

## ORIGINAL RESEARCH

# Parents' experiences with neonatal home care following initial care in the neonatal intensive care unit: a phenomenological hermeneutical interview study

Michaela Dellenmark-Blom & Helena Wigert

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Correspondence to M. Dellenmark-Blom:  
e-mail: michaela.m.blom@vgregion.se

Michaela Dellenmark-Blom MSc RN  
Manager of Health Care Improvement,  
Specialist Nurse in Pediatric Nursing,  
Division of Paediatric Emergency Care and  
Paediatric Surgery, The Queen Silvia  
Children's Hospital, Sahlgrenska University  
Hospital, Gothenburg, Sweden

Helena Wigert MSc PhD RN  
Senior Lecturer  
Institute of Health and Care Sciences, The  
Sahlgrenska Academy at the University of  
Gothenburg, Sweden  
and Division of Neonatology, Sahlgrenska  
University Hospital, Gothenburg, Sweden

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## Abstract

**Aim.** A descriptive study of parents' experiences with neonatal home care following initial care in the neonatal intensive care unit.

**Background.** As survival rates improve among premature and critically ill infants with an increased risk of morbidity, parents' responsibilities for neonatal care grow in scope and degree under the banner of family-centred care. Concurrent with medical advances, new questions arise about the role of parents and the experience of being provided neonatal care at home.

**Design.** An interview study with a phenomenological hermeneutic approach.

**Methods.** Parents from a Swedish neonatal ( $n = 22$ ) home care setting were extensively interviewed within one year of discharge. Data were collected during 2011–2012.

**Findings.** The main theme of the findings is that parents experience neonatal home care as an inner emotional journey, from having a child to being a parent. This finding derives from three themes: the parents' experience of leaving the hospital milieu in favour of establishing independent parenthood, maturing as a parent and processing experiences during the period of neonatal intensive care.

**Conclusions.** This study suggests that neonatal home care is experienced as a care structure adjusted to incorporate parents' needs following discharge from a neonatal intensive care unit. Neonatal home care appears to bridge the gap between hospital and home, supporting the family's adaptation to life in the home setting. Parents become empowered to be primary caregivers, having nurse consultants serving the needs of the whole family. Neonatal home care may therefore be understood as the implementation of family-centred care during the transition from NICU to home.

**Keywords:** family care, hermeneutics, home care, neonatal care, nursing, parenting, phenomenology

### Why is this research needed?

- New questions arise with respect to the role of parents as their responsibilities for neonatal care have grown concurrent with greater survival rates among infants with risks of future morbidity.
- The establishment of parenthood in a neonatal intensive care unit is a complex process accompanied by risks of a negative influence on parent–child interaction.
- Parents' assumption of full responsibility for the infant after discharge from the neonatal intensive care unit may be difficult and tailored support in the transition to home may be needed.

### What are the three key findings?

- Neonatal home care empowers the parents to establish independent parenthood and anchors the perception that parenthood reflects an evolution from having a child to being a parent.
- The nurse facilitates establishment of parenthood by providing the parents support to maintain their role as advocates, care providers and decision makers with respect to their infant's well-being.
- Neonatal home care is experienced as a care structure adjusted to incorporate parents' needs following discharge from the neonatal intensive care unit.

### How should the findings be used to influence policy/practice/research/education?

- There should be explicit disclosure of organizational strategies in the neonatal intensive care to support parents' participation in their infant's care and to provide early preparation of parents for neonatal home care.
- Nurses should be aware of their unique position to influence the extent of parents' participation in their infants' care and to help parents process emotional difficulties.
- Future studies should examine whether positive effects of neonatal home care can be translated into a different or larger population and whether similar benefits can be achieved among different healthcare systems and countries.

## Introduction

In family-centred care (FCC), it is considered beneficial for the child and family health to have parents serve the role of primary caregivers (Harrison 1993). Under the influence of FCC, parents' role during the hospital stay has changed from being mere visitors to being considered partners in care (Jolley & Shields 2009, Harrison 2010). The benefit of parents' participation in care must continuously be evalu-

ated for its contribution to the advancement of care (Harrison 2010, Shields 2010, Kuo *et al.* 2012).

