

# **THE PARENT'S EXPERIENCE IN THE NEONATAL INTENSIVE CARE UNIT**

(Work in progress)

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## **INTRODUCTION**

Few people would disagree that being a parent of a critically ill baby being cared for in the Neonatal Intensive Care Unit (NICU) is a stressful event (Ellenchild Pinch & Spielman 1996; Pehudoff 1990). Neonatal nurses provide care for the baby and the baby's family. In order to ensure that the care given to parents of a critically ill baby is appropriate, nurses need to understand the parent's experience of this event. Previous North American and New Zealand studies exploring parents' perceptions of the NICU have focused on several aspects of the experience and identified fear, grief, and stress as the key factors influencing the parent's experience in the NICU (Ellenchild Pinch & Spielman 1996; Shellabarger & Thompson 1993 & McCluskey-Fawcett, O'Brien, Robinson & Assay 1992). Few studies have used qualitative research methods to explore the parent's experience. This paper presents the preliminary findings of a qualitative study that explores what it is like to be a parent of a critically ill baby in the NICU.

## **BACKGROUND OF THE STUDY**

During my experience as a Registered Nurse caring for neonates, infants, children and their families in the intensive care environment I often wondered how the parents were feeling and how they were coping from day-to-day. I can remember numerous situations when caring for the very unwell baby I would empathise with the parents' sorrow and fear of living with an unknown outcome for their baby. Parents would ask me questions such as '...is my baby going to be alright?' Or they would look for reassurance and say '...he'll be alright won't he?' I often felt frustrated because I could not satisfy their need to know about what lay ahead. The motivation for this inquiry evolved from my personal experience as a nurse and as a parent. In particular I wanted to understand how the parents of a critically ill baby felt so that I could provide quality care and support.

## **LITERATURE REVIEW**

Being a parent in the NICU means that parents hand over care of their baby and they share the parenting of their newborn with complete strangers, nurses, doctors and allied health professionals. In the normal course of events, the process of separation from the baby may not occur until parents feel ready to wean themselves away from their baby. When this occurs the parents usually surrender the care of the baby to a close friend or relative (Bergum 1997).

Several studies (McCluskey-Fawcett et al 1992; Swanson 1990; Mooney Smith 1987) have explored the concept of care, the provision of care and the process of parenting in the NICU. A diversity of issues are discussed including parental adaptation to the NICU and how staff may influence parenting. The findings of a number of studies (Lawhorn and Melzar 1988; Taylor 1986; McGrath and Conliffe-Torres 1996) indicate that parental involvement in the care of their baby may contribute to avoiding bad outcomes and the facilitation of developmentally supportive care.

McCluskey-Fawcett et al (1992) interviewed 13 mothers at least twelve months after their baby was discharged from the NICU with the view that this distance from the experience would provide a more balanced description of the experience of being a parent in the NICU. The authors maintain that the birth and recent unfavourable events may influence the responses to interviews conducted during the critical time of admission to the NICU. The mothers in this study identified fear and stress during the labour as they awaited the unknown outcome of their premature labour. The comments and concern from nursing staff in the delivery suite were described as helpful. The participants described comments and behaviours of medical and nursing staff in the NICU as disappointing. Parents expressed the desire to be involved in their baby's care and described a lack of involvement and lack of contact with their baby as very distressing. The parents describe how over time the nursing staff became their allies and close relationships developed. The study is limited by the potential for parents to view the experience differently twelve months following the admission of the baby to the NICU. For example, the parents in this study did not remember feelings of grief or ambivalence as reported by parents in the Swanson (1990) study conducted during the baby's admission.

Mooney Smith (1987) confirms the importance of consistency and continuity of care from a mother's perspective. The author emphasises that her baby's transfer to a unit providing primary nursing care was accompanied by a dramatic improvement in her baby's condition. The baby was discharged within two weeks of the transfer. The primary nurse provides individualised care for the neonate and is capable of detecting minor changes in heart rate, respiratory rate, oxygenation and behaviour which may indicate the neonate is stressed or becoming unwell (Lawhorn and Melzar, 1988). Similarly, Swanson (1990) highlights the importance of consistency in care as a way of avoiding bad outcomes in her phenomenological study exploring parents and staff providing care in the NICU. Swanson (1990) interviewed physicians, parents and nurses asking the question *what is it like to be a provider of care in the NICU?* The study identified four essential themes in the provision of care in the NICU: 'caring', 'attaching', 'managing responsibility' and 'avoiding bad outcomes'. Swanson (1990) reveals how staff became attached to the babies and parents as they shared caring for these babies with this group of parents. This supports the experience reported by Mooney Smith (1987) and highlights the importance of consistency of care and developing relationships with parents and the midwife's attachment to the baby.

