Parents and Nurses in a Neonatal Intensive Care Unit – The development of a mutual beneficial partnership in the care of the infant.

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To Sunniva, Henrik and Ben

FIGURES AND TABLES:

PREFACE

While it has been both exciting and demanding to do this study, it has also been immensely satisfying. It is often said that the road towards a PhD degree is lonely, and in my case this has been both true and false. All along this has been my project, my choices, and my professional and academic development – no-one could walk this road for me. Even so, a lot of people have accompanied me on this road, and without their encouragement and support the road would have been much more difficult to travel. It is all these individuals who deserve a big "thank you" at this moment in time.

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I am grateful to all you mothers, fathers and nurses who welcomed me into your daily lives for weeks and months on end; you are the ones who made it possible for me to complete my research project. You generously shared your thoughts and experiences with me and helped me better understand what it is like to be parents and nurses in a neonatal intensive care unit. Without your contribution there would be no doctoral thesis, and I am deeply grateful to you, one and all.

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entire process. Her speedy and constructive feedbacks, her clarity and support have been invaluable to me. Through her supervision she inspired me and helped me to achieve my utmost both academically and as a human being; to med she epitomises the ideal supervisor.

The writing of this thesis in English has been a demanding and useful part of my research education. Thank you to my primary supervisor Professor Sølvi Helseth who challenged me to write in English, and to my language consultant Ingrid Hanssen who helped me present my study and its results as clearly as possible.

The finishing touches were done at The Xristos Study Center at Lesvos. When I look back on the long process a doctoral education is, I owe my family and friends the greatest thanks. Thank you to close friends who at all times showed interest in the project and had my best interest and care at heart. Thank you to my children Sunniva and Henrik who for years have treated their studying mother with loving patience, and not the least to my husband Ben who in every way has been supportive, encouraging, and taken care of everything so that I have been free to focus on my studies.

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Kristiansand 28.09.08   Liv Fegran

1.0   INTRODUCTION

When I first started my nursing career in paediatric and neonatal units my intention was to care for hospitalised children. I soon, however, realised that in addition to the children, their parents also constituted a crucial part of my responsibility. To become parents to a critical ill newborn baby may be enormously distressful, and a hospital stay that lasts for weeks and even months is demanding for the entire family. I wanted to learn what the needs of these parents are, and how nurses best may support them and help them cope with this experience.

A first step in turning practical nursing experiences into theoretical studies, I wrote a Master Thesis based on an empirical study of what characterised the interaction between parents and nurses in a Neonatal Intensive Care Unit (NICU) (Fegran 1996). The interaction appeared to be characterised by a) clarification of roles, b) education and information and c) support. I found that the quality of the interaction impacted greatly on parents' experiences, even though the title of the thesis: "Who owns the child?" points to the complexity of the parent-nurse relationship.

In my PhD work I decided to explore the parent-nurse relationship further. What made some relationships positive while others were experienced as complicated and demanding? Why did the parent-nurse relationship seem to become more complicated the longer the hospitalization? Did mothers and fathers experience the hospital stay differently, and why were the fathers' voices conspicuously absent in the research literature? How did the extensive changes in neonatal care influence the nurses caring for the infants? These and other questions were starting points for my wanting to learn more about the parent-nurse relationship in the NICU.

While reading up on parents and nurses in NICUs, I realized that the philosophy of Family-Centred Care (FCC) was strongly influencing neonatal care both among scholars and in nursing practice. Although there seem to be an increasing number of voices questioning the concept and its implementation in nursing practice, an extensive number of researchers find FCC to be the best approach in neonatal and paediatric care. Hence, my study findings of the parent-nurse relationship in the NICU are discussed in light of the FCC philosophy.

2.0   PERSPECTIVES ON NEONATAL CARE – FROM AUTOCRACY TO PARTNERSHIP

I will start this presentation of my study's theoretical framework with a historical overview of the development of neonatal care. The historical introduction is followed by a presentation of the philosophy of FCC, which currently is recognized as the best approach to neonatal care (Shields et al. 2007, Cooper et al. 2007, Malusky 2005, Shields et al. 2006). Lastly, various aspects of the implementation of FCC into nursing practice are described.

Finne et al. (2001) suggest that prematurely born infants constitute the greatest challenge in neonatal care. In 2006 6,3 % of all infants born in Norway were premature (The Medical Birth Registry of Norway 2006, Finne et al. 2001). An infant is diagnosed as premature if born prior to 37 weeks of gestation, or if its birth weigh is less than 2500 grams (Finne et al. 2001). The number of premature infants is growing due to an increased number of multiple pregnancies caused by artificial insemination, and to early terminated pregnancies due to mothers' health problems (Finne et al. 2001). Advances in obstetrics and neonatology have increased the survival rates of ever younger premature infants, and issues of ethics and treatment costs in relation to extremely premature infants are afforded increased attention (Msall and Park 2008, Smith 2005, Russell et al. 2007). Physical immaturity problems, as for instance respiratory, eating, and digestion problems, inadequate regulation of temperature and circulation, and complications such as cerebral haemorrhage and infections, are main reasons why children need hospitalization (Finne et al. 2001). The younger the premature infant the longer the hospital stay before discharge to home.

A premature birth and the following hospitalization constitute an emotional and physical strain both on mother and father (Jotzo and Poets 2005). Normal pregnancy and birth are transformed into a situation for which the parents are unprepared. Any feeling of control and preparedness is lost, as expressed by a Norwegian father of a prematurely born baby:

> "Å elske er å risikere. Det er å gå på line uten sikkerhetsnett. Ingen vet hva neste steg bringer – tilværelsen kan i løpet av sekunder bli snudd opp ned, fra total balanse til et plutselig fall ned i et mørke der du ikke kjenner bunnen. Å elske et barn er å strekke seg etter glede, men samtidig risikere å bli utlevert til lidelsen. Hudløst og forsvarsløst. Når noe er galt[1]."   (Rye 1998, p. 9)

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[1] "To love is to take a chance. It is like a balancing act with no security net. No-one knows what the next step will bring – one's world may be turned upside-down in seconds, from total equilibrium to a sudden fall into a dark place where you cannot touch bottom. To love a child is to reach for happiness, but at the same time to risk exposure to grief. Overly sensitive and unprotected. When something is wrong."

Parents of a prematurely born infant find themselves amidst a situation where the infant is critical ill, and where the mothers' health also may be seriously threatened. Adapting to their new parental role put great demands on parents, and their time in the NICU is experienced as unpredictable and challenging both physically and emotionally (Steele 1987, Holditch-Davis et al. 2003, Fegran 1996, Shields et al. 2003b). Into this setting nurses bring knowledge and experience as they take care of these fragile infants and their parents.

Modern development in neonatal care may be characterized by three factors (Davis et al. 2003). The advances in medical and public health practices have resulted in declining mortality rates for mothers and infants. This new knowledge led to increased hospitalization and professionalization which separated and isolated mothers from their infants. Finally research emphasized that a close mother-infant relationship was important both for the infants' developmental outcome and for the mothers' ability to become attached to and care for their infants. The change from an exclusive focus on the infant to an incorporation of its parents has led to profound changes in hospitals' policies regarding parental presence and involvement in their infants' care. As an introduction to current practices and views on parents' role in the care of their infant, an overview of the developments in neonatal care is presented below.

2.1   1900–1940: Focus on the child's basic physiological needs

Until the Second World War (1940) the main focus in neonatal care was the infant's physiological needs: maintaining a constant and normal temperature, providing adequate nourishment, and preventing infections (O'Donnell 1990).

Incubators saved the lives of many premature infants through the creation of an environment similar to the intrauterine state, with constant and normal temperature and humidity (Smith 1911). The first well publicized incubator with warm, moistened air enclosed in a glass case was designed in 1880 by Tarnier (a French obstetrician) and Martin (a hatchery keeper) (Webster 1931, O'Donnell 1990). To communicate this knowledge the incubator was demonstrated at several exhibitions in Europe and later also in the USA. As premature infants were not expected to survive, German physicians were allowed to use such babies in the exhibitions. Even though the exhibitions were highly commercial ventures in dubious

taste, they brought recognition of the success of this technology in caring for premature infants who otherwise would not have survived (Davis et al. 2003).

In spite of this progress it was at this time still no consensus in Norway about the usefulness of incubators. Professor Brandt at Rikshospitalet's Maternity Clinic in Oslo presented in 1933 his personal opinion on incubators: "We do not use incubators of any kind. It is 30 years since we in Kristiania discontinued the usage of this not only a superfluous, but a downright harmful device" (Finne 1993, p. 152). Nurses' contribution to the survival of premature infants was however emphasized: "They [the nurses] feel a real sportsmanlike pleasure in the treatment of them, and for the premature infants to survive the nurses put all their effort and pride into their work to succeed" (Finne 1993, p. 154).

The prevention of infections through contagion was another main issue concerning the survival of premature infants. The infants' contact with other human beings therefore was minimised and limited to medical procedures only, and some places even the physicians were barred from the nursery (Klimaszewski and Jeanette 1944, Connell and Bradley 2000). Parents were totally absent from their infant's care, and mothers' contribution was restricted to the 'milk stations' where they supplied their own and other's infants with breast milk (O'Donnell 1990). At one stage there were even discussion whether human milk really was the better nutrition for babies, and in 1945 cow's milk was suggested to be superior to human milk and more advantageous for premature infants: "It should no longer be said that human milk is the 'ideal' food for premature infants and that it is 'essential' to their welfare during the early weeks of life" (Dunham 1945, p. 516). Today mothers have regained their position as primary milk-providers, and maternal breast milk is by far the preferred nutritional choice (Henderson et al. 2007).

The commencement of respiratory support in the 1930s and the introduction of oxygen therapy to infants with respiratory problems, or who were below a certain birth weight, were credited with increased survival rates (O'Donnell 1990). The arrival of antibiotics in the 1950s created even higher expectations, although the treatment of these vulnerable little ones was implemented without the necessary scientific investigation into possible side effects. Excessive concentrations of oxygen in the incubators caused blindness in more than 10 000 children around the world due to retrolental fibroplasia. And while antibiotics offered new hope in the prevention of infection in the prematurely born, their untested and

indiscriminate use left some infants entirely or partially deaf, while others suffered kernicterus (jaundice) and even fatal brain damage (Davis et al. 2003). During the 1940-1950s there was an increased focus on unforeseen complications from treatment procedures like oxygen treatment and the use of antibiotics.

2.2   1940–1970: Institutionalization and professionalization of neonatal care

After the World War II premature death constituted almost 50 % of all deaths during the first month of infants' life in the USA (O'Donnell 1990). Prematurity and neonatal death became a public health problem, which led to institutionalization and professionalization of neonatal care. Hygiene and sterility to prevent infections were regarded more important than infants' contact with mothers, and mothers' only 'contact' with their child was usually to watch their infants through a glass window during the one daily visit allowed to them (O'Donnell 1990). However, during the 1960s the perception that children's adaptation to hospitalization would profit from limited or no contact with parents gradually changed (Kledzik and Howell 1996, Connell and Bradley 2000). One began to realize the emotional consequences of mother-child separation, and Bowlby's research on attachment and loss became a turning point for the understanding of children's reactions to separation (Ahmann 1998, Bowlby 1969). Robertson explored Bowlby's theory on hospitalized children further and described indifference, apathy and lack of thriving in children who were deprived of contact with their mothers during their hospital stay (Robertson 1970). This new understanding contributed to the recognition of the fundamental role of parents in optimal care of premature infants (Davis et al. 2003, Kledzik and Howell 1996). But there was still a long way to go, and even after parents were given access to their infants in hospitals, a few decades passed before views were changed and one realised that children fare much better with their parents at their side (Connell and Bradley 2000).

2.3   1970–2008: Admission of parents' entrance and ethical discussions

In 1970 neonatal medicine was recognized as a medical speciality, and special units for treatment of premature babies were established (Finne 1993, Malusky 2005). The improvement of incubators and technical equipment, and equally important, of mechanical

ventilation and surfactant substitution for treatment and prevention of Respiratory Distress Syndrome (RDS) impacted greatly on premature infants' chances of survival (Obladen 2005, Wheeler et al. 2007, Higgins et al. 2007, Robertson 2005). There was furthermore an increased focus on prenatal treatment and continuous observations of risk pregnancies, and a growing awareness concerning delivery methods and birth timing. While only 71 % of infants born before 32 weeks were declared live births in Norway in 1970, this number had increased to 88 % by 1989. In 2000 39 % of treated children under 23 weeks survived, and as many as 93 % of children born at 27 weeks survived (Bratlid 2006).

Today a steadily growing number of infants survive ever greater health problems, deformities and handicaps, causing unpredictable complications, reduced survival prognoses, and reduced quality of life for those who do survive. As technology and knowledge push the limit for survival ethical discussions are not so much concerned with our ability to make increasingly younger premature infants survive, but with our moral obligation to critically discuss our practices and their consequences (Lorenz 2005, Brinchmann et al. 2002). We are challenged by new issues: Should a limit be drawn to how young and immature babies ought to be treated (Brinchmann 2000)? Do we have adequate knowledge about long-term effects of premature birth (Msall and Park 2008, Syvertsen and Bratlid 2004)? What support do families with disabled children receive after discharge from hospital (Førde and Vandvik 2004, Brinchmann 1999)? Whose responsibility is it to make decisions in ethically difficult situations (Brinchmann et al. 2002, Førde and Vandvik 2004)?