At the same time as an increasing proportion of infants survive despite being born with more extreme prematurity and with critical illnesses and an increased risk of morbidity (Larroque *et al.* 2003, Delobel-Ayoub *et al.* 2006, Ehrenstein *et al.* 2009, Fellman *et al.* 2009, Cazzato *et al.* 2012), parents' responsibilities for neonatal care have grown to a commensurate degree (Griffin 2006). Neonatal home care (NHC) is defined as a care structure that provides supportive care to the family of such infants who still have special medical needs, but who are physiologically stable. This supportive care is provided through regular home visits by a paediatric nurse specialist (PNS) following the infant's initial hospital-based care in the neonatal intensive care unit (NICU) and is closely connected to the medical competence of the NICU staff. Provision of NHC leads to new questions about the role of parents in the care of premature and ill infants and the perceived quality of advanced neonatal care.

## Background

The experience of having a premature or critically ill infant in the NICU is associated with great stress among parents (Pinelli *et al.* 2008, Lefkowitz *et al.* 2010, Bergström *et al.* 2011, Watson 2011). Feelings of fear, worry and lack of influence are common (Hall 2005, Arockiasamy *et al.* 2008, Hollywood & Hollywood 2011, Watson 2011) and the separation of parent and infant that is associated with admission to the NICU elicits parental feelings of guilt (Jackson *et al.* 2003, Erlandsson & Fagerberg 2005, Wigert *et al.* 2006). As the infant's health is dependent on professional care, parents may be made to feel that they are not needed in the care of their infant (Hall 2005, Heermann *et al.* 2005, Wigert *et al.* 2006). However, parents' participation is important as it facilitates the desired parent–infant bonding (McGrath 2001, Mok & Leung 2006, Fegran *et al.* 2008, Fenwick *et al.* 2008, Blomqvist *et al.* 2012) and prepares the family for discharge from the NICU (Fegran *et al.* 2008, Rehm & Bisgaard 2008). Previous studies have shown that parents' adjustment to assuming full responsibility for the infant may be difficult and that the family may need additional support in the transition from NICU to home (Rehm & Bisgaard 2008, Nicolaou *et al.* 2009, Murdoch & Franck 2012). Research on NHC is sparse, but preliminary reports from Sweden (Altman *et al.* 2009) and the UK (Dixon *et al.* 2011, Walston *et al.* 2011) suggest certain advantages accrue from its implementation, including shortened hospital stays and a low rate of readmissions.

NHC has, however, not been studied from the perspective of the parent and questions remain unanswered about the experience of having NHC.

## The study

### Aim

The aim of this study was to reach a deeper understanding of parents' experiences with neonatal home care following initial care in a neonatal intensive care unit setting.

### Design

The study was conducted in accordance with the reflective lifeworld approach described by Dahlberg *et al.* (2008), which epistemologically unites the phenomenological and hermeneutic philosophy and which may be used to understand meaning in the lifeworld. The lifeworld is the world of lived experiences of everyday phenomena. Knowledge of these experiences is gained through shared narratives (Dahlberg *et al.* 2008) and interviews were therefore used to collect data on parents' experiences with NHC. The phenomenological hermeneutical method used in the data analysis (Lindseth & Norberg 2004) is influenced by Ricoeur's interpretation theory (Ricoeur 1976), where narratives should be fixed in texts and then be interpreted. As in the philosophy of hermeneutics, the textual interpretation aims to find new and fruitful ways to understand human thoughts, emotions and activities at a deeper level. The process of deciphering moves from the manifest to the latent meaning of the text by the dialectic movement between understanding and explanation, that is by synthesizing the parts and the whole of the text (Ricoeur 1976, Lindseth & Norberg 2004).

### Setting

Parents were recruited from an NHC setting at one University Hospital in Sweden. The infants were initially treated at a Level III NICU (Stark 2004), which provides care for approximately 1000 newborns annually, including extremely premature and critically ill infants. The NICU consists of two units with an aggregate 38 beds, including eight family rooms. Approximately, 200 infants are treated in the NHC setting each year in accordance with specific criteria (Table 1). These premature or ill infants are physiologically stable, but still require neonatal care such as gavage feeding, growth checks, blood sampling and phototherapy. Prior to NICU discharge, parents

must have received education and training tailored to their infant's specific needs and must stay with their infant in a family room at the hospital for no less than two nights. The NHC team consists of six PNS, each of whom returns to the NICU work setting every 6 weeks. During weekdays, two PNS provide care for several families and is responsible for advice on feeding, growth checks and support of parent-child interactions. Until discharge from the NHC, families have regular home visits by the PNS every week.