Providing developmental care has been the focus of a number of studies. Developmental care refers to the importance of considering the individual baby's physiological tolerance to any handling as well as the risk of sensory deprivation. McGrath and Conliffe-Torres (1996) assert the inclusion of parents and family in the provision of care for the neonate is essential to the concept of developmentally appropriate care. The authors call for a move away from task-orientated provision of care in the NICU to a more individualised, family-focused approach to care. McGrath and Conliffe-Torres (1996) confirm the findings of Mooney Smith (1987) and

highlight the ability of the parents and the family to 'tune into' the neonate's subtle behavioural cues. It is suggested that medical and nursing staff work closely with parents and the neonate will receive individualised care hence minimising adverse effects of handling and disturbance to the baby. For example, pain and stress have been linked to immunosuppression in the neonate and the negative consequence of sepsis, a potentially fatal condition in the neonate (Witek-Janusek and Cusack 1994).

While a variety of methodologies have been utilised to explore the experiences of parents in the NICU, a number of similar themes are evident in the literature. Essentially, the experience of being a parent of a term baby at home can be confronting and challenging in the normal course of events. The literature reveals how becoming a parent or being a parent in the public forum of the NICU can be an isolating, stressful and daunting experience for parents. A number of studies highlight discrepancies between nurse's perceptions and parents' perceptions of parenting (Walker 1998 and Taylor 1986). The need for consistency in the provision of care of the baby indicates a need for clarification of parental perceptions of their experience whilst being with their sick baby in the NICU. Furthermore, the findings of the review of the literature highlight a need for future research validating the parents' role in caring for their baby in the NICU.

## **AIMS OF THE STUDY**

The aims of this study are to: a) explore the experience of parents whose babies have been admitted to the NICU, b) identify the most significant aspects of the parent's experience and c) describe the parents' experiences from their perspective. It is hoped that the findings of the study will provide a rich description of the impact of the admission of a baby to the NICU on parents in an Australian setting. Furthermore, it is hoped that the findings will assist medical and nursing personnel in providing appropriate emotional and social support to reduce parental stress and improve the quality of care for the neonate and their family.

## **METHODOLOGY**

Phenomenology was the research methodology used in this study. Van Manen (1990) maintains that 'lived experience is the starting point and end point of phenomenological research' (p.36). Phenomenology seeks to understand the meaning of lived experience (van Manen 1990). It attempts to understand the experience of being in the world in a particular situation. The research question for this study *What is it like to be the parent of a baby in the NICU?* seeks to gain a deeper understanding of the experience of being a parent of a baby in the NICU.

Solomon (1989) describes the process of phenomenological research as an attempt to understand what it is like to be in someone else's shoes - without taking off our shoes first. The researcher can never really know what it is like for the participants in the study. By analysing the descriptions provided by the participants, the researcher endeavours to uncover the pre-reflective meanings the participants give to the experience and provide a description of the experience. Bergum (1997) asserts the purpose of phenomenological research is to understand another person's experience from their point of view, as opposed to explaining actions or patterns from an outside point of view (p.5). Because phenomenology aims to discover experience as it is lived, it was chosen as the most appropriate research methodology through which to explore the parent's experience of having a critically ill baby in the NICU.

## THE CONTEXT OF THE STUDY

The study was conducted in a tertiary referral centre in New South Wales providing antenatal, perinatal and neonatal intensive care support for high-risk pregnancies and complicated deliveries. Babies admitted to the NICU because they are critically ill may require respiratory support, advanced life support therapies and invasive monitoring (\*see note below). Babies admitted to the level two nursery may require respiratory support, would weigh more than 1.5 kilos and would not require invasive central monitoring, such as intra-arterial lines.

## CRITERIA FOR INCLUSION IN THE STUDY

The criteria for inclusion in the study included the following:

- the parents had to be adult participants aged between 20-40 years;
- the parents had to be adult participants and able to communicate without any obvious difficulties or discomfort;
- the parents' baby had to be admitted to the level three or the level two nursery.