The fact that ever younger infants survive makes neonatal care increasingly complex. Despite this, there is a growing recognition of the importance of parents' involvement in the care (Darbyshire 1993, Shields et al. 2007, Åstedt-Kurki et al. 2001). Not only parents, but also siblings and grandparents are now welcomed into the NICU (Hall 2007, Beavis 2007). Nurses have always been mindful of the family's ability to provide care to their sick baby, but less attentive to the individual family member (Kirkevold 2001). Until the 1990s the research focus in neonatal care was almost exclusively on the mother or the family as a unit, while fathers' experiences and needs were more or less ignored (Söderbäck 1999, McAllister and Dionne 2006, Dokken and Ahmann 2006, Corlett and Twycross 2006, Fegran 1996, Board and Ryan-Wenger 2000, May 1996, Pruett 1998, Katz 2002, O'Shea and Timmins 2002, Lundqvist and Jakobsson 2003, Lindberg et al. 2008, Fegran et al.

2008). As researchers started to study parents' individual needs, differences in mothers' and fathers' experiences and emotional reactions were described (Brown and Barbarin 1996, Shields-Poe and Pinelli 1997, Franck and Spencer 2003, Jackson et al. 2003, Grootenhuis and Last 1997, Premberg et al. 2008, Chesler and Parry 2001). Mothers were said to be more involved in their baby's care, while fathers felt squeezed between considerations of work and of family (Grootenhuis and Last 1997, Chesler and Parry 2001, Sloper 2000). These days the importance of fathers' presence in hospital is fully appreciated in Norway, and from 2008 fathers are given rights to care benefits that enable them to stay with their critically ill prematurely born infant in hospital (Ministry of Labour and Social Inclusion 2008).

3.0 THE PHILOSOPHY OF FAMILY-CENTRED CARE

FCC emerged in North America during the 1960s from a strong advocacy movement on the part of persons with disabilities and parents of children with special educational needs (Shelton 1987). It was a reaction to the strong professional dominance in health care, and FCC has gradually become the underpinning philosophy in paediatric care (White 2004, Kirkevold 2001, Ahmann 1998, Connell and Bradley 2000, Davis et al. 2003, Shields et al. 2006, O'Donnell 1990, Fegran et al. 2006, Dokken and Ahmann 2006, Wiedenbach 1967). FCC is a philosophy of care where the approach to the planning, delivery, and evaluation of healthcare is governed by mutually beneficial partnerships between healthcare providers, patients and families (The Institute for Family-Centered Care 2008, Shields et al. 2006, Åstedt-Kurki et al. 2001). According to Malusky's (2005) concept analysis of FCC, a *family* is defined as anyone who is related biologically, emotionally, or legally to the child, which means that the family defines itself. *Centred* is a mode of care which identifies the family as an integral part of the health care team, and finally *care* is defined as a necessary element for the maintenance of health (Malusky 2005).

The bases for FCC in the NICU are the participants' willingness to create a balance of power that facilitates a mutually satisfactory collaboration, and the availability of enough time and an environment which make implementation of FCC possible (Hutchfield 1999, Malusky 2005). The parent-nurse relationship is based on respect for the family's strengths, individuality and diversity, combined with honest and open communication (Malusky 2005). The Institute for Family-Centred Care (2008) holds four core concepts as essential to patient- and family-centred care: 1) Parents should be approached with *dignity and respect*, and nurses should listen to and honour patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds should be incorporated into the planning and delivery of care. 2) Information sharing should be facilitated so that nurses communicate and share *complete and unbiased information* with patients and families in ways that are affirming and useful in order to effectively participate in care and decision-making. 3) *Participation* by patients and families in care and decision-making at the level they choose is encouraged and supported. 4) Patients and families should be invited to *collaborate* in policy and program development, implementation, and evaluation of health care facility design and in professional education, as well as in the delivery of care.

An increased number of NICU's have embraced the philosophy of FCC, the physical environment in NICUs has been re-designed to facilitate FCC, and parents' role has changed from that of visitors to partners in care (Dokken and Ahmann 2006). Research reveals positive outcomes of FCC: shorter hospital stays, fewer readmissions, enhanced breastfeeding outcomes, reduced parental stress, increased parental confidence after discharge, more successful bonding, and increased staff satisfaction (Malusky 2005, Dunn et al. 2006). Despite today's acceptance of family-centred care as crucial to the care of children, current studies describe various challenges in the implementation of FCC into nursing practice (Galvin et al. 2000, Letourneau and Elliott 1996, Lansberry and Richards 1992, Turrill 1999, Bruce and Ritchie 1997, Trivette et al. 1993, Darbyshire et al. 1994, Coyne 1996, Shields et al. 2006, Shelton and Stepanek 1995, Nethercott 1993). It is obvious that cooperation, collaboration, and negotiation are not always evident in the care, and the provision of support for parents may at times be inadequate.

3.1   From a philosophy to nursing practice

Shields et al. (2006) define FCC as "a way of caring for children and their families within health services which ensures that care is planned around the whole family, not just the individual child/person, and in which all the family members are recognized as care recipients" (p. 1318). According to this definition, parents are not only granted their rights as parents, but together with other family members they are seen as receivers of care. Being both relatives and receivers of care indicate a possible role conflict, something which Shields et al (2006) illustrates by emphasizing negotiation between staff and families, and the importance of both nurses' and parents' roles as main factors influencing the delivery of FCC.

There have been several attempts to develop the philosophy of FCC into a theory and a guide to clinical practice. Hall (2007) has attempted to develop the philosophy of FCC into a Theory of Family Professional Dynamics (TFPD). TFPD is put forward as a theory where philosophical and empirical facets together help disclose the complex dynamics of paediatric care. According to Hall (2007) the family dynamics, professional dynamics, and family-professional dynamics contribute to parents' wellbeing when guided by the inter-related phenomena caring, knowing, mutuality, and pleasant tone.

To better understand implementation of FCC Malusky (2005) has presented a hierarchy to describe the development of the parent-nurse relationship and how FCC in its fullest sense may only be implemented in certain cases. The lowest hierarchical level is *parental involvement*: on this level parents feel involved in what is happening to their child, and their role is to give their child emotional support and care, and to be their child's advocate. The parent-nurse relationship and communication is nurse led, with primarily the nurses providing information. The second level is *parental participation*, with parents as voluntary participants and where nurses tend to be gatekeepers. The sharing of knowledge and the establishment of rapport are essential, and the relationship becomes more collaborative as parents are actively deciding what care they do or do not want to provide. On the third level, *partnership with parents*, parents are empowered to give care while the nurses' role is to be supporters, advisors, and facilitators. With the increasing recognition of parents' equal status, negotiation of roles becomes important. As parents gradually take on more responsibility, it is important that nurses ensure that they are given breaks and adequate time to rest. *FCC* constitutes the highest level which is led by the parent/parents and characterized by mutual respect and the involvement of many family members. The nurse is counsellor or consultant, and parents have become experts in all aspect of their child's care.

This American philosophy has been implemented and adapted throughout the world, and the need to translate the philosophy into specific nursing practice and into various settings is evident. Using the FCC to approach families of for example chronically ill children, is different from in acute care settings, and institutional settings are different from those of private homes (Shelton 1987, MacKean et al. 2005, Nethercott 1993, Trivette et al. 1993, Letourneau and Elliott 1996, Johnson 2000b, Hutchfield 1999, Malusky 2005, Darbyshire 1995, Brown et al. 1991, Bruce and Ritchie 1997, Galvin et al. 2000, Johnson 2000a, Johnston et al. 2006, Peterson et al. 2004). The list of hospitals integrating family-centred principles into their standard practices and guidelines is growing, although transference of FCC philosophy and its practice from one setting into another may be complicated (Trivette et al. 1993, Letourneau and Elliott 1996, Dunn et al. 2006, Shields and Tanner 2004). Critical questions have been raised concerning whether the implementation of FCC is guided by professionals' understanding rather than by and as a result of collaboration with parents (MacKean et al. 2005). Conflicts may also arise between the traditional professional

role and family-centred care (Kirk 2001, Coyne and Cowley 2007, Letourneau and Elliott 1996, Fenwick et al. 2001).

Tools have been developed for the implementation, evaluation and improvement of FCC practice. Dunn et al. (2006) produced an innovative Web-based family-centred care map to enhance the ability of health care teams to coordinate and deliver care to families in a holistic manner, to meet their developmental, physical, and psychosocial needs. Hanson and Randall (1999) suggested several tools for the evaluation and improvement of FCC practice: written surveys and checklists, guidelines for focus groups or interviews, suggestions of how to use health care scenarios to gather information about family-centred approaches to care, and questions to help nurses reflect upon their practice.

3.2   Summary

In this chapter I have described the development of neonatal care to illuminate how changing perspectives on children's needs has had great impact on parents' involvement. The philosophy of FCC developed in the context of children with learning disabilities have been transferred to various settings, and FCC characterized by parent-nurse mutuality and collaboration is today permeating neonatal care. Despite the consensus of FCC there is a growing amount of research revealing its complexity, and issues like role conflicts and lack of negotiation are described.

4.0   SCIENTIFIC APPROACH AND RESEARCH METHOD

The study here presented has an explorative design based on Gadamer's (1989) philosophical hermeneutics. Semi-structured interviews and observations have been utilised in my ethnographic fieldwork to obtain in-depth insights into the development of relationships between parents and nurses in a NICU (Erlandson et al. 1993, Lincoln and Guba 1985).

The aim of this study has been twofold: Firstly, to discover how the participants – mothers, fathers and nurses – experience their reciprocal relationships. Secondly, to explore how the relationships between nurses and parents develop throughout the infant's hospital stay. An explorative design was chosen, and the research questions developed at the beginning of the study were open in character:

1.   What characterizes the relationship between parents and nurses from the infant's birth to discharge from hospital?
2.   How do mothers, fathers and nurses experience this relationship?
3.   Is there a difference in mothers' and fathers' experiences of the relationship?
4.   What characterizes the nurses' experiences of the relationship with parents of prematurely born infants?

Below research design and methodological approaches are presented, followed by a description of the research process.

4.1   Gadamer's philosophical hermeneutics

Hermeneutics, known as the art of interpretation, stems from the 17th century as a method to interpret biblical and classic texts (Gadamer 1989). The terms hermeneutics and phenomenology are often used interchangeably (Dowling 2004). However, while phenomenology has its focus on a person's lived experience and on commonalities and shared meanings, hermeneutics assumes that human beings experience the world through language, and that this language provides both understanding and knowledge. Phenomenology has developed into two different understandings: *descriptive*

phenomenology and *hermeneutics*, also called interpretive phenomenology (Benner 1994, Dowling 2004, Moran 2000). Descriptive phenomenology, also referred to as objective hermeneutics, is guided by the work of Husserl (1859-1938) where bracketing of one's fore-knowledge is used to obtain the desired goal of objectivity in interpretation. Heidegger (1889-1976) was critical to Husserl's fundamental emphasis on description rather than understanding. Instead of striving to maintain objectivity, Heidegger developed a form of hermeneutics where the aim is to uncover hidden meanings and to clarify under what conditions understanding occurs (Dowling 2004). This study is based on a hermeneutic tradition boardering on interpretive phenomenology.

As a student of Heidegger, Gadamer (1900-2002) developed Heidegger's hermeneutics further. Through his book *Truth and Method* (1989) Gadamer placed hermeneutics at the very centre of contemporary philosophical debate. The two central positions of hermeneutics advanced by Gadamer are *prejudgement* and *universality* (Dowling 2004). Prejudgement is our horizon of meaning that is part of our linguistic experience, referring to the historically and culturally produced pre-understandings which both enable us to understand and limit our understanding of people. Universality means that those who express themselves and those who understand that which is being expressed are related by a common human consciousness which makes understanding possible (Gadamer 1989).

The circular process of interpretation within hermeneutics, the so-called hermeneutic circle, is a dialogical approach whereby the horizons of the interpreter and of the person being interpreted are fused. Understanding is developed through personal involvement in a reciprocal process of interpretation, inextricably linked with one's being-in-the-world (Spence 2001). Rather than a methodological circle, the hermeneutic circle is the ontological structure of understanding (Gadamer 1989).

4.2   Ethnographic approach

To explore and interpret parents' and nurses' behaviours in the NICU an ethnographic approach was chosen. Ethnographic research approaches are derived from anthropology's tradition of interpreting the processes and products of cultural behaviour. For the

ethnographic researcher to identify issues that emerge within the focus of the inquiry she must overtly or covertly involve herself in people's lives over an extended period of time (Lincoln and Guba 1985, Hammersley and Atkinson 2007, Tedlock 2000).

What differentiates ethnography from positivistic inquiries is its fundamental reflexivity, acknowledging that the researcher will never be neutral but rather be a participant in the social setting studied (Lincoln and Guba 1985, Hammersley and Atkinson 2007). The ability to act in the social world and simultaneously be able to reflect upon our own being-in-the-world and actions as objects in that world is essential. As the researcher by her participation is the research instrument per se, to clarify one's pre-understanding and perspectives are an important and necessary part of the interpretation process. The challenge is *whether* one's pre-understanding can be made conscious, and *how,* and to acknowledge one's pre-understanding's influence on one's interpretation (Erlandson et al. 1993, Hammersley and Atkinson 2007, Thorne 2000, Nyström and Dahlberg 2001, Dowling 2006a).