### Participants

Using medical records, nearly 200 families were identified as meeting specific inclusion criteria: (i) neonatal care was initially rendered in a level III NICU and followed by NHC; (ii) the study interview was conducted within 12 months of discharge from NHC; (iii) parents spoke and understood Swedish. With the particular study design used, the requisite number of respondents to achieve reliable data cannot be determined prior to data collection. Instead, variability among respondents is considered more important to achieve reliable data (Dahlberg *et al.* 2008). The aim was therefore to ensure sample variation with respect to infant sex, gestational age at birth, birthweight and length of stay in the NICU and NHC respectively. Sample selection was also undertaken, so as to permit the participation of a majority of NHC nurses and to include families for whom NHC participation occurred during different parts of the calendar year. Accordingly, a representative sample of 16 families was strategically selected and, on contact, each of these sixteen families agreed to participate in the study. At the time of the last interview, no significant new data were

**Table 1** Infant and parent inclusion criteria for having neonatal home care.

|  |
|--|
| Infant inclusion criteria  |
| • Gestational age $\geq 34 + 0$  |
| • Weight $\geq 1700$ grams   |
| • Non-occurrence of apnoea or bradycardia $\geq$ a week                                  |
| • Normal body temperature ( $\geq 36.5^{\circ}\text{C}$ ) without incubator or water bed |
| • Closed caffeine treatment  |
| • No intravenous catheter/access   |
| • Expected length of stay $\geq$ a week  |
| Parent inclusion criteria  |
| • Knowledge of the Swedish or English language   |
| • Reachable on the phone   |
| • If the infant is gavaged, parents learn to ensure the place of the nasogastric tube    |

revealed and, therefore, no additional families were contacted.

**Data collection**

Open-ended interviews were conducted and recorded digitally in the parents' home by the last author during October 2011–January 2012. Interviews lasted between 26–52 min-

utes (mean 39.7 min.; median 40.0 min.). All interviews began similarly by a request of the parents to provide a narration of their experiences with NHC, such as: 'Please tell me how you experienced NHC'. Further questions, such as 'Can you tell me more about...' and 'How did you feel when...', were aimed to probe the parents in greater depth. Additional follow-up questions were posed to clarify statements and to confirm the interviewer's correct understanding.

**Table 2** Example of the structural analysis.

| Interview text  | Meaning unit  | Condensation   | Subtheme               | Theme                               |
|---|---|--|------------------------|-------------------------------------|
| It felt more safe to have neonatal home care than leaving the hospital without any support, otherwise we would have stayed for a longer time in the hospital.<br>Now, you are kind of worried...when you go home from the neonatal intensive care unit,,but it felt reliable to have them and to be able to call and ask them to come | Leaving the NICU with trusted support   | Having a link of trust from the neonatal intensive care unit to the home | Bringing reliance home | Establishing independent parenthood |
| They spread their trust around, they were just so present...and not anywhere else, not on their way to visit the next family, no..you felt that you had the time you needed...considerate...empathetic...and you got the feeling that they genuinely cared...about the baby and the parents that they visited                         | Experiencing the nurse's consideration, interest and time in the whole family               | Experiencing the nurse's focus   | Being significant      | Establishing independent parenthood |
| Since I was so comfortable with someone coming home and seeing me and our baby, that he was healthy and..., there were other eyes to look at him, that was what I needed to be comfortable enough to bring him home in my own home, because he was so small. That was what I needed   | Needed the nurse's confirmation and support to dare to care for a vulnerable infant at home | Learning to bear the worry in the care of the infant at home             | Enduring insecurity    | Establishing independent parenthood |

## Ethical considerations

The study was carried out in accordance with the Declaration of Helsinki (The World Medical Association Declaration of Helsinki 1964, updated 2008). All parents gave written, informed consent and were informed about guaranteed confidentiality and the right to discontinue the interview at any time. Approval was obtained from the University's Research Ethics Committee.