The parents of a baby with a poor prognosis were **not** included in the study and the parents of a baby who subsequently died were **not** included in the study. Finally, the parents of a baby who was cared for by the researcher were **not** included in the study.

## RECRUITMENT

The Clinical Nurse Consultant (CNC) for follow-up care, in the unit included in this study, approached parents of babies who satisfied the inclusion criteria within one week of admission of the baby to the NICU. The CNC was fully informed of the purpose of the study, the inclusion criteria and the recruitment process during several visits to the NICU by the researcher. The CNC was not expected to explain the study to the parents. The CNC was asked to identify suitable participants and distribute the 'Participant Information Letter' outlining the aims of the study and the expectations of the participants.

## ETHICAL CONSIDERATIONS

Prior to proceeding with the study the tertiary referral centre ethics committee and the University Ethics Sub-Committee approved the study. Participants were informed of their rights and of any arrangements made should counselling be required. Prior to proceeding with the interview, informed consent was obtained. In the light of the potential for the interview process to cause distress during a sensitive and emotional time for the participants, all parents involved in the study were offered the support of a local community counselling service.

\* The different levels of neonatal care are categorised in relation to the degree of technical support and nursing care the baby requires and provides a guide for allocation of funds and staffing. For example, Level One represents the minimal support required for babies in the maternity ward. Level Two represents the level of care available to complicated deliveries and high-risk pregnancies such as unstable hypertension or diabetes. The baby admitted to a Level

Two nursery may require frequent feeding or monitoring, blood glucose levels or non-invasive respiratory support. A centre designated a Level Two centre will not be able to provide long-term, invasive respiratory support or neonatal surgery. The Level Three nursery will be able to provide neonatal surgery, invasive respiratory support, such as intubation and ventilation, and advanced central line access for monitoring the baby (Merenstein & Gardner 1998).

If at any time during the interview the parent or the baby became distressed the interview was ceased temporarily. There was no physical risk to the participants at any time in the study. Participants were informed of their right to withdraw from the study at any time, their right to the findings of the study and their right to access their data at any time.

Privacy, anonymity and confidentiality was ensured throughout the research process. Confidentiality was maintained by ensuring privacy during interviews and in any discussion between the researcher and the supervisors about the research findings or interview content.

## **DESCRIPTION OF THE PARTICIPANTS**

Six parents consented to participate in the study. One couple chose to be interviewed together, the rest of the interviews were conducted with the mother of the baby. I have used pseudonyms to present the participants' descriptions of their experience. I shall describe each parent, the type of delivery they experienced and specific features of their experience. Joanne experienced a rapid normal vaginal delivery of her baby girl at 24 weeks' gestation. Joanne described her experience in the NICU as 'a roller-coaster ride'. Sally and Jim were interviewed as a couple and described their experience in the NICU as 'a positive experience'. Their baby girl was born following an emergency Caesarean Section when Sally was 29 weeks' gestation. Sally and Jim described the tour of the NICU as beneficial to their coping with the experience. Michele experienced a traumatic haemorrhage at home before delivering her little girl at 31 weeks via an emergency Caesarean Section.

Michele was told when she woke up from her delivery that she had experienced a cardiac arrest during the Caesarean section and had required significant fluid replacement. Michele described her experience of being in the NICU with her baby as 'terrifying'. Michele was constantly in fear of losing her baby from the moment she began to bleed at home until her baby was discharged from the NICU. Peta described her experience in the NICU as a 'walk in the park'. Peta had to be transferred to another tertiary referral centre due to insufficient beds available at the site of the study. Peta delivered her twin girls at 30 weeks' gestation. Two years before the twins were born Peta had been through a difficult time with her first child in an oncology ward for 2 years. Peta acknowledged that this time in hospital prepared her for NICU as she was accustomed to the equipment and the idea of leaving her babies in the care of strangers. Penny experienced blood loss at home and delivered her baby via an emergency Caesarean Section at 29 weeks gestation. Penny described her experience in the NICU as daunting and felt she was unprepared for the experience.