Epistemological reflexivity is also evident in Gadamer's philosophical hermeneutics as understanding is derived from a human being's personal involvement in reciprocal processes of interpretation related to one's being-in-the-world (Gadamer 1989). The researcher will bring her pre-understanding into the situation, and will influence and be influenced by the social phenomenon studied. Hence, the researcher has an active role to play within the research focus, and a systematic exploitation of this participation provides a crucial contribution to the accounts that are being produced about the social world studied (Erlandson et al. 1993). To find the right questions to ask the historically effected consciousness is, according to Gadamer (1989), to recognize that understanding becomes a scholarly task only under specific circumstances and that it is necessary to recognise these circumstances as being hermeneutical.

5.0   IMPLEMENTATION OF THE STUDY

The study's 27 weeks of field research were conducted over two periods: From October 2003 until March 2004, and from September until November 2004.

5.1   Setting

The fieldwork was conducted in a 13-bed NICU at a Norwegian hospital. The unit is a regional centre for treatment of premature infants down to a minimum of 26 weeks gestational age, with an average number of admissions of 350 patients per annum. Most infants are admitted directly from the hospital's maternity ward; the rest from the postnatal ward, or from home. In 2007 12 % of all newborn infants in this hospital were transferred from the maternity ward or post-natal ward to the NICU for observation or treatment. The unit consists of two incubator rooms for the most critically ill infants, two bedrooms for infants in need of less surveillance, and three parents' rooms in addition to staff and utility rooms (medication room, nurses' and physicians' rooms et cetera). The NICU is organized in primary nursing care groups. Each family is allotted a team consisting of two-three nurses, an auxiliary nurse, and a physician as their primary caregivers.

5.2   Participants

The selection process reflects the wish to obtain relevant data by including parents and nurses who could provide rich information about the parent-nurse relationship in the NICU. A convenience sample of parents was obtained based on the following inclusion criteria:

1. Their infant's gestation age should be 32 weeks or less. The aim of the project was to focus on families who had to stay in hospital for an extended period of time. A rough thumb rule for expected length of premature infants' hospital stay is discharge around the date of full term birth. A low gestational age was therefore chosen.
2. Their infant stayed in this hospital from birth until ready for discharge to home. The aim of this study was to follow the family from birth until discharge. Infants born in other

hospitals, or those who were transferred to other hospitals before discharge to home, were not included.

3. A two parent family. This study's focus was on both mothers and fathers. As all infants meeting the inclusion criteria had two parents, no family was excluded on account of this criterion.

4. Both parents must agree to participate in the study. One parent did not want to participate due to language problems, and this family was therefore excluded.

All couples who met the inclusion criteria were consecutively invited to participate in the study. The inclusion process continued until redundancy of information was reached (Sandelowski 1995, Erlandson et al. 1993). Six out of eight couples agreed to participate, and these were given further oral and written information (attachment 3), and informed consent was obtained (attachment 5). In table 1 parents' background data are presented:

Table 1: Parents' and infants' background data

Parents' demographics (mothers n=6, fathers n=6)

Mothers	25-42 years (median 31, 3)
Fathers	27-59 years (median 36, 1)
Mothers' education	
High school	2
College/university	4
Fathers' education	
Elementary school	4
High school	2
College/university	0

Infants' demographics (n=7)

Length of hospital stays	4-12 weeks (median 7)
Gestation age range	28-32 weeks (median 30)
Birth	
Caesareans	4
Vaginal births	2
Gender	
Girls	4
Boys	3
Single/twin births	
Twin birth	1
Single births	5

A convenience sample of Registered Nurses was obtained based on the following inclusion criteria:

1. Every nurse should be primary caregiver to one of the included families. The unit's more experienced nurses were given the responsibility for the youngest premature babies. As I wanted to include the nurses most able to supply me with rich data about the parent-nurse relationship, this inclusion criterion was chosen.

2. The nurse should have worked in the unit for at least one year. A presumption was that experienced nurses familiar with the unit's high-tech environment and able to focus on both the baby, the instrumental tasks, and the parents' needs would be best able to supply rich data about the parent-nurse relationship. A minimum one year experience stipulation was therefore chosen.

3. The nurse should work at least half time (50 %) in the NICU. As many of the more experienced nurses did not work full time, a 50 % minimum was chosen.

The nurses were informed about the project and their role as potential participants in a meeting in the NICU in May 2003 (attachment 4). Nurses who met the inclusion criterions were invited to participate, and informed consent was obtained (attachment 6). In table 2 nurses' background data is presented:

Table 2: Nurses' background data

Nurses' demographics (n=6)

Age	29-44 years (median 34, 5)
Work experience from NICU	2-12 years (median 5, 75)
Gender	
Female	6
Male	0
Further education	
Paediatric nursing	2
NIDCAP®* observer certification	1
Supervision pedagogy	1
None	2

* Newborn Individualized Developmental Care and Assessment Program

5.3   Researcher's role

As a contrast to classical ethnography, where the researcher endeavours to adopt an objective position, there is today an increased focus on the researcher's participating role and a recognition that the observer and the participant perspectives may be harmonized and together construct the ethnographic 'truth' (Angrosino and Mays De Perez 2000). The harmonisation of the two perspectives presupposes that the researcher is in a dialectic relationship with the participants, and that there is a vacillation between participation and an analytic reflective distance (Hammersley and Atkinson 2007). The reflective character of ethnography makes it crucial to clarify the researcher's pre-understanding and perspectives to ensure open-minded data collection and analysis (Angrosino and Mays De Perez 2000, Fontana and Frey 2000, Gadamer 1989, Nyström and Dahlberg 2001). My pre-understanding was influenced by my experiences as a RN from 1979 to 1992, working with infants and their parents in various paediatric and neonatal units. I had furthermore studied parent-nurse interaction both theoretically and empirically through my Master's thesis work (Fegran 1996). I am also a mother of two grown up children.

5.3.1   Peripheral-member-researcher role (PMR)

My aim was to adopt a more or less peripheral position to maintain an intellectual balance between over-identification and alienation, and a social balance between being a stranger and a friend. A peripheral-member-researcher role (PMR) was chosen, and by choosing this position I wanted to acknowledge that the insider perspective is vital to form an accurate appraisal of human life (Adler and Adler 1994). By observing and interacting closely with participants one aspires to get an insider's perspective, even though one does not take part in the activities which constitute the core of group membership. During the field work I wore a nurse's uniform, primarily for hygienic reasons, but to fit in as well. I also wore the same kind of identification card as the staff, although my card read "researcher". The nurses introduced me both to staff and parents as "a researcher, but she is also a nurse who used work in this unit some years ago".

There was a need to find a balance between the positions of participant and researcher (Adler and Adler 1994, Kite 1999). I therefore did not assume functional roles within the group since this would make me cross the line into the realm of expertise characterizing

professional nurses (Kite 1999). Crossing this line could have made me loose my analytic distance and hence forgo my role as researcher (Fontana and Frey 2000).

5.4   Data collection

A good qualitative research design implies a set of procedures that are simultaneously open-ended and rigorous, and which do justice to the complexity of a social setting (Janesick 2000).

To be able to understand the experiences of parents and nurses, there is a need to gather data from a variety of sources (Lincoln and Guba 1985, Erlandson et al. 1993). Non-participating observations of various activities in the NICU and individual interviews were the data collection methods chosen (table 3 p. 82). The interviews were conducted consecutively during the field research period. Interview and observation data influenced each other reciprocally as the interviews provided leads for the observations, and vice versa (Borbasi et al. 2005, Erlandson et al. 1993, Janesick 2000). I myself did all transcriptions of data from observations and interviews, which gave a profound insight into and closeness to the extensive data material.

5.4.1   Observations

Through observations one gets insight into the participants' world, and to capture the interaction between the parties in real time and to grasp what is going on in this specific setting one has to live according to the participants' time frames (Janesick 2000, Erlandson et al. 1993). Over the 27 weeks of data collection I spent 160 hours of field work in the NICU.

Data collection started when the infant was transferred to the NICU and placed in an incubator in one of the surveillance rooms, and continued as the infant was moved to a bedroom to prepare for discharge. The surveillance rooms contained up to six incubators, and with chairs and bedside tables and surveillance equipment these rooms could be very crowded. The smaller bedrooms could take two beds if needed, however this left little room

for parents. During observations I placed myself on a chair in the periphery of the room to be able to observe and hear what was going on without disturbing the interaction.

The main data collecting focused on the parents' involvement in the infant's nursing care, feeding times, and their giving their infant closeness and physical contact. Most parents were present in the NICU between 10 am and 15 pm, and after a break they came back between 18 pm and 21 pm. Parents who lived in the vicinity of the hospital went home to rest and sleep, while the others stayed either in a parent room in the NICU or in an apartment on the hospital precincts. As the infant stabilized one parent was usually present in the morning while both parents and the child's siblings visited in the afternoon. Observations were conducted both during the day and in the evening to grasp these various patterns.

In addition to observations of the parent-nurse interaction the nurses' oral joint report at change of shifts were observed. I wanted to learn whether and how the parent-nurse relationship was a topic at these reports. As it turned out, the main focus at these reports appeared to be on the baby's condition. Instead parental issues were handled at the patient's bedside as the nurse who was leaving reported to the nurse coming on duty. Also these individual reports were part of my observational data. I also attended parent-nurse meetings as I expected these meetings to deal with various issues concerning the parents' presence and overall situation. However, the main issues at these meetings were nurses informing the parents about their legal rights while in hospital. Also these data became a part of my field notes and were transcribed.

I structured my field notes according to a schema that included setting and participants, activities and interactions, as well as frequency and duration (Emerson et al. 1995). While this was helpful in the beginning, a less structured format turned out to be more practical after a while.

I wrote my field notes while I was sitting in the room observing. In the beginning the field notes were brief and in a keyword format, but gradually I developed wordier field notes with much thicker descriptions of my observations and more penetrating reflections thereof (Erlandson et al. 1993, Emerson et al. 1995). It was crucial to use all my senses and truly observe, listen, smell, and feel the surroundings and the interactions; to the best of my

ability to grasp what it actually was like for the participants to be in that particular situation. After every session the field notes were elaborated and structured as descriptive notes, and transcribed together with my theoretical and methodological reflections.

5.4.2 Interviews

Individual retrospective interviews of mothers and fathers were planned conducted in connection with their infant's discharge from hospital. Even tough it was difficult to schedule interviews ahead of time due to the infant's unpredictable progress, both parents and nurses attempted to keep me informed if discharge had been moved forward due to a baby's quick recovery. Both nurses and parents did their best to make sure that interviews would not fall through. One of the babies, however, was unexpectedly discharged over the weekend before a time for an interview was set. This interview had to be performed after discharge.

At the beginning of the interview parents were asked about their experiences of becoming mother or father to a prematurely born infant. Their respective roles in the NICU were furthermore addressed as well as their views on their relationship and collaboration with the NICU staff, particularly their relationship with the nurses both as professionals and as individual human beings with their personal feelings and reactions, and their development of rapport with the nurses during the hospital stay. The interviews were audio-taped and conducted in a separate room in the NICU; each interview lasted an average of 40 minutes.

The interviews with nurses were conducted during the hospital stay of the infant who was their primary care responsibility. These interviews addressed their experiences working with parents in the NICU in general. Initially nurses were asked what characterizes being a nurse in a NICU. Questions then addressed how nurses perceive their role in the NICU, the relationship between their professional and personal identities in their collaboration with parents, and the development of rapport with parents. Also these interviews were audiotaped and conducted in a separate room in the NICU. Each interview lasted an average of one hour.

For the researcher there is always a question of whether transcriptions should be conducted verbatim or whether to adopt a more fluent language rendering of what was being said. The

main issue here is to report what was being said in interviews correctly to avoid that intended meanings changes through the transcription process or through the presentation of quotations when taken out of their original context (Spangen 2007). I have endeavoured to keep my transcriptions true to the interviewees words and to present data as close to this raw text as possible. Repetitions and superfluous words were removed to present a more fluent language. Some places explanatory words are added and marked in the text with brackets: "( )". During the interviews the participants often stopped to think, and these pauses are marked as "…". As the transcribed texts were analysed in their original Norwegian linguistic form, it has been important to execute good and correct translations true to the original words and meanings in the quotations that are being presented in the English language papers.

5.5   Analyses

All field notes and reflective notes concerning substantial and methodological issues were transcribed consecutively, as were the taped interviews of mothers, fathers and nurses. As is common in ethnographic research the analytic process started as a dialectic process between this data collection and reflections on the findings (Erlandson et al. 1993).

Through this dialectic process certain issues come to the fore and become prominent, and these issues give rise to new questions for later interviews and new things to look for during observations (Hammersley and Atkinson 2007). An example of this was parents' experiences of the emotional and physical burden of having a child hospitalized for weeks and months. During interviews I understood that parents experienced the stabilizing phase as demanding, as many of them reacted with strong emotions like bursting into tears when they talked about it. This was added to the list of issues to look for during observations, and in this way new data about the stabilizing phase gave new insights and extended prior knowledge as discussed in paper III.