## Data analysis

Interviews were transcribed verbatim. A phenomenological hermeneutic method, which consists of three methodological steps, was used (Lindseth & Norberg 2004). The text was read naïvely several times to grasp its meaning as a whole. To formulate a naïve understanding, the text was to speak by itself, to touch and to move the researcher. For structural analysis, the researchers divided the texts into meaning units, which were condensed and abstracted into preliminary subthemes, themes and a main theme. The text was then re-read and both the parts and the whole were discussed in a dialectic movement between understanding and explanation until the authors reached agreement. To improve understanding, the researcher reflected deeply on the text and then formulated a comprehensive understanding. Table 2 illustrates an example of the structural analysis.

## Rigour

Sample variations were ensured by a strategic selection of respondents. Data reliability is a function of the respondents' level of comfort during the interview (Dahlberg *et al.* 2008). As a result, the 16 families contacted were permitted to decide which of the parents would partake as well as the time and place of the interview. All parents were encouraged to speak openly about their experiences and follow-up questions were used to confirm the researchers' understanding of the narratives provided. During data analysis, validity was strengthened through thorough discussions among the researchers about the relationship between parts and the whole of the text (Lindseth & Norberg 2004). As the authors have themselves previously worked in a NICU, objectivity during data analysis was gained through awareness of the pre-understanding which is 'bridled' to gain openness to the phenomena. Moreover, quotes from the interviews were used to verify the findings retrieved from the data (Dahlberg *et al.* 2008).

## Findings

Parents ( $n = 22$ ) were interviewed within six months of discharge from NHC (mean 5.4; median 6.0). Five PNS members of the overall NHC team provided care for the families participating in the study during various times of 1 year. For six families, parents were interviewed together, whereas single parent interviews were conducted for the other 10 families. Two families were of non-Scandinavian descent and two families had twins. A majority of infants were born premature or significantly preterm, two were born extremely premature and two were born at full term. Among all 18 infants in the study, 13 were gavaged and breastfed, two were gavaged and bottle fed, two were solely gavaged and one infant was bottle fed during NHC. None of the infants was readmitted to the hospital during the NHC period. Sixteen parents met with one nurse during NHC and six parents had encounters with two nurses. Additional infant and parent characteristics are shown in Table 3.

### Naïve understanding

Parents' experiences with NHC can be understood as an inner emotional journey to reach parenthood. The crisis of having one's infant admitted to the NICU blinds the parents and makes it difficult to see themselves as parents. Feeling at first alienated in the process, NHC means that the parents instead experience an affinity for parenthood that is increasingly restored while the inner emotional chaos is gradually diminished.

### Structural analysis

Parents' experiences with NHC are illustrated by the main theme, 'From having a child to being a parent'. An overview of themes is presented in Table 4.

### Establishing independent parenthood

#### *Bringing reliance home*

It was the parents' experience that NHC bridged the gap of worry between hospital and home by linking the trust and reliance established in the NICU with the home. Providing opportunities for telephone availability and regular but successively fewer home visits, the PNS reinforced feelings of not having been abandoned after discharge from NICU. Being given an opportunity to choose the degree of NHC support needed, parents acquired sufficient courage to bring their vulnerable infant home:

**Table 3** Descriptive characteristics of parents, families and infants.

|                                   | Frequency (%) | Range    | Mean/Median   |
|-----------------------------------|---------------|----------|---------------|
| Parents ( <i>n</i> = 22)          |               |          |               |
| First time parent                 | 18 (81.8)     |          |               |
| Second child                      | 4 (18.2)      |          |               |
| Mother                            |               |          |               |
| Numbers                           | 15 (68.2)     |          |               |
| Age (year)                        |               | 23–36    | 30.5/30.0     |
| Father                            |               |          |               |
| Numbers                           | 7 (31.8)      |          |               |
| Age (year)                        |               | 27–39    | 31.3/30.3     |
| Families ( <i>n</i> = 16)         |               |          |               |
| Parental leave during NHC         |               |          |               |
| Both parents fulltime             | 13 (81.3)     |          |               |
| Mother fulltime, father halftime  | 2 (12.5)      |          |               |
| Mother fulltime                   | 1 (6.3)       |          |               |
| Infants ( <i>n</i> = 18)          |               |          |               |
| Gender                            |               |          |               |
| Boys                              | 9 (50.0)      |          |               |
| Girls                             | 9 (50.0)      |          |               |
| Gestational age (weeks)           |               | 25–37    | 32.9/33.5     |
| Birthweight (g)                   |               | 870–3200 | 2006.9/1947.5 |
| Time since discharge (months)     |               | 0.5–12   | 5.4/6.0       |
| Age at interview (months)         |               | 1–12     | 6.9/7.5       |
| Length of stay in the NICU (days) |               | 5–49     | 13.4/12.5     |
| Medical treatment in the NICU     |               |          |               |
| Mechanical ventilation            | 2 (11.1)      |          |               |
| Nasal cpap                        | 5 (27.8)      |          |               |
| Intravenous drug                  | 11 (61.1)     |          |               |
| Phototherapy                      | 11 (61.1)     |          |               |
| Surgery                           | 1 (5.6)       |          |               |
| Nasogastric tube                  | 18 (100)      |          |               |
| Length of stay in the NHC (days)  |               | 10–34    | 19.7/17.0     |
| Medical needs in the NHC          |               |          |               |
| Nasogastric tube                  | 17 (94.4)     |          |               |
| Oral drugs                        | 18 (100)      |          |               |
| Growth check                      | 18 (100)      |          |               |

NHC, neonatal home care; NICU, neonatal intensive care unit.

That they didn't leave us...ok here you are, now you're finished at the hospital and now you're about to go home...you were with them even though you were home... it felt really good....You could say to them, this week you don't have to come, we've been very calm, or you could say that they need to come immediately. (Mother)

Parents' sense of security was anchored by the PNS providing both time and opportunity to calmly discuss new questions and concerns that invariably arise on return to the family home:

I found trust in the situation because they never left us with unanswered questions. (Father)

#### *Being significant*

Due to stress among NICU staff and a frequent lack of NICU beds, parents sometimes had a feeling of 'being in the way' and perceived themselves as visitors to the hospital. One mother said that she felt 'forsaken' and like someone who 'only delivered the baby'. Another mother explained that she felt 'like a cow bringing the infant milk':

In the hospital, you're at someone else's place, their place, it's their NICU. (Mother)

The homecoming, conversely, makes the nurse a visitor in the parents' home and parents instead recognized the focus and interest of the PNS to be a desire to know about their experiences as parents. The time afforded these conversations highlighted the commensurate attention given. In turn, this emphasis made it easier for parents to perceive themselves as significant to both nurse and infant:

It really felt like they were there for our sake and wanted the best for us, not because it was their job, but because they really cared. (Father)

She [the nurse] supported us, she knew us from the NICU and she never laughed at our questions like they did in the NICU. (Mother)

#### *Enduring insecurity*

Parents described their responsibilities in NHC as being great. The lack of heretofore nearby NICU staff made them fear a perceived inability to see whether their infant is, or becomes, ill. Parents thus needed the PNS for confirmation that their infant is healthy and for reassurance that they are performing well as parents:

From the beginning you're not fully able to see what you should notice when you take care of a premature infant. You had what you can call...a confirmation that everything was alright. (Mother)

**Table 4** Overview of subthemes, themes and the main theme.

| Main theme | From having a child to being a parent                              |  |  |
|------------|--|--|--|
| Theme      | Establishing independent parenthood                                | Maturing as a parent   | Processing experiences during the period of NICU           |
| Subtheme   | Bringing reliance home<br>Being significant<br>Enduring insecurity | Strengthening the bond<br>Assimilating trust to a confident parenthood<br>Seeing your infant with new eyes | Settling down<br>Reliving memories<br>Trying to understand |

The adjustment to routines that differed from those learnt in the NICU is, at first, difficult. Infant growth checks are an example, as these are undertaken less frequently in NHC. Similarly, parents' checks of infant weight permitted parents to learn how they handle their job as parents at home. Parents successively learnt to accept and live with insecure feelings between the PNS home visits:

We learned to deal with her coming in two days or tomorrow. (Mother)

### Maturing as a parent

#### *Strengthening the bond*

Parents reported that NHC provides new opportunities to spend time alone with their infant, to get to know each other in their parenting roles and to focus on family life. Spending time alone with the infant facilitates their perception of the infant as their own:

I had a discussion with a nurse at the NICU, but he is your baby, you can do as you want. Then I thought, yes he is mine, but you are the one in charge...and then suddenly you're home, he's mine and I am the one in charge. Then he really was mine. It made me bond in a new way. (Mother)

Parents described that the PNS focused communication on both parents, showed consideration and empathy and was responsive to the whole family, including sibling(s) when applicable. Being treated as an entire family strengthened the parents' bond to the infant:

It wasn't just A. (child) that was treated, but also me in some way and this made us one. (Mother)

#### *Assimilating trust to a confident parenthood*

Parents expressed a need to adjust to everyday life at home and the more time spent with the infant, the more able to settle into parenthood. Compared with the NICU, where parents merely participated in the care of the infant, the NHC setting imparts a responsibility for the infant and for

which they longed. When parents became responsible for the infant, they also started to contemplate and make their own decisions about their infant's health and well-being:

Here (at home) I kind of had to think first, which you wouldn't have done at the hospital. At the NICU you would have asked for help and they would have solved your problems and that was what was so good about coming home. You made your own decisions. (Mother)

Knowing the infant better made it easier to determine when happy and relaxed and to decipher whether the infant is healthy or not. This lessened worry and increased confidence in the role as parents.

#### *Seeing your infant with new eyes*

In NHC, parents reported that both the PNS' and their own perspective of the infant changed from a vulnerable, immature or ill infant in the NICU to a strong and healthy infant at home:

When we were staying at the hospital, we felt that, in some way, our child was a small and ill child and when we came home, at least I felt that the feeling disappeared...that, yes she is prematurely born, but not ill in some way, it was another kind of way to look at her....another way to see her. (Father)

Tube feeding was strongly associated with an ill infant and one father described it to be the last symbol of the time in the hospital. Many parents perceived their infant as 'a real baby' when the tube is removed, because it makes it possible to see the infant's whole face. Parents also believed that they were 'parents for real' when they managed everyday life at home and were able to take care of the infant without the support of NHC.

### Processing experiences during the period of NICU

#### *Settling down*

Parents reported NHC to be an alternative that made it possible to leave the hospital environment early. The NICU was surrounded by stress and suffering and the painful experience of seeing other critically ill infants and sad

parents in the NICU vanished on coming home. The departure from the hospital thus provided room for more positive experiences:

I think that the hospital is a kind of...even though the NICU staff are super and nice, it's a kind of depressing milieu compared to the home. Everything felt more difficult in the hospital. (Father)

In the NICU, parents must involuntarily adjust to other families and the routines of the NICU staff. This confinement changed on coming home to a free and unrestricted setting where parents could focus on their own needs. The privacy that is gained provides peace and quiet and, in turn, enabled rest from a chaotic time and environment:

Kind of being alone...having some peace...it was such a relief. (Mother)

#### *Reliving memories*

Although everyday life at home reminded parents about how different everything felt in the hospital, it also provided strength to remember those difficult experiences. One mother likened it to leaving 'a bubble', a world where life is dominated by fear and worry over losing an infant's life:

At the hospital, I couldn't see those days in front of me, that we would be here, days where we were to have things like other parents. (Mother)

As they experienced a strengthening bond to the infant during NHC, parents simultaneously remembered the pain of involuntary separation and leaving the infant in the hospital:

No, I cried all the way home, the whole night long, the whole morning and the whole way to the hospital. Then I sat in the lunch room, I sat there and was devastated, even though he was nearby I couldn't stop crying...I was devastated for several days. (Mother)

Some mothers revealed a feeling of guilt and accountability for the infant's need for professional care in the NICU. For one mother of a small for gestational age infant, an obstetrician explained at first that her infant had poor nutrition during intrauterine life. In the subsequent NHC setting, she woke up diaphoretic at night, fearing that she was still not providing sufficient food for her infant.