## DEMOGRAPHIC PROFILE OF THE PARTICIPANTS

Name	Age	Religion	Nationality	Age of Baby	Gestation of baby	Age (in years) and gender of other children
Joanne	31 years	C of E	Aust.	12 months	24 weeks	Boys 10 and 5
Sally & Jim	28 years 33 years	Uniting Church	Aust.	8 weeks	29 weeks	Boy 2
Michele	31 years	Catholic	Aust.	12 months	31 weeks	Girls 9,7 and 1, and Boy 6
Peta	35	None	Aust.	8 weeks	30/40	Girl 5
Penny	30	None	Aust.	8 weeks	29/40	None

## THE INTERVIEWS

All interviews were conducted in the participant's home, thus ensuring a private place in which the participants felt comfortable to describe how they felt during the time of their baby's admission to the NICU. Prior to conducting the interview a time of 20 minutes to one hour would pass before the baby was settled or fed and the parents felt comfortable to talk. I found this time facilitated a 'settling in stage' for a beginning rapport to develop between the participants and myself. In this time, the purpose of the study, my background in neonatal and paediatric nursing and my personal interest in the parents' perspective was explained. The interviews would commence with questions pertaining to demographic data. This was followed by an opening question such as:

*When did the experience begin for you?  
How did you feel when you first arrived in the NICU?  
What were some of the most significant aspects of the experience?*

During the course of the interview, any significant aspects of the experience were further explored with questions such as:

*Can you remember how you felt at that time?  
How did that make you feel?  
What was that like?*

At times the participant would be interrupted during the interview or would mention a key issue in the course of the discussion. I would then need to direct them back to their comments by saying:

*Earlier you mentioned... can you tell me a little more about that?  
Could you talk a bit more about that?  
Can you remember what you said at that time?*

## DATA ANALYSIS

The final interview was conducted in July 1999 and intensive data analysis has been in progress since that time. Phenomenology relies on language and text to derive meaning from an experience, therefore the process of data analysis involves reading and re-reading the transcripts, listening to the interviews and reflecting on the significant statements or descriptions within the parents' narratives. The method of data analysis has been guided by Colaizzi (1978 cited in Holloway and Wheeler 1996 p.125) and outlined as follows:

1. the transcripts of the participants' narratives were read in order to acquire a feeling for their ideas in order to understand them;
2. key words and sentences were extracted from the transcripts relating to the phenomenon;
3. meanings were then formulated for each significant statement;
4. this process was repeated for each description from the participant and formulated meanings arranged into clusters of themes;
5. the next step will be to integrate these themes into an exhaustive description of the phenomenon;
6. the exhaustive description of the phenomenon is in progress.

## THE PRELIMINARY FINDINGS

In writing a phenomenological description of the experience of being a parent of a baby in the NICU, I have endeavoured to be true to the parents' descriptions of their experiences. Van Manen (1990) refers to the phenomenological description as that which draws the reader in and re-creates the essence of the experience. This phenomenological description aims to provide the audience with a sense of the experience of being a parent of a baby in the NICU. The themes and sub-themes, which have emerged from the preliminary data analysis, are described separately, yet they are inter-related. The two main themes that have emerged from the data are *parenting from a distance* and *putting your life on hold*.

### PARENTING FROM A DISTANCE

For the purpose of this paper I shall discuss an aspect of the theme *parenting from a distance*. *Parenting from a distance* captures the parents' description of being with their baby in the NICU. Five sub-themes form part of this description. Parents described *watching out for their baby*. Here they expressed the need to protect and oversee the care that the baby was given.

*Being useful/ feeling useless* describes the paradox of wanting to help do things for the baby and yet feeling useless when the only things they could do were limited to cleaning the baby's eyes, changing the nappy and cleaning the baby's mouth.

Parents described *wanting to be near the baby* as they felt detached from the baby. The mothers in the study described giving birth and having nothing there except an empty cot or other people's babies. These descriptions were often from memories of their stay in the post-natal ward.

Some parents described *feeling guilty* about why the baby was born early and why this happened to them. They also describe feeling guilty about leaving the baby.

Parents described the overwhelming joy of *holding the baby for the first time*. Touching the baby through the crib was not the same as holding the baby close. Their first cuddle provided the first close contact with the baby and in this way the parents felt attachment with the baby.

In the following discussion I focus on one of the sub-themes *watching out for my baby*.