In the same way as some observation themes grew out of interviews, some issues became prominent during observations and were elaborated on in the semi-structured interviews. One example is observations of fathers' comprehensive skin-to-skin contact with their infant immediately after birth, while mothers' health condition seemed to inhibit them from being

in close proximity with their infant. These findings resulted in an increased focus on parents' individual experiences of the early attachment process during the following interviews.

I continued the analysis of parents' different experiences of the attachment process after the data collection was completed. To compare mothers' and fathers' experiences I decided to analyze the interview question "Could you tell med about your experiences of becoming a mother/a father to a prematurely born baby?" combined with data from the fieldwork. Through the use of NUD*IST QSR software (N6 Full version Copyright © QSR International Pty Ltd 1999–2002) transcribed data from interviews and observations were split into free nodes (meaning units). These free nodes were then grouped into a hierarchical index tree providing an outline of all the category levels. The analysis continued until I reached a stable set of categories. The categories were then given names or labels which as closely as possible mirrored their content. Some of the labels stem from concepts found in the raw data, while others were formulated by me. The two categories 'taken by surprise' and 'building a relationship' confirmed, as presented in paper II, the striking difference in mothers' and fathers' experiences. This approach enabled me to pursue this issue which had emerged through dialectic interpretation, and it also gave a smooth start and a step-by-step approach to the process of analysing the entire data material.

After initially having analysed only a part of the data I continued the analytic work by systematically analyzing the entire supply of data from interviews and field work. I listened through the audio taped interviews several times as well as read the transcriptions of interviews and fieldwork several times before I made condensed versions of the material. Themes that emerged were: involvement, trust, unpredictability, strain, protection, normalizing, and appearance. These themes gave insights into how the parent-nurse interaction was experienced.

After having condensed the data I analyzed the entire supply of data using the NUD*IST QSR software, and the two main categories *interaction* (with subcategories 'anticipations', 'roles', and 'increased responsibility') and *trust building* (with subcategories 'respect' and 'taking care of'), gave an overall picture of relationships and interactions.

After having split the text into nodes and categories I needed to draw back and look beyond – or above – the structured categories to gain a comprehensive perspective on the parent-nurse relationship (Gadamer 1989, Nyström and Dahlberg 2001). As in the analytic process, the writing of papers about my findings grew out of a dialectic process between the initial open research questions, the transcribed and condensed texts, and the node tree. When writing my papers I focused on themes, utilising data from several categories, rather than on presenting main- or subcategories.

1. The explorative question "What characterizes the relationship between mothers, fathers and nurses from the infant's birth till discharge from hospital?" is an open one, and the focus concerning this question evolved throughout the analytic process. Step by step a description of three phases characterising the parent-nurse relationship grew out of the analytic work, with the stabilizing phase receiving the most attention (paper III).

2. The open question "How do mothers, fathers and nurses experience the relationship?" was focused through a discussion of the development of neonatal care from an ethical and historical angle. The presentation of the history of neonatal care was meant as a backdrop for current practices and challenges (paper I).

3. The open research questions produced at the beginning of the study became more focused during the analyzing process: The question "Is there a difference in mothers' and fathers' needs and experiences of the relationship?" was focused by discussing the parents' attachment process. The greatest difference between mothers' and fathers' needs came to the fore through the study of their individual attachment process. In the same way as these findings were striking, it is striking that hardly any research has been published on this issue (paper II).

4. Through the exploration of the question "What characterizes the nurses' experiences of the relationship with parents of prematurely born infants?" it became clear that for nurses a prominent issue was to find a balance between a professional and a personal relationship with parents (paper IV).

During data collection and analysis comprehensive transcription files, data reduction files and data reconstruction files were created. The comprehensive transcription files contained data from interviews, observations and informal conversations. Data reduction files contained condensed data from the transcribed texts, and finally some files included

NUD*IST analysis with Node summary and Node trees to visualize the different nodes and their interrelationships.

5.6   Ethical considerations

The study observes the ethical principles of the Declaration of Helsinki (World Medical Association 2004). The study protocol was approved by the Regional Committee for Medical Research Ethics (attachment 2), the Ombudsman for Privacy in Research at the Norwegian Social Science Data Services (attachment 1), and the hospital's research department.

5.6.1   *The peripheral-member-researcher role (PMR)*

Ethical issues arising in ethnography are primarily those concerning the behaviour of the researcher and its consequences for the people studied (Hammersley and Atkinson 2007, Lowes and Gill 2006). As the researcher is 'the research instrument', the participants' welfare was seriously considered throughout the project.

Balancing between closeness and distance during the field work became a central issue. As I was present in the intensive care room at regular intervals for weeks I became a familiar person to parents. The PMR role had been clarified before commencement of the data collection periods, but this clarification had to be repeated during the field work. When parents started to ask me about my opinion concerning things like breastfeeding and nursing care, I would assist them acquire help from nurses while reminding them of my observational role. Maintaining an observer role emphasized the need to stay in the periphery of the room during observations.

Respecting the participants' privacy was an important issue during data collection (Erlandson et al. 1993, Hammersley and Atkinson 2007). Parents staying in the NICU find themselves in a crowded room together with other families and professionals. On top of this I was present as a visitor and a spectator. However, my being an observing participant situated apart from the ongoing work and interactions, but close enough to hear and see what was going on, seemed to be in accordance with parents' need of privacy. Sometimes nurses would put up a folding screen to give parents more privacy in the overcrowded room. As a 'visual outsider' I was able to hear what was going on while still respecting parents' need for privacy

Ethical sensitivity is an obligation when one observes and interviews people in marginal situations. An important issue is the interrelationship between what I see and what I write down, and how I handle the acquired data (Emerson et al. 1995). Situations may arise when the researcher should consider moving from her passive research's role into an active role if there is a need of action to protect participants from harm or negative influence (Hammersley and Atkinson 2007). My role was to observe parents' and nurses' interactions, which made me discover and reflect on things which could be missed by the nurses. I once experienced a situation where I chose to intervene because I feared that not passing on what I saw would be harmful to those involved. I decided to inform the Head Nurse about my observations, and this led to a new and different approach towards one of the families. Neither the Head Nurse nor any of the nurses discussed this issue further with me.

5.6.2   Informed consent

When I started the inclusion process of parents I began to reflect on how early after the infant's admission parents ought to be asked to give their informed consent. Even though the Regional Committee for Medical Research Ethics allowed me to start my observations on the infant's admission, I decided to let the Head Nurse evaluate when would be the best time to approach parents and take the first contact with them to protect them from possible added distress. This was considered to be less traumatic than to introduce myself and the project when parents' were preoccupied with their infant's survival, and besides, valuable information would have been lost if I had not taken field notes from the very beginning. On a few occasions parents were observed for some hours before they had given their informed consent, in which case field notes would have been deleted if they had refused to participate. None of these parents did refuse to participate.

Parents and nurses received oral and written information about the project and what their participation would imply, including their right to withdraw at any time. As the research context and the infant's condition were constantly developing and changing, it was difficult to discuss the implications with the participants in full at the beginning of the study (Erlandson et al. 1993). The participants were therefore encouraged to ask clarifying questions concerning their informed consent at any time during the project, and both parents and nurses asked explanatory questions. None of the participants chose to withdraw after having been included in the study.

Data were anonymized and transcripts coded by naming participants children 1-6, mothers 1-6, fathers 1-6 and nurses 1-6. The admission and discharge date of each child were registered, but these data are not connected to other identifiable patient data (table 3 p. 82).

Data have been treated confidentially. Audio-taped data were transferred electronically in vocal form to my computer and transcribed. The audio files were deleted after data had been transcribed and analyzed. Transcribed data were stored on my personal computer in my locked office, and separate passwords were needed to open the computer and the documents. Transcripts will be destroyed when the doctoral degree is awarded.

5.7 The study's trustworthiness

A study's trustworthiness depends on whether one has adopted research strategies that safeguard that the study and its findings remain as close to the 'real world' as possible. The research process should be explained in such a way that the reader is enabled to assess whether the methods used and the findings arrived at seem apt, logical, and believable. This is done through steps that ensure credibility, applicability through transferability, consistency through dependability, and neutrality through confirmability (Lincoln and Guba 1985, Erlandson et al. 1993).

5.7.1 Credibility

Through prolonged engagement, persistent observations, triangulation, peer debriefing and members checking credibility is secured (Erlandson et al. 1993).

Twenty-seven weeks of observations enabled me to learn to know the NICU culture over an extended period of time. As these 27 weeks were spread over a one year period, this made me able to identify variations within the culture. Some periods were busy and the unit overcrowded with patients and parents. At other times there were few infants in the unit, although one critically ill infant could make the unit at least as busy as when the unit was filled to capacity. There were also seasonal variations, for instance spring being a time for many births.

Prolonged engagement enabled me to build a trusting relationship and rapport with the nurses. Although my primary placement was inside the incubator rooms, I was for instance invited by the nurses to enjoy a cake which was a present from some parents or to eat my lunch together with them. These occasions were used as opportunities for informal conversations on issues near to their heart, and these discussions were as windows into their life in the NICU.

I also developed rapport with parents during their many weeks in the hospital. While the nurses usually had several children and parents to take care of I could concentrate on specific parents, which made me a familiar person to parents. I used to say hello when I arrived in the unit and asked how things were and showed interest in their infant's development. Sometimes I spent time alone with parents because the nurses were busy in another room, and this opened up for light conversations which appeared to have an ice-breaking effect and to make my presence more harmless. However, when parents and nurses interacted I assumed the observer role sitting at the periphery of the room observing and making field notes. Physical distance and not to participate in nursing tasks were important to keep a certain physical and emotional distance in the NICU rooms.

Persistent observation was used to actively seek out sources of data identified by the emergent research questions. I tried to anticipate and be present in situations where parents' and nurses' collaboration was focused. Although the incubator rooms became my main arena for observations, I moved to bedrooms with less professional surveillance and more parents' responsibility when the participating infants were transferred there. This gave me information about the development of the nurse-parents relationship and the detachment process prior to discharge (paper III). In addition observations of oral nursing reports and parents-nurse meetings were performed to broaden the picture of the parents-nurse interaction.

Triangulation leads to credibility by the use of multiple data sources and/or multiple research methods (Lincoln and Guba 1985, Erlandson et al. 1993). The inclusion of both parents' and nurses' perspectives (6 mothers, 6 fathers and 6 nurses), and different data collection methods as prolonged and persistent observations combined with individual in-depth interviewing were used to ensure this project's credibility (Lincoln and Guba 1985).

My open research approach facilitated multiple perspectives of interpretation. Rather than to hunt for anticipated issues I chose to pose open research questions to be able to recognize issues in the 'real world' which appeared to be essential, and to pursue these further. Through the data collection parents' and nurses' experiences of the demanding aspects of their relationships were discovered. This lead to a thorough exploration of both theoretical and empirical knowledge on the issues at hand, revealing the emotional labour and commitment experienced in such prolonged relationships (paper IV). This perspective may not come to the fore if my pre-understanding and prejudgements alone had guided the direction of my study, but became pivotal due to the multiple perspectives that developed during the project.

Peer debriefing helps build credibility by allowing an outsider who is also a professional peer analyse the data material and critically discuss design, research methods and findings (Lincoln and Guba 1985, Erlandson et al. 1993). During the planning, implementation, analysis and writing phases the project was regularly discussed with my supervisors. Findings were furthermore presented and discussed with other peer groups at university seminars and at international conferences. But perhaps the most critical peers were the reviewers of the international scientific journals where my papers were published. To critically reflect over their feedback on submitted manuscripts improved these texts' clarity and trustworthiness.

In qualitative research members checking increases a project's credibility by allowing members of stakeholder groups test the results (Barroso and Sandelowski 2003, Lincoln and Guba 1985). Even though testing of qualitative findings is not feasible in the positivistic sense, I checked with participants whether I had understood them correctly during the individual interviews, and I would ask them to elaborate points when this seemed necessary. At the end of interviews I always asked whether there were issues they would like to talk about which had not been touched upon during our talk, or if they wanted to add anything before we concluded the interview. Some of the parents said they would like to express their satisfaction with their infant's hospital stay, and they almost felt guilty if they had said anything negative about the hospital or caregivers – overall they expressed gratitude and that they were very satisfied. Other than this they had little if anything to add, also after the tape recorder was turned off. I also used the opportunities opened up by informal

conversations during observations to ask nurses and parents about certain issues, and in accordance with the participants' agreement also these talks became part of my field notes.

During the data analysis period after the conclusion of the empirical work, I repeatedly presented my thoughts and findings at NICU nurses' meetings, and through these discussions findings were validated and elaborated.

5.7.2   Transferability

Transferability depends upon the degree of similarity between two or more contexts, and hence an inquiry is judged according to what extent its findings can be applied in diverse but similar contexts or to different people similarly placed (Lincoln and Guba 1985, Erlandson et al. 1993). Thorough descriptions enable readers to be active assessor of the study by being informed step-by-step about background ideas, choices made throughout the process, why these particular choices were made, and what consequences they had on findings. These descriptions attempted to enable the readers to follow and assess the research process in light of what actually took place in the described setting(s) during the inquiry. Descriptions of the research process presented in chapters 5.1 to 5.6 are aimed to clarify the process and thereby the study's transferability.

