinical routines. Professionals need to be sensitive to the fathers’ role as a guardian of the family. One way to confirm the fathers’ importance in the care of the preterm infant is to establish a two-way communication, not only with the mother but with the father as well, as early as possible. It may be a challenge for professionals to balance between

the needs of the child, the mother and the father, and to encourage the parents' feelings of becoming a family. If professionals are able to encourage and support fathers' transition to proximity, they in their turn may support mothers' transition to motherhood as the father prioritize their partners' needs.

One limitation of this study is the lack of ethnic diversity among the fathers. Future research requires more attention to the understanding of fathers with different ethnicity. Further research may also focus on longitudinal studies about fathers' experience as a parent of a preterm born infant and how a preterm infant affects the family as a whole.

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Table 1. Essential Theme, Themes and Subthemes

Essential Theme: From distance towards proximity

| Feeling distance | Feeling proximity |
|------------------------------|-----------------------------|
| <i>Living beside reality</i> | <i>Returning to reality</i> |
| <i>Becoming an outsider</i> | <i>Becoming a family</i> |
| <i>Living with worry</i> | <i>Facing the future</i> |