## WATCHING OUT FOR MY BABY

*Watching out for the baby* involved eagerly watching staff for signs of their confidence in giving care to the baby and monitoring their level of competence with technical procedures such as suction of the baby's airway. They also gauged the nurses' caring behaviours. The parents described watching staff and visitors as they entered the NICU to ensure that they washed their hands thoroughly. In some cases parents sat in the NICU watching out for other people's babies. The following exemplar portrays this feeling:

*It's like you're watching out for other babies and like even when visitors come in and you might not see them washing their hands and you think 'Oh, they're not washing their hands, are they bringing any infections in here', because you've got your children in there that are fighting for their lives ...prone to infection and germs and things and you feel like going up to them and ..'wash your hands' (Joanne).*

Joanne is not only seeking to protect her baby she is describing a sense of responsibility for all the babies in the unit. She is 'watching out' for any risk to her baby and the other babies. Once Joanne is transferred back to the referral hospital she describes how once more she needs to be on the look out for her baby as she begins a new assessment of a new place with new people.

*Yes, I was very uncomfortable when I first arrived there with her, and watching everyone like a hawk, and ...it did get easier once you got to know the nurses (Joanne).*

Integral to the experience of being a parent in the NICU and *watching out for the baby* is the need for parents to trust the carers of their baby. Developing trust was often measured by the actions of caring staff. Parents would watch the staff very carefully and if they detected signs of staff not being interested in the baby or them they would feel uncomfortable about leaving their baby.

Sally and Jim were interviewed as a couple and described their feelings of concern for their baby as they watched a sterile procedure being performed carelessly by a staff member. When they acted upon their misgivings and expressed their concerns, the nurse confirmed their misgivings through a thoughtless comment. Jim describes how he felt at this time.

*Anyway, we were sitting down and he was doing this procedure and I said 'Isn't this a sterile procedure?' and he said 'Oh yeah, but it's only this baby here in the corner' – but 'only this baby in the corner' – I don't give a stuff about any other babies – this is my baby... it's 'only this baby in the corner' and I thought ...there is no way I want to leave her there (Jim).*

Jim's anger is palpable. He decides not to leave his baby in the hands of someone whom he feels he cannot trust and talks about not feeling confident to leave. In *watching out for the baby* parents describe needing to act on feelings of doubt and mistrust. In this situation, Sally and Jim

wait until the shift is finished before leaving their baby, during which time they discuss their concerns with managerial staff and in this way act on their anger and are able to leave their baby feeling confident that she was in safe hands.

Parents describe watching out for their baby by monitoring the behaviours of the nursing staff as they cared for their baby. Penny described feeling confident to leave her baby with a nurse or medical officer whom she describes as being genuine in their care of her baby. Nursing and medical staff who portrayed feelings of genuine care for the baby made parents feel relaxed and reassured that they could leave the baby with someone who would be kind and caring towards their baby, as Penny describes in the following:

*Knowing you've got to leave them [the baby] up to these people, yeah like, as I said I took comfort, because you could tell it was a genuine care, whether it was the doctor, you know, like one of the interns or the nursing staff, you could tell that it was genuine care. So um that definitely makes a big difference (Penny).*

Trust in the carer or carers of the baby develops over time and in this way the experience of being a parent of a baby in the NICU changes with time. Parents describe feeling comfortable and relaxed once they had developed trust or faith in the place and the people caring for their baby in the NICU. The parent's description of *watching out for my baby* creates images of tension and of being on the lookout and potentially feeling stressed by the experience. Yet as faith would slowly develop some parents felt they could relax and confidently leave their baby in the hands of people who would protect their baby. In the following exemplar Joanne describes her unquestioning faith in the medical staff:

*I guess it was just comforting knowing that she had the best care. So umm... then it came to blood transfusions and everything else I just put my belief into doctors and umm.. I just started believing in them. You have to put faith in people (Joanne).*

In conclusion, the parents in this study describe the experience of being a parent of a baby in the NICU as daunting and frustrating. They often felt useless and guilty and describe watching out for their baby and wanting to be near their baby. The closeness of the first cuddle begins to close the gap of *parenting from a distance*. Parents describe the first time they hold the baby as overwhelming. The following prose portrays some of the emotions expressed by the parents in the study as they found themselves *parenting from a distance* whilst in the NICU with their sick baby:



## **‘PARENTING FROM A DISTANCE’**

*Right from the beginning she was just...not around*

*I just didn't have the baby there with me*

*It's almost as if it didn't happen*

*You feel so useless*

*I didn't want to leave her*

*I just cried and cried*

*They are so small and fragile and...*

*You feel helpless*

*I was worried about losing her*

*I had to see her everyday*

*She needed us more than anything*

*You feel so useless*

*The first cuddle*

*Skin to skin*

*The real touch...just lovely*

*The closeness*

*So instantly calming*

*It's like*

*‘Oh, my baby’.*



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