Purposive sampling is governed by the need to acquire rich data, seeking out both typical and divergent information. The sample of nurses were by and large quite homogenous, although there were differences in the respective nurses' ages, education and experiences. The parents constituted a somewhat more homogenous group apart from variations in age and in number of children in the family. Even so, there were some 'extreme cases' within the group of participating parents which helped broaden our understanding of parents' experiences.

5.7.3   Dependability and confirmability

A study's dependability refers both to the stability and the trackability of explainable changes (Lincoln and Guba 1985, Erlandson et al. 1993). Maintaining a running log on decisions made during the project to clarify the steps taken and changes made to the original plan, increased this study's dependability and confirmability. In addition to creating the

transcription data files, the data reduction files, and the data reconstruction files, the findings were discussed, analysed and reanalysed in drafts, presentations of findings in essays with different perspectives (research philosophy, methodology, and nursing science), and papers submitted to journals. Thorough descriptions of the setting, the inclusion process, and the data collection and analytic process increase the study's confirmability even further (Erlandson et al. 1993).

Rather than aiming at objectivity, this study focuses on how findings may be tracked back to their sources, and whether interpretations of findings are logical (Erlandson et al. 1993). After the analytic work was concluded I offered to return to the unit to share my findings with them, and I have been regularly asked to come back to discuss my findings. These meetings have created a well-founded link between clinical nursing practice and my research, and the nurses have told me that they find these dialogues rewarding and educational. Perhaps the most important response I got was when nurses in the NICU told me: "yes, you are probably right and your findings seems true, however we have never seen it that way before." Presenting the results not only gave me new insights, it also helped the nurses develop their nursing role.

5.7.4   Reflexivity

Reflexivity increases a study's credibility, and may be divided into two forms: personal and epistemological reflexivity (Dowling 2006a). Personal reflexivity is self-awareness regarding the relationship between the researcher and the environment studied, which involves an intersubjective process of tension between oneself as subject and an object as discussed in this chapter. The ongoing vacillation between in-depth scrutiny and a bird's-eye view of the nurse-patient relationship has been necessary and rewarding.

Epistemological reflexivity addresses the researcher's reflections on epistemological questions about the world and about knowledge. What do nursing research and my present findings tell about the parent-nurse relationship in NICU's, and how do they compare with my personal experiences? This reflexivity functions as a hermeneutic circle, describing how the researcher is influenced and influences both the research setting and results (Gadamer 1989).

To visualise and critically discuss the research process as I have done in this chapter, contribute to this study's trustworthiness.

6.0   FINDINGS

6.1   Paper I: Nurses as moral practitioners encountering parents in neonatal intensive care units

Abstract

Historically, the care of hospitalized children has evolved from being performed in isolation from parents to a situation where the parents and the child are regarded as a unit, and parents and nurses as equal partners in the child's care. Parents are totally dependent on professionals' knowledge and expertise, while nurses are dependent on the children's emotional connection with their parents in order to provide optimal care. Even when interdependency exists, nurses as professionals hold the power to decide whether and to what extent parents should be involved in their child's care. This article focuses on nurses' responsibility to act ethically and reflectively in a collaborative partnership with parents. To illuminate the issue of nurses as moral practitioners, we present an observation of contemporary child care, and discuss it from the perspective of the Danish moral philosopher KE Løgstrup and his book *The ethical demand.*

6.2   Paper 2: A comparison of mothers' and fathers' experiences of the attachment process in a neonatal intensive care unit

Abstract

The aim of this article was to compare mothers' and fathers' individual views and experiences of the attachment process in a neonatal intensive care unit within the first week after a premature birth. The attachment between parents and children is a precursor to the consolidation of parenting skills, the growth and development of the infant and the establishment of a bond between parent and child. Premature birth and the resultant hospitalization disrupt the normal attachment process between parent and child. Most of the literature on attachment theory focuses on the mother–child connection and is being criticised for regarding the father's role as supportive and peripheral. The design of this study was descriptive with a hermeneutic approach. Twelve parents (six mothers and six fathers) in a 13-bed neonatal intensive care unit in a Norwegian regional hospital participated in a field study addressing the encounter between parents and nurses. This paper is based on the semi-structured interviews with the parents at discharge. The interview analysis revealed two main categories. (a) Taken by surprise: For mothers, the premature birth created a feeling of powerlessness and they experienced the immediate postnatal period as surreal and strange. The fathers experienced the birth as a shock, but were ready to be involved immediately. (b) Building a relationship: Mothers experienced a need to regain the temporarily lost relationship with their child, whereas the fathers experienced the beginning of a new relationship. Comparing parents' experiences of the attachment process within the first days after a premature birth reveals a striking contrast between the mother's experience of surrealism and the father's ability to be involved immediately after birth. Relevance to clinical practice: parents' of premature children's different starting points should be acknowledged as professionals encourage parents to have early skin-to-skin contact with their premature infant.

6.3 Paper 3: Development of parent–nurse relationships in neonatal intensive care units – from closeness to detachment

Abstract

The aim of this study was to explore the development of relationships between parents and nurses in a Norwegian Neonatal Intensive Care Unit. As increasingly smaller premature children survive, the prolonged hospitalization that follows makes the relationships between parents and nurses crucial. A collaborative partnership in which all the family members' needs are acknowledged is argued as the best approach. The design was explorative with a hermeneutic approach. The sample consisted of six mothers, six fathers, and six nurses from a 13-bed Norwegian Neonatal Intensive Care Unit. Overt participant observation and in-depth interviews were used to study interactions between parents and nurses. Data were obtained over 27 weeks from 2003 until 2004 during which 18 individual interviews and 160 hours of observation were conducted. The partnership between parents and nurses developed in three phases: the acute critical phase, the stabilizing phase, and the discharge phase. The stabilizing phase seemed the most challenging. As exhausted parents expressed the importance of maintaining the trusting relationship with their primary care nurses to become confident when assuming more responsibility and adjusting to the new situation, the nurses purposely withdrew and reduced their contact with parents facilitating their independence and confidence as caretakers. Parents and nurses seem to rarely discuss with each other the discrepancy in their understanding of the detachment process. Acknowledging the need for parents and nurses to discuss the processes of involvement and detachment may contribute positively to the development of family-centred care in Neonatal Intensive Care Units.

6.4   Paper 4: The parent–nurse relationship in the neonatal intensive care unit context—closeness and emotional involvement

Abstract

Family-centred care, which acknowledges parents as partners in care, is a desirable and essential part of neonatal nursing. There has been extensive research on parents' experiences of parenting in Neonatal Intensive Care Units, but there is little research on nurses' experiences of being in these enduring close relationships. The aim of this paper is to explore parents' and nurses' experiences of the close parent–nurse relationship when a premature child is hospitalized. The design was exploratory with a hermeneutic approach. The methods used were participant observation and in-depth interviews with six mothers, six fathers and six nurses in a Norwegian 13-bed Neonatal Intensive Care Unit. Eighteen individual interviews and 160 hours of observations were conducted over 27 weeks from 2003 to 2004. The study complies with the principles of the Declaration of Helsinki. The Regional Committee for Medical Research Ethics, the Ombudsman for Privacy in Research at the Norwegian Social Science Data Services, and the hospital's research department approved the study protocol. The Neonatal Intensive Care Unit context is a highly technological environment where human interaction is a crucial issue. The character of the context and the ongoing interactions drive parents and nurses into close relationships. Closeness increases the emotional involvement and the boundary between the professional and the personal approach is threatened. The commitment of being close, combined with the emotional involvement, can be an emotional burden to both parents and nurses. Parent–nurse closeness in Neonatal Intensive Care Units is desirable; however, the emotional burden of this closeness seems to be seldom problematized. Awareness about the need to strike a balance between closeness and distance can positively influence parents' independence and nurses' ability to maintain professional relationships with their primary care parents.

7.0   DISCUSSION

In this chapter central issues in the thesis will be discussed. The first part of the chapter will deal with methodological issues, and in the second part the study's substantial issues will be discussed.

7.1   Discussion of methodological issues

The aim of this study was to produce true accounts of the encounters and relationships between parents and nurses in a NICU. To be trustworthy a study must guarantee credibility, communicate findings in a way that enables application, and finally enable its audience to check the process of inquiry and the study's findings (Erlandson et al. 1993). Below methodological issues which strengthen or limit the study's trustworthiness will be discussed.

7.1.1   Setting

The study was conducted in a NICU at a Norwegian regional hospital. The characteristics of this NICU context, a relatively small unit in a European country with middle-class white participants, could possibly reduce the study's transferability to other parts of the world. To increase the findings' trustworthiness the characteristics of the setting have been thoroughly described both in this text's method chapters and by narratives as in papers I and IV.

The fact that this study supports findings of other studies does however increase this study's trustworthiness. This indicates that parents' and nurses' experiences are basic and appear cross-culturally and cross-contextually, like for instance the issues of attachment (paper II) and emotional involvement (paper IV).

7.1.2   Sampling

The sample size in a qualitative study should be judged by the purpose of the sampling and the intended qualitative product (Sandelowski 1995). Obtaining in-depth knowledge of the

parent-nurse relationship was this PhD study's main focus, and the chosen sample size endeavoured to meet this aim. Demographic data were included in order to have coverage of issues that might become important, but only some were followed up during the study (for instance type of birth, age and gender). These decisions could both be a strength and a limitation to the study, and these issues will be discussed further in the following chapter.

Parents

One of the inclusion criterions was that both parents should participate in the study, suggesting that they both were a part of the infant's care team. After inclusion we realized that one father decided not to be present in the NICU. This led to discussions whether it was possible to obtain data about a relationship when one of the participants was absent? As both parents in the other couples were present, this couple constituted extreme or deviant participants, and the inclusion of this couple increased the study's credibility by revealing different ways of coping with the challenges in connection with a premature birth. (Lincoln and Guba 1985, Erlandson et al. 1993, Fangen 2004, Malterud 2002). It also increased credibility as it challenged the researcher's and the nurses' norms concerning parental participation and their ability to respect parents' perspectives and choices (Shields and Hunter 2008, The Institute for Family-Centered Care 2008).

Maternal age at birth in Norway has been increasing continuously since 1975, and in 2004 mothers' average age was 29.6 years and fathers' 33,1 years (The Medical Birth Registry 2006). Due to this study's small sample size one couple's ages increased the average age for both mothers and fathers (table 1, p.16). While the inclusion of parents of various ages increases credibility, it might reduce transferability due to the small sample size (Lincoln and Guba 1985). Furthermore, the absence of adolescent parents may be a limitation as their needs appear to be somewhat different than those of older parents (Letourneau 2001). Parents' and nurses' corresponding ages provide in-depth data on how this may increase nurses' identification with parents which again may increase their emotional involvement, as discussed in article IV. This increases the study's credibility.

Two mothers and three fathers had no previous children while the rest of the parents had one or more children 2-12 years of age, and one of the fathers also had two grown up children. The lack of previous experience may be an extra challenge to first time parents.

Parents with previous children may experience to be pulled between the infant in the hospital and the children at home. The variation in parents' backgrounds increases the study's trustworthiness as the inclusion of both first time parents and those with previous children creates a variation in data concerning parents' endeavour to cope with hospitalization, as discussed in article III. On the other hand the small sample size of parents is a limiting factor and may the reduce transferability of findings.

The study did not include extreme premature infants born before 26 weeks as the youngest child was born at 28 weeks gestational age. The lack of extreme premature infants may prove limiting to the study, but then again no infants were excluded because of low gestational age. If the study had been conducted in another hospital, or extended over a longer period of time, inclusion of younger infants may have been possible. Inclusion of extremely premature infants may have increased credibility by providing further data about issues which concern extreme premature infants (Kent et al. 2007, Schroeder 2008, Miljeteig et al. 2007).

Only four mothers' had education on college/university level. An inclusion of parents with a higher level of education may have influenced our findings concerning active information seeking, coping strategies etcetera. (Lorig 2002, Shaw and Baker 2004).

All the parents except one mother were employed. While fathers had to go back to work after the critical phase was passed, the mothers had maternal leave. Even if mothers' maternal leave favoured their possibilities to be present, the fact that both parents had work outside their home may have contributed to their joint efforts both at home and in the hospital.

The fact that more than half of the births were caesareans may have influenced our findings as a caesarean birth produces a different pattern recovery of the mother than do vaginal births (paper II). The number of caesareans is increasing worldwide, and in 2005 more than 16 % of births in Norway were caesareans (Backe et al. 2003). The increased tendency of caesarean deliveries increases our findings transferability.

No parents withdrew from the study after they had been included. It may be possible that these parents who had their infant hospitalized for weeks experienced an obligation to participate due to their dependency on the required care for the child.

Nurses

Each primary care team responsible for infants less than 32 weeks of gestational age was led by an experienced nurse. The NICU nurses had been informed about the parental inclusion process, and that these families' primary caring nurse would be asked to participate. This gave them a chance to agree or refuse to be chosen as the included parents' primary care giver, and hence to be a participant in the study. All primary caring nurses in question agreed to participate. While this selection process was a strength as motivated and experiences nurses were able to give rich information about their relationship with parents, it may also have been limiting if it excluded nurses who did not feel confident enough to participate and who probably could have contributed valuable and wider rage of data.