#### *Trying to understand*

Several mothers had difficulty remembering all the events of the period of time in the NICU and some mothers had feared depression. They expressed difficulty in understanding what they have endured and how they have managed

the situation. However, time spent with the infant at home has permitted a realization that time in the hospital is over and that the infant has survived. Further perspective on the hospital experience was gained through conversations with the PNS. These conversations were more easily held in their own home and parents encountering the same nurse in both the NICU and NHC setting believed this further helped the processing of memories from the NICU period because the nurse had interacted with them in several contexts and knew their journey:

We were going to have a child in six weeks, so this whole carousel...you weren't there in your mind...it was so valuable to talk about this afterwards. (Mother)

Parents also began to think about the personal meaning of the experience of having a premature or ill infant and tried to ascertain whether they have sufficient courage to have more children:

That's why I definitely do not want to be pregnant again, because of all the things I know right now, that these things happen. (Mother)

If we have more children, we want neonatal home care. (Mother)

#### **Comprehensive understanding**

Parents' experiences with NHC illustrate the perception of parenthood as a journey from NICU to home and as an evolution, from having a child to being a parent. NHC was described as a bridge between hospital and home, supporting the adaptation to life at home after discharge from the NICU. Coming home meant that parents had opportunities to gain responsibility for the infant and to establish independent parenthood. Parents believed that parenthood was facilitated by the emotional understanding and educational support provided by the PNS. Coming home also meant that the parent-nurse relationship undergoes change. Thus, the experience of no longer needing the support of NHC was to experience oneself as a parent. Everyday life at home not only reminded parents that the infant had survived but also helped them realize that the family has managed a difficult period that is now over. During NHC, parents therefore increasingly perceived the infant as a healthy infant. As reminders of the chaotic experience of the NICU diminished, the sense of parenthood was increasingly restored. Feelings of alienation and separation changed to feelings of belonging and feelings of void of influence over the infant's care was replaced by feelings of empowerment. Parents came to perceive the infant as their own.



## Discussion

The main theme of the findings is that parents experience NHC as an inner emotional journey, from having a child to being a parent. This finding derives from three themes: establishing independent parenthood; maturing as a parent; and processing the experiences during the period of NICU. The PNS was described as a facilitator of independent parenthood by responsively providing the family emotional and educational support.

In agreement with other findings (Jackson *et al.* 2003, Fegran *et al.* 2008, Black *et al.* 2009, Hall *et al.* 2013), this study demonstrates that homecoming from the NICU was a significant event of parenthood. Moreover, we found that parents increasingly perceived themselves as parents of their own infant during NHC and that they were in charge in their own home setting in contrast to a location that does not belong to them. The question of child ownership discussed during the hospital stay (Shields *et al.* 2003) was not as essential in the NHC setting. Previous studies have demonstrated a risk that roles of responsibility for the infant's care remain unclear in the NICU environment (Heermann & Wilson 2000, Fenwick *et al.* 2001b). According to our findings, this uncertainty is not apparent during NHC. The change in the parent–nurse–infant relationship that accompanies homecoming may be a contributing factor. As a consequence of spending more time with the infant, parents become more familiar with the infant than the nurse, which facilitates parents' independence, shifting the balance of power over the infant's care in favour of the parents (Fenwick *et al.* 2001b, 2008, Heermann *et al.* 2005, Fegran *et al.* 2006). Findings from this study suggest that the parent–nurse relationship during NHC is consistent with the concepts of FCC as described by Harrison (1993), where parents are the infant's primary caregiver and the nurse serves as a consultant. Similar to the concepts of FCC, nurses in this study supported and enabled the parents to maintain their role as advocates, care providers and decision makers with respect to their infant's well-being. As a result, there was an evolving parent–infant relationship whereby the infant becomes the parents' own family member. Shields (2010) questions the evidence of FCC in today's environment of short hospital stays, high technology and extremely costly health care. In the context of Shields' assertion, this study demonstrates that NHC provides support for FCC, in contrast to the findings of several studies demonstrating its lack in the NICU (Petersen *et al.* 2004, Coyne *et al.* 2011, Trajkovski *et al.* 2012).

Interviews among parents about NHC have also provided us insights into their experiences with transition from NICU to the home. Parents reported that NHC provides support in the adjustment to the family's everyday life at home and congruent with a Brazilian study (Tatiana Coelho *et al.* 2007), parents' increased responsibility for the infant in the NHC setting is perceived as positive and important to the parent–child interaction. Several studies have indicated that families of NICU infants need support in the transition from NICU to home. Rehm and Bisgaard (2008) found that NICU parents must be carefully prepared for everyday life after discharge because they meet challenges that are different from those encountered in the hospital. Consistent with this, two studies in the United Kingdom demonstrated the prominence of insecurity and stress as features resulting from the increased responsibility for the infant after homecoming (Nicolaou *et al.* 2009, Murdoch & Franck 2012). Mothers felt unprepared for the psychological mother–infant interaction and worry over a perceived lack of necessary expertise in the care of premature infants that was present among health professionals in the community (Nicolaou *et al.* 2009). In contrast, Smith *et al.* (2009) found that a majority of parents feel prepared to independently take care of the infant at the time of discharge from the NICU. One possible explanation of these different findings may be methodological in nature. Although Smith *et al.* (2009) conducted a large quantitative study acquiring data on the day of discharge from the NICU, all other studies (Tatiana Coelho *et al.* 2007, Nicolaou *et al.* 2009, Murdoch & Franck 2012) were qualitative in nature and data are based on interviews undertaken months to years following discharge from the NICU. Organizational differences in discharge planning and in parent–nurse collaboration in the NICU represent another possible explanation of the incongruent findings observed (Fegran *et al.* 2008).

In this study, parents revealed difficult emotional experiences during NHC. As in previous studies, parents described that emotional responsiveness (Fenwick *et al.* 2001a, Bialoskurski *et al.* 2002, Mok & Leung 2006) and staff continuity (Bialoskurski *et al.* 2002, Wigert *et al.* 2006) supported them in their parenting roles. The need for support in the transition from NICU to home is further underlined by the risk of persistent stress, worry and fatigue among parents of NICU infants, each of which can negatively influence the parent–child interaction (Davis *et al.* 2003, Eiser *et al.* 2005, Garel *et al.* 2007, Pinelli *et al.* 2008, Zolkowitz *et al.* 2009, Forcada-Guex *et al.* 2011). NHC may address this need to a significant degree.

## Study limitations

Findings should be assessed on the basis that the study was conducted in a country where both the health insurance system and the organization of healthcare delivery permit and promote the presence of parents during the infant's hospital stay. The study context may therefore, like the small number of participants, limit applicability of the findings. However, the aim of the study, according to the methods used (Lindseth & Norberg 2004, Dahlberg *et al.* 2008), was to advance the understanding of parents' experiences with NHC. Consistent with the overall aim of neonatal care, to provide the infant with independent parents at discharge, these results are informative and the variations among parent and infant characteristics (Table 3) illustrate the context transferability and thus strengthen the results (Dahlberg *et al.* 2008).

As some parents were interviewed together, there is a risk of interference among the respective narratives. On the other hand, parents' choice of interview context seems to have promoted openness to the interviewer (Dahlberg *et al.* 2008) and parents' stories seem to have grown together. Reliability is increased by noting that each potential participant contacted expressed a desire to partake in the study. Conversely, the findings only represent the experiences of families having chosen NHC as a form of care.

## Conclusion

This study suggests that NHC is a care structure adjusted to incorporate parents' needs following their infants' discharge from a NICU. NHC appears to bridge the gap between hospital and home and to support the family's adaptation to life at home. Parents become empowered to be primary caregivers, having nurse consultants serving the needs of the whole family. Neonatal home care may therefore be understood as the implementation of family-centred care during the transition from NICU to home. The results highlight the importance of explicit and visible organizational strategies in the NICU in support of parents' participation in their infant's care. The organization should provide the family of the NICU infant an offer of continued neonatal care at home. Nurses should be reminded and aware of their unique position and ability not only to influence the extent of parents' participation in their infants' care but also to help parents process emotional difficulties. Further studies are, however, needed to determine whether the findings in this study can be observed in a different or larger population. It would be beneficial to explore differences among healthcare systems and among different coun-

tries and to address questions about different perceptions of the premise of parenthood in the NICU as compared with the NHC setting. It would be interesting also to quantitatively explore the nature and duration of the effects of NHC.

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## Conflict of interests

No conflict of interest has been declared by the authors.

## Author contributions

All authors have agreed on the final version and meet at least one of the following criteria (recommended by the IC-MJE: [http://www.icmje.org/ethical\\_1author.html](http://www.icmje.org/ethical_1author.html)):

- substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;
- drafting the article or revising it critically for important intellectual content.

Both authors were responsible for the study conception and the design. HW performed the data collection and both authors analysed the data. MDB was responsible for the drafting of the manuscript and HW supervised the study.

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