The nurses' average age was 34,5 years (29-44 years) (table 2 p. 17), and their working experience in neonatal care was in average 7,1 years (4-12 years). Nurses' age and working experience indicated that they were skilled professionals. The nurses provided a picture of purposefully working to become better at what they do, and that working with parents offered new challenges and learning experiences. Their being of an age with the parents seemed to increase their sensitivity and sympathy with them, but could also make it difficult to keep a professional distance (paper IV). One of the inclusion criterions for nurses was a minimum one year work experience. This criterion may have been a limiting factor as it excluded the specific challenges facing inexperienced nurses in the unit.

Three of the most experienced nurses had post-bachelor specialty educations directly related to their present nursing role. They described how their specialty education made them more flexible and confident as nurses, an experience which corresponds with previous research findings (Rasmussen et al. 2005, Benner 1984, Samson and Cnaa 2006, Power and Franck 2008). Two of the nurses had no post-bachelor specialty education. One nurse had a post-bachelor specialty education which she described as indirectly useful to her work in the NICU. Although a small sample, something which reduces transferability, these findings

indicate that post-graduate specialty educations and work experience influence nurses' work performance in a positive way.

All participating nurses were female, and the study's credibility may have profited by participants of both genders as this would have offered a picture of possible variations in female and male approaches. Although interesting since gender was an issue in parents, the one male nurse employed at the unit was not assigned as a primary care nurse for the included parents, and was therefore prevented from participating.

7.1.3   Data collection

While my previous experience as a RN decreased the amount of time needed to become acquainted with the NICU context, it may also cause over-reporting or premature closures (Erlandson et al. 1993). An open-minded and reflexive approach in data collection and interpretation, as described in chapter 5.7.1, was used to increase the study's credibility.

Prolonged engagement in the field over a one year period was essential to build rapport but did also increased the need to find a balance between closeness and distance, and the decision to assume a peripheral membership role appeared to support me gain equilibrium in my position as researcher (Lincoln and Guba 1985). My previous nursing experience facilitated cultural understanding, but it also made it harder to maintain the analytic position.

By limiting my presence in the NICU to 2-3 days a week created room to withdraw and reflect upon my findings and how to proceed in my data collection (Lincoln and Guba 1985). The down-side of this strategy was the possibility of missing important events in the unit while absent. To reduce this potential loss of information I talked to parents and nurses about the last days events as soon as I was back on the ward.

The inclusion of all participants' perspectives increases this study's trustworthiness. This multi-faceted perspective was demanding, however, both during data collection and analysis. I did my best to let all the different voices be heard, which was a demanding task, as if some participants' voices were given more focus on the expense of others, this would cause a distorted and biased presentation. This danger has been addressed during data collection by making field notes focusing on both parents and nurses, and by presenting excerpts from all the interviews in the articles.

The use of different data sources and data collection methods increased my understanding of what and why things happened as they did. During an interview a particular incidence could be brought up by, say, the mother, and then later by the father and the nurse respectively in my interviews with them. If I furthermore had observed the incidence in question, this would increase the trustworthiness of my interpretation of this incidence. Most of studies on parent-nurse issues focus either on parents or nurses, with no comparison between their experiences. The inclusion of all participants is one of this study's strengths, as mothers', fathers', and nurses' respective experiences offered invaluable insights into their different views on their collaboration, something which is presented and discussed in the papers.

7.1.4   Analysis

Triangulation by using various data from the fieldwork (observations, informal conversations, reports and parent-nurse meetings) and from the interviews facilitated a dialectic analytic process. As discussed in chapter 5.5, the open and systematic analysis increases this study's dependability and confirmability.

The decision to use the N6 computer software program was useful for organizing and sorting data; however in some respects the N6 was not particularly functional. It was for instance impossible to restore text once it was changed, and the graphics of the node tree turned out badly in print. I became aware of the fact that these problems had been sorted out in a newer version of the computer program (NVivo7). I therefore transferred my data from version N6 to NVivo7. Due to incompatible data programs (Word version and NVivo version) this created a problem as only a part of the analyzed data material was transferred properly. These problems made me go back to the N6 version even though the upgraded version appeared to be more functional. There is a slim possibility that these technical problems may have decreased this study's dependability.

Some qualitative researchers have expressed curiosity and interest concerning the use of programme N6, while others have expressed a lot of scepticism. Questions whether to dissect a text and make sentences into data nodes may decrease the finding's dependability have been raised. In this study interpretation of data has been an ongoing process from the day the empirical data collection started until now, and in spite of critics of N6 this

electronic analytic tool was used to sort and visualize the great amount of data that came in during the data collection process.

Even so, it became obvious that I also needed to detach myself from the structured N6 categories to be true to the flexibility and creativity that characterizes qualitative analyses. I recognized that the software was primarily a tool for managing data, while I, as a researcher, had to do the imaging, conceptualizing, linking and understanding of data (Jennings 2007). Through analyses and reflections combined with discussions with tutors, colleagues and other PhD students, interesting and scarcely published aspects of the relationship between parents and nurses in NICU's have been found and presented in my papers. The researcher's creative process and intuition combined with a systematic data organizing process have been pivotal during the interpretation process. While the condensed data gave an impression of the participants' experiences, the main- and subcategories in N6 also showed the evolving character of the relationships. I find that the use of a computer software program helped to interpret the data further, and thereby to increase confirmability.

As support facilities were scarce my lack of experience in the use of the N6 may have affected my ability to exhaust this electronic tool's range of possibilities, which again may have decreased my study's dependability. It would have been a great help if more researchers known to me had been users of this software program, as this would have increased collaboration and reciprocal aid in the utilization thereof. To become a fully proficient user of such computer software, frequent training and upgrading to new versions as well as collaboration and networking with other users are essential. I therefore see my use of this qualitative computer analyzing programs in my PhD work as the beginning of a long journey. My clarification of my usage of N6 as an analytic tool in combination with the use of creativity and intuition hopefully increases this study's dependability.

7.1.5 Results

The ongoing interpretation process came to its conclusion during the writing of research papers. To communicate the extent and diversity of the data material expressive quotations from interviews and descriptions from observation sessions were used. This multiform presentation of data increases the study's trustworthiness through the visualisation and

illustration of the findings, allowing the readers to get an impression of the participants' world (Richardson 2000).

Through the discussions of the philosophy of FCC from multiple perspectives (ethical angle in paper I, attachment theory in paper II, the development of FCC in paper III and finally the commitment of closeness in paper IV) new perspectives of the philosophy of FCC are arrived at. These contributions to the development of FCC strengthen the trustworthiness of this study.

Several people – researchers, colleagues, and practising nurses – have been involved in this study's various processes: the creation of research design, data collection, analyses, and presentation of findings. Such peer review and investigator evaluation increase the study's trustworthiness further through a hermeneutic process of interpretation from a variety of perspectives.

7.1.6   Conclusion

My findings are derived from a study conducted in a Norwegian NICU. The small sample size combined with the cultural characteristics of Norwegian health care constitutes this study's main limitations. To increase trustworthiness and transferability it has been essential to thoroughly describe and discuss the sample, the context, and the research process.

The main strength of this study is the focus on all parties in the encounter – mothers, fathers, and nurses – and their experiences. Their individual experiences have provided data which contribute to our understanding of the implementation of FCC in a NICU. The differences and variations between the parents' and nurses' understanding and between the mothers' and fathers' experiences increase our understanding of the challenges in the application of FCC.

7.2   Discussion of the results

In this study the encounter and the development of relationships between parents and nurses in a NICU have been explored. Together with my co-authors I have focused on how

mothers, fathers and nurses experience the encounter, and how the parent-nurse relationship develops during the infant's hospitalization.

The word 'encounter' was chosen to illustrate the nature of these relationships as something which always requires effort and which at times even may be complicated and challenging. I have learned from linguists that a discussion on the development of an encounter linguistically is problematic, as an encounter only exists the minute it happens. I therefore chose to discuss inter-human 'relationships' between the studied parties rather than their 'encounters' whenever lasting or developing relationships are the topic.

7.2.1   The research questions

As mentioned in chapter 4.0, the research questions were posed rather openly to enable an open-minded approach to the experiences of mothers, fathers, and nurses. Even though the wording and the focus of the research questions have not been changed during the research process, the discussion of them have become more focused and narrowed down as data collection and interpretation developed (see chapter 5.5). The four research questions have been discussed in the four papers presented as part of the thesis.

1. "How do mothers, fathers and nurses experience the relationship?"

A central aspect of this study was to let all the participants' voices be heard, and research question no. 1 is answered in papers I-IV as data from all the participants are presented in these papers.

2. What characterizes the relationship between mothers, fathers, and nurses from the infant's birth till discharge from hospital? (paper I and III).

To understand current approaches to parents in the NICU a historical background for the development of neonatalogy and neonatal care was presented in paper I. Our current ideal of a parent-nurse partnership is further discussed from an ethical angle, suggesting that the parent-nurse relationship of power-dependency create an obligation for nurses to take care of the vulnerable and dependent parents.

The development of the parent-nurse relationship during hospitalization is described in paper III, showing how parents' and nurses' responsibility and roles gradually change, and how the child's stabilizing phase is the most challenging. Parents' need to adapt to their emotional experiences and develop their roles as independent caregivers seem to be focused less the more the child grows independed of professional care. More effort seemed to be put into the building of a trusting relationship and good raport than into the parent-nurse detachment process in the NICU.

3. Is there a difference in mothers' and fathers' needs and experiences of the relationship? (paper II)

During the data collection process mothers' and fathers' experiences of the attachment process became an interesting issue. There was a striking difference between how mothers and fathers experienced their relationship with the infant during the first days after birth. This issue has scarcely been focused in previous studies, something which was commented on during the journal's review process.

4. What characterizes the nurses' experiences of the relationship with parents of prematurely born infants? (paper IV).

The focus of this article is the question of equilibrium between a professional and a personal parent-nurse relationship, raised by the nurses. Visibility and lack of privacy combined with close relationships may push the professional relationship towards a more private one. If the roles become blurred, this is demanding on both parents and nurses, and it may increase parents' dependency and nurses' overinvolvement.

7.2.2 The development of a mutual beneficial relationship

Neonatal care has for decades been governed by professionals who autocratically decided what was best for the infant and its parents (Corlett and Twycross 2006). Even if there has been a shift towards a collaborative partnership between parents and nurses (Davis et al. 2003, O'Donnell 1990, Fegran et al. 2006), shared responsibility with parents as depicted in the family centred approach, is not truly arrived at yet (Cescutti-Butler and Galvin 2003, Galvin et al. 2000, Malusky 2005).

Parents' in Norwegian NICU's have since 1988 had a legal right to have their presence and involvement in their infant's care through the following legislation: a) 'The rights of parents of small children in Norway' (Ministry of Children and Family Affairs 2003), 'Regulations for children staying in hospitals' (Ministry of Health and Social Affairs 2000), and 'Adjusted practice concerning care benefits for parents of prematurely born infants' (Ministry of Labour and Social Inclusion 2008). Even so, each parent-nurse relationship has to be built individually during the infant's hospitalization, and nurses' attitudes and activities may counteract or facilitate parents' participation (Power and Franck 2008, Soderstrom et al. 2006).

The work initiated by Bowlby has gradually changed the perception of parents' role from exclusion to active involvement. Despite this, today's many discussions on the power of professionals and the dependency of parents in neonatal care are tell-tale signs of the complexity of the parent-nurse relationship (Fegran et al. 2006, Connell and Bradley 2000, Bretherton 1997, O'Donnell 1990, Schore 2000, Alsop-Shields and Mohay 2001, Tuckett 2005, Corlett and Twycross 2006). It is therefore in the patient's best interest to critically discuss professionals' and parents' respective roles in the NICU (Palviainen et al. 2003).

The theoretical framework chosen for this study is FCC, a philosophy of care which is an approach to planning, delivery and evaluation of health care based on a *mutually beneficial partnership* between parents and nurses (Shields et al. 2006, The Institute for Family-Centered Care 2008). According to Lee (1999), the antecedents of partnership are the development of equality of care between parents and nurses through negotiation, and to involve parents in their child's care. Stein-Parbury (2005) defines mutuality as the middle point between paternalistic and autonomous nursing care, where paternalistic care is determined by the nurse without reference to the patient, and autonomous care is determined by the patient independent of the nurse. But what does equality of care in the NICU actually mean, and how is mutuality understood and implemented in NICUs? The described discrepancy between philosophy and caring practice creates a need to critically discuss implementation of FCC in the NICU setting (Malusky 2005, Shields et al. 2006, Shields et al. 2007, Lundqvist and Nilstun 2007, Stein-Parbury 2005).

Findings reveal that the parent-nurse relation is a crucial but demanding part of neonatal nursing. The parent-nurse relationship develops from the infant's birth till discharge from hospital through three phases as presented in paper III. The evolution of parents' and nurses' respective responsibility are illustrated by the following figure, and the stabilizing phase marked in grey colour, appears to be the most demanding (Fegran et al. In Press):

Figure 1: Development of parents' and nurses' responsibilities during the infant's hospitalization.
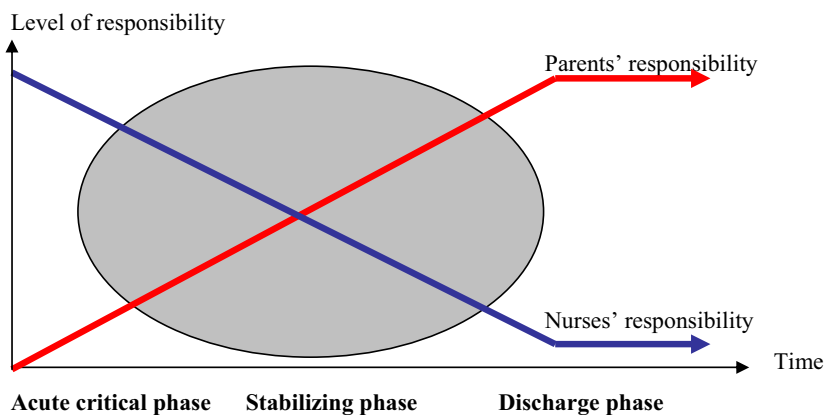
The horizontal line shows the development of the infant's condition through three phases. The vertical line indicates level of responsibility. The diagonals represent distribution of responsibility through the three phases. The discussion of findings will below be structured according to these three phases: the acute critical phase, the stabilizing phase and the discharge phase.

7.2.3 The acute critical phase

The nurses in our study expressed the importance of building rapport with parents from the very beginning, which supports previous research studies concluding that the parent-nurse relationship is crucial to promote effective partnerships with parents and to support their coping and adaptation (Hall 2007, McAllister and Dionne 2006).

Findings reveal parents' and nurses' different starting point when initiating the relationship. The NICU is the professionals' domain and the nurses had strong anticipations both

regarding the parents' role and their own nursing role. The parents on the other hand were totally unprepared for this new situation and forced into what to them was a surreal world different from anything they ever had anticipated or wished to know about.

Immediately after birth and during the acute critical phases the professionals assumed a paternalistic approach to the parents who were totally dependent on their competence and experience. In this acute critical phase care was led by nurses while parents' role was diminutive. This compares well with Malusky's (2005) parental involvement level, and parents appreciated that experienced professionals took over while they felt helpless and useless. Parents regard their dependence on the professionals and their vulnerability as the main reason why they enter into the parent-nurse relationship, a finding supported by for instance Stein-Parbury (2005) and Ward (2005) who describe parents' relief in letting competent professionals take charge.

As discussed in paper II, fathers did not experience their lack of presence during labour as negative. These findings may be caused by the fact that the births were emergency births, and the fathers expressed that their immediate involvement after the infant had been transferred to the NICU as meaningful and sufficient. The nurses' power in their role as competent professionals seemed to make parents confident, and in this context their power created trust (Grimen 2004, Corlett and Twycross 2006, Shattell 2004, Palviainen et al. 2003, Almerud et al. 2007). However, if parents experienced being excluded from their infant's care, this would be an example of how professional power is used to reduce parents' involvement, and how this affects the parent-infant relationship negatively (paper I).

The professional-parent relationship that develops in connection with a premature birth is different from such relationships in paediatric care because these parents have no previous experience with their infant. As discussed in paper III, the main focus for nurses during this phase is the infant's survival and monitoring. Even so, the nurses' caring behaviour revealed that they simultaneously supported parents in their involvement and bonding with their infant. According to Lundqvist et al. (2007), men's experience of early fatherhood is influenced by their ability to experience control. When concern, stress, and helplessness are coincided with low levels of happiness, support, and security, fathers feel lack of control. Conversely, when they experienced support, security, and happiness, they feel in control and able to handle the situation (Lundqvist et al. 2007). During this phase the fathers felt

confident that the professionals were in control, and they expressed no need to become involved until after the infant's birth. The fathers furthermore described how their immediate involvement in the NICU made them become more confident in their caring role, and that preterm birth give fathers a closer relationship with their infant which is supported by other studies (paper II) (Lindberg et al. 2008).

Mothers' need to control seemed to be directed towards achieving a feeling of motherhood in the NICU. Ambivalent emotions may influence the attachment process the first days after delivery, as discussed in paper II. The mothers' need to find their position as mother, both inside and outside the hospital, is supported by previous studies (Simms & Cole 2007, Heermann et al. 2005, Bowie 2004). These findings are important, as there are hardly any descriptions of differences between mothers' and fathers' experiences of the early attachment process in the literature, a fact which also was mentioned by the reviewers of paper II. From around 1995 there has been increased research focusing on fathers' experiences, and the findings presented in this thesis contribute to the understanding of fathers' experiences as well as those of the mothers (May 1996, Pruett 1998, Tiedje and Darling-Fisher 2003).

Nurses' attention towards parents during this phase was mainly to include, inform and support them, and even if parents experience the acute critical phase as surreal and difficult, their relationship with the nurses was experienced as supportive and overall positive. This phase is characterized by close interaction and clear distribution of responsibility, something which may explain why this phase was experienced as relatively uncomplicated. For nurses to be able to give optimal individual support to parents, it is important to recognize the difference in mothers' and fathers' experiences of the early attachment stage here described.

7.2.4 The stabilizing phase

During the stabilizing phase when the infant need less professional care, parents' contribution and responsibility increase while nurses assume a more withdrawn position. The label 'stabilizing phase' may be questioned as the transition from the acute critical phase to the stabilizing phase was anything but unchanging and stable when it comes to the parent-nurse relationship. Parents are not only supposed to adjust to their new parental role,

they are also at the same time expected to find their position as collaborators in their infant's caring team. And while the nurses appreciate the importance of close nurse-parent collaboration, they are well aware of the demanding aspects of such close and prolonged relationships.

This phase corresponds with Malusky's (2005) parental participation and partnership phases where negotiation of the evolving parent-nurse relationship becomes essential. Below negotiation of positions, divergent opinions, and the balance between a professional and a personal relationship will be focused as the parties adjust to their changing roles throughout the stabilizing phase.

Negotiation of positions

Despite the appearing consensus on including parents in neonatal care, the lack of effort to negotiate the parents' contribution to this care has been criticized (Schroeder, 2008). This may explain why the number of descriptions of parental resentment seem to be growing (Shields et al. 2007, Corlett and Twycross 2006, MacKean et al. 2005, Fegran et al. 2006, Conner and Nelson 1999, Espezel and Canam 2003, Kirk 2001, Darbyshire 1994, Shields et al. 2006). Mothers' and nurses' may for instance struggle about "who owns the child" (Lupton and Fenwick 2001, Shields et al. 2003a, Fegran 1996), a fact which reveals the complexity of the partnership.

A central issue concerning the development of a good parent-nurse relationship is the professionals' power to include or exclude parents in their infant's care. As their involvement increases parents' anticipations and ability to be involved increases as well. Some parents want to actively collaborate in decision making beyond regular care while others only want to be involved in regular caring activities (Gardner et al. 2002, Fenwick et al. 2002). Parents' voice is not always heard, however, especially if there are discrepancies between parents' and professionals' opinions (Hallstrom and Elander 2004, Brinchmann et al. 2002).

The nurses explained the fact that parents were excluded from physicians' rounds by physicians' and nurses' need to discuss the infants' treatment. I observed no parents objecting to this routine. The question is how parents can be able to collaborate actively if

they are excluded from the professionals' decision-making process? Løgstrup (1997) claims that trust is related to the interdependency existing between people and that there is an ethical demand on those in power to take care of those in a dependent position. Did parents agree with this practice because they were reluctant to disagree with the nurses, or did the established routine and the professionals' authority create trust (Grimen 2004)? Were the routines established to support parents, or did they mirror routinely anticipated parents' needs? Both parents and nurses talked about the importance of reciprocally respecting each other as individuals and collaborators. If parents genuinely wanted to be involved in medical decision-making, one may possibly interpret current routines as lack of respect for parents' wish to be involved.

Limiting parents' involvement may be a way for nurses to demarcate responsibility. The positive side of this was for instance when nurses helped parents find a workable balance between their presence in the NICU and their life outside the hospital (Graber and Mitcham 2004). The down side was if parents were excluded from collaborating, for instance through the withholding of information. Comprehensible information and control of information appear to be crucial for the development of mutual understanding and to enable parents to become collaborators in decision-making and care (Ward 2005, The Institute for Family-Centered Care 2008, Shields et al. 2007). Parents in the present study wanted to be informed, and were frustrated when they felt information had been withheld. Even so, some parents appreciated when nurses realised when they were unable to absorb more information and reduced the amount of information accordingly (paper III). These findings are supported by studies questioning truth-telling as the only appropriate way to inform parents (Soderstrom et al. 2006, Tuckett 2004). Furthermore, cultural differences also need to be considered, as the western culture's autonomy and disclosure policies may be viewed as unethical and even harmful by members of other cultures (Hanssen 2004). Information is important, but nurses should carefully gauge parents' need of information, and to the best of their ability capture their readiness to be informed (Benner 1984).

Language is an important issue when a relationship is to be developed, and the use of professional language may be experienced as excluding (May et al. 2001, Browne et al. 2004, Shields et al. 2003a, Soderstrom et al. 2006). A father described the importance of being talked to in a way he could relate to (paper II). If not, language may act as a barrier to parental involvement (Corlett and Twycross 2006). Small-talk was described as an

including and positive way of communicating; it was a relief to talk about normal issues like food, football games, and politics. Both parents and nurses appreciated these talks as they gave them a break from treatment and nursing care (paper III).

Parents' perception of the nurses influenced their relationship with them. While some nurses made parents feel confident and relaxed, others made them feel insecure and stressed. According to Thompson et al. (2003) there is a correlation between trust development and whether expectations of care are being met. This may explain why parents repeatedly linked disagreement with nurses to a feeling of uneasiness. While nurses who according to parents took good care of their infant made them feel confident, those who did not act according to their wishes caused frustration and a feeling of threat to their infant's wellbeing. Parents explained how nurses came open up or close their connection with their infant (paper II), which is in accordance with Callery's (2002) study describing mothers who felt that they needed permission to touch and care for their infants.

Parents' feeling that their opinions were not respected was another difficult issue. Examples of this were parents who felt certain that their infant was in pain while the nurse minimized the problem, or when parents and nurses disagreed whether the infant's needs were met in an appropriate and adequate way. Such situations could make parents feel pulled between their obligations to the infant and the nurses, and they would wonder whether agreement with the nurses' decisions indirectly would help their infant – or should they be their infant's advocate whatever cost (Blessing 2006, Conner and Nelson 1999)? These situations were similar to those identified in studies describing discrepancy between parents' and nurses' understanding of decision-making and difficult situations (Shields et al. 2003b, Hurst 2001).

If nurses expected parents to adopt the role as independent caregivers, this could act as a barrier rather than furthering negotiations of roles, and could confuse both parties (Kirk 2001). If nurses withdrew from parents while parents still needed them to remain close, if the nurses started the detachment process without negotiating this with parents, this may make parents withdraw from active participation (Corlett and Twycross 2006, Shields et al. 2006).

Parents' focus on the infant's needs may override their own needs and reduce their ability to adapt to their parental role. This may explain why some parents are experienced as 'difficult', and may even make nurses reluctant to develop a partnership with them (Wigert et al. 2006). If parents disregard their needs over time, this may cause negative long-term effects like depression and anxiety, which may have a negative effect on their bonding process with their baby and complicate their adaptation to their parental role, and even reduce their ability to care for their infant (Carter et al. 2005, Corlett and Twycross 2006).

Divergent opinions

Parents described difficult situations as situations where they felt they were not heard. Different sets of parents had similar experiences of being disappointed and frustrated when nurses for instance did not act according to an agreed plan, something which makes parents feel excluded and undervalued as contributors. My findings seemingly contradict studies that describe nurses as more focused on routines and time schedules than on individualizing care. But, not acting according to a plan does obviously not necessarily mean that one give individualized care (Shields et al. 2003b, Shields et al. 2004). Perhaps parents are more independent than the staff realize, and that this discrepancy in outlook makes the struggle about 'who owns the infant' visible? According to Henson (1997) mutuality means a balance of power and respect, and with the professional's power comes an obligation to respect parents and an acknowledgement of their contribution, as discussed in paper I.

Even when parents did not agree, they were loath to express their disappointment in nurses' behaviour. Could this be caused by a fear of being labelled as difficult parents? According to Callery (1997b) difficult mothers were either those who were quiet and introvert and with a different value systems from the nurses, or those who were loud or demanding. To recognize parents' need to be important contributors in their infant's care is crucial, and to be regarded as a good parent may prevent parents spread negative attitudes on the ward (Shields et al 2003a, Fenwick et al. 2002, Callery 2002, Fenwick et al. 2001, Callery 1997a, Spencer and Edwards 2001).

The parties' visibility in the NICU setting influences parents' and nurses' experiences of each other (paper IV). Parents describe their reactions to nursing behaviour they disagree with or dislike, and also their frustration if they are not being listened to. Modern parents no

longer trust professionals blindly; they collect information through the internet, magazines, and other parents to assure themselves that optimal care is given (Samson and Cnaa 2006). These 'new parents' may be perceived as threats to nurses, and this is a possible explanation why nurses more or less consciously may inhibit parental inclusion by clinging to their routines and set activities.

Nurses acknowledged that parents' trust in them as professionals is essential to their relationship, and that distrust must never be ignored. When nurses experienced that their relationship with parents somehow were suffering, nurses attempted to talk to parents to regain trust or to offer them a change of primary care nurse. I found, however, that when nurses admitted their mistakes or insecurity, parents' respect for the nurse's work was boosted and the impaired relationship was restored. Parents often pointed out that the nurses were "only human beings like us" and when nurses talked openly about these issues with parents, this was a positive way to handle problems that furthermore strengthened their relationship. These findings support studies that found truth-telling to be intrinsic good, although the fact that truth is not always preferred should also be considered (Tuckett 2004).

Balancing a professional and a personal relationship

Closeness and detachment were experienced as equally important to the reciprocal trust-building process, and the nurses talked a lot about the need of a balance between a professional and a personal relationship with parents (paper IV). The lasting nurse-patient association which was explored appeared to be similar to the characteristics of 'befriending' (Bignold 1995), where the formal parent-nurse relationship is replaced by a more informal association, as discussed in article IV. Even if parents and nurses alike regarded closeness as important and rewarding, crossing the professional-personal barrier may increase the danger of over-involvement in nurses. Particularly the nurses frequently talked about closeness and detachment during the interviews, which illustrates the challenge of finding equilibrium in their involvement (Dowling 2006b, McQueen 2004, Wing and Carter 2004). Williams (2001a, 2001b) suggests that intimacy has psychological, emotional, and physical aspects. Encountering parents in marginal situations opens up for an intimate psychological and emotional relationship, and the need to focus and consciously assess these parent-nurse relationships (Brodie et al. 2002, Bakker et al. 2005) is discussed in paper IV.

As the recovery of a prematurely born infant is unpredictable with ups and downs, parents describe the time in hospital as living aboard a roller coaster (Almerud et al. 2007). Parents' approach to their infant is emotional and sometimes ambivalent, pulled as they are between the desire to protect and support their infant and the fear of becoming attached to a infant they might loose (Aagaard and Hall 2008, Lundqvist et al. 2007, Almerud et al. 2007). There is a need to explain the emotional storm parents experience as a normal response to a stressful event and to protect and support parents during emotional outbursts (paper III) (Jotzo and Poets 2005). Additionally, the character of the NICU setting make their behaviour public and visible (paper IV), and creates an obligation for nurses to protect parents in a vulnerable situation (Byers et al. 2006, Spencer and Edwards 2001).

During long hospitalizations there is a need to optimize normal family functioning and care of parents, which entailed supporting parents' disengagement and help them mentally prepare for assuming responsibility for their infant (Franck and Callery 2004). Nurses supported parents' attempt to normalize their everyday life by help them plan both their presence and involvement in the infant's care and the care of children at home, and to take time off to do things outside the hospital (paper III). Another mode of helping parents to normalize their lives was what parents called "the nurse behaving like a mother" (paper II). When the nurse dressed the infant in real baby clothes, when the infant was covered with colourful blankets instead of white hospital blankets, and when the incubator was covered with pictures, toys or other things normal for a newborn infant, this was appreciated by parents. And what perhaps made parents most happy was when nurses responded to the infant's signals of hunger, pain, or discomfort, as this made them feel confident that the child was taken care of in their absence. This corresponds with other studies (Simms et al. 2007). The opposite was the case when parents experienced that their infant was treated differently than they expected and wanted. The visibility in and openness of the NICU could be revealing and make parents feel responsible for their infant's care also when they were absent, and even prevent them from leaving their infant to go home. The need to normalize their life and gradually take control was a way of 'jumping off' the roller coaster life of the NICU.

Closeness is a crucial part of rapport building even though it could make complicated relationships even more challenging. To the nurses "complicated relationship" were relationships where they were unable to support or help parents rather than with people they

did not want to collaborate with (paper II and IV). Some of the nurses used the label "lack of chemistry" to describe difficult parent relationships, something which was also described by Stein-Parbury (2005). Stein-Parbury writes that parents' emotional appeal to nurses influences their involvement. It is as important to be aware of this inter-human factor in care situations as in our ordinary lives. A question that is little discussed in the literature is whether one in a difficult relationship always should try to improve it, or whether another nurse should take over as a primary nurse (paper III).

Nurses' main focus during the stabilizing phase was to gradually transfer responsibility to parents and initiate a withdrawal process to make parents independent caregivers. Parents appreciated to be involved, but this change in interface between the professionals' and their responsibility appeared to complicate and challenge their collaboration. While both parties wanted a close relationship, parents' and nurses' understanding of the detachment process differed. The nurses expressed a need to balance their involvement and withdrew gradually to avoid becoming over-involved as well as to help parents become more independent, while parents seemed to need their close support in their attempt to adapt to the situation and develop into confident caregivers.

7.2.5   The discharge phase

The discharge phase which is characterized by preparations to take the infant home corresponds with Malusky's (2005) hierarchical level FCC, which is the highest level of the parent-nurse relationship. Parents are now supposed to be the experts and nurses the consultants, and independent and confident caretakers is the ultimate goal of nursing in the NICU. Malusky claims that true FCC is only sometimes achieved, something which reveals a discrepancy between FCC as an underpinning philosophy and Malusky's description of FCC as an ultimate goal for neonatal care. Does this mean that FCC only exists when parents have become the experts in care, and that FCC as a mutually beneficial partnership only is reached if parents develop expertise equal to that of nurses? These questions illustrate the lack of consensus about what constitutes FCC, and the need to discuss variations of FCC depending on the context. Rather than a state/condition FCC is an approach to neonatal care, indicating that the parents-nurse relationship develops throughout hospitalization and has to be agreed upon by the parties. FCC develops through the

negotiation of transfer of responsibility from professionals to parents based on the child's condition. Parents' ability to take over care as discussed in article III (Stein-Parbury 2005, Fegran et al. In Press, The Institute for Family-Centered Care 2008).

A parent-nurse caring team may be able to give the infant optimal care, but optimal care is dependent on the members filling their role (Hall 2007, Coyne and Cowley 2007). My findings indicate that the parent-nurse relationship is relatively uncomplicated during the discharge phase, due to clarified roles and extensive parental involvement and responsibility (paper III). These findings correspond with Hall's (2007) study of dynamics of FCC, showing that clear roles constitute healthy dynamics within the family. Parents' focus was primarily on bonding with their infant and participation in care. Findings supported by studies indicate that parents want to contribute, although in a different way than nurses (Coyne and Cowley 2007, Power and Franck 2008, Dokken and Ahmann 2006, Simms and Cole 2007).

The parent-nurse relationship in a NICU is different from those in many other health care settings because parents, in addition of being partners in care, generally also are receivers of care, which makes the 'mutually beneficial' aspect of the relationship even more complex (Shields et al. 2006). What is mutually beneficial will differ according to parents' and nurses' respective perspectives, choices, values, beliefs, and cultural backgrounds (Lupton and Fenwick 2001, Stein-Parbury 2005, Lundqvist and Jakobsson 2003, Campbell and Tracey 2000). During the discharge phase parents needed to feel confident to take their infant home, and their involvement and participation during this phase influence their experiences in a positive way (paper III). Parents and nurses collaborated closely in a mutually beneficial partnership; parents became confident caretakers even if discharge was characterized by joy mixed with dread, while nurses felt confident to transfer total responsibility for their infant's care to them. Nurses' support parents who prepare for life outside the hospital. Although parents may feel they are thrown out into the empty void, nurses provide them with a security net of knowledge and support, a fact which probably explain why the discharge process was experienced as positive. The nurses need to be confident to be able to trust parents to take their infant home on leave, and the nurses said that their experience and post-bachelor specialty education made them able to approach the families with more flexibility, something which corresponds with Benner's (1984) description of the experienced nurse.

The question is whether the discharge phase had been perceived to be this uncomplicated if parents' had been forced to play a less influential role. An issue discussed in modern neonatal care is early discharge from the NICU to normalize the families' lives. This is also seen an important part of FCC (Jonsson and Fridlund 2003, Rose et al. 2008). Is the goal of a transfer of traditional nursing procedures as tube feeding, provision of oxygen, and even coping with resuscitation to parents in their private homes the normalization a family's life only? Suspicions are voiced that early discharge constitutes a pattern of pushing responsibility from the professional onto parents (Blessing 2006, Reedy 2007, MacKean et al. 2005). While this may be the best choice for some families, the option to negotiate time of discharge or even refuse discharge at a given time must be there for some families to build sufficient confidence (Corlett and Twycross 2006, Lee 2007). One may wonder whether routine early discharge in some cases is a modern form of an autocratic attitude towards parents in the guise of collaborative care. Early discharge may furthermore in some cases be seen as an example of economic issues camouflaged as benevolence to avoid difficult ethical discussions, as for instance treatment of extreme premature children versus cost-benefit (Brinchmann et al. 2002, Schroeder 2008, Msall and Park 2008, Miljeteig et al. 2007, Russell et al. 2007). In spite of these questions, it is important that future development in neonatal care the philosophy of FCC and parents' involvement in decision-making and evaluation of care is not lost (Griffin and Abraham 2006, Kirk 2001, The Institute for Family-Centered Care 2008).

According to FCC parents should be collaborators in policy and program development, implementation and evaluation in education as well as in the delivery of care to actively influence neonatal care (The Institute for Family-Centered Care 2008, Shields et al. 2007). One example of how parents do contribute on a more systemic level is a Norwegian father's efforts that lead to improved economic rights for fathers who stay with their critically ill child in hospital (Ministry of Labour and Social Inclusion 2008). Parents of premature children are furthermore contributors in bachelor- and master health education, and they share their experiences through writing (Rye 1998, Dokken and Ahmann 2006), and also through support organizations led by parents of prematurely born children (www.Prematurforeningen.no).

As mentioned above, the parent-nurse relationship during the discharge phase seemed relatively uncomplicated, probable due to a clear roles. Parents and nurses seemed to respect

each other and their respectively changing levels of responsibility, and to be confident in the other's contribution. This is in accordance with Hall's (2007) study of dynamics of FCC, showing that clear roles constitute healthy dynamics within the family.

8.0   CONCLUSION

The relationship between parents and nurses in a NICU is essential to provide optimal care both for the infant and its parents, and is influenced by the actual context as well as the participants' individuality and experiences. This study's findings are a contribution to enhance our understanding of their reciprocal relationship as they are perceived by parents and nurses, and of what promotes as well as what inhibits the development of their relationship.

One of the main findings of this study was the development of the parent-nurse relationship described through three phases. The middle phase characterized by the infant's stabilization surprisingly appeared to be the most challenging for the parent-nurse relationship. While previous studies have described the respective parties' collaboration as complicated; in this study the interchange of responsibility is identified as the most challenging issue.

Another crucial finding was derived from the participants' experiences of collaborating in a context characterized by visibility and lack of privacy. The characteristics of the NICU context combined with the endeavoured parent-nurse closeness seemed to challenge the balance between a professional and a personal approach. The experienced emotional burden of this closeness rarely seems to be problematized.

While the great majority of previous studies of parents' experiences focus on mothers or parents as a unit, this study focused on mothers' and fathers' individual experiences. This approach revealed a striking difference in their experiences of the premature birth and the following early attachment process, and emphasize fathers' crucial role immediately after birth. Such a difference in parents' experiences have not been described previously, and may contribute to new understanding of parents' needs in connection with a premature birth.

After having immersed myself in specific issues while writing the papers (attachment theory, FCC, ethics and professional relationships), the overall presentation enabled me to treat the study as a whole. Realizing the dramatic evolvement of parents' and nurses' responsibility during the stabilizing phase made me wonder whether certain issues prominent during this phase may be characteristic for the relationship as a whole, even though they appear as less distinct and powerful in the acute critical phase and the discharge

phase. Three issues were identified as central for adapting to changed responsibility: 1) negotiation of positions, 2) balance between a professional and a personal relationship, and 3) divergent opinions. This made me elaborate figure 1 (Development of parents' and nurses' responsibilities during the infant's hospitalization) (figure 2):

Figure 2: Parents' and nurses' process of changing responsibility through three phases.

Level of responsibility

| Acute critical phase | Stabilizing phase | Discharge phase |
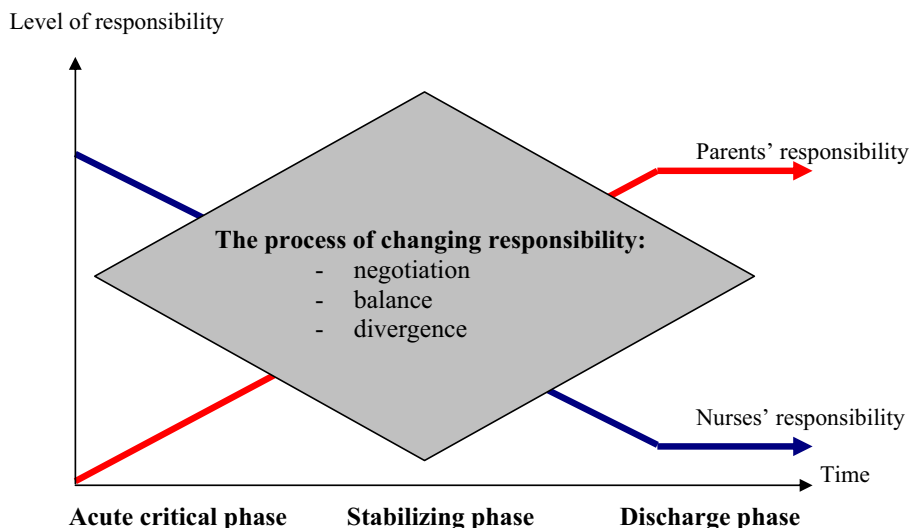
In figure 2 parents' and nurses' adjustment to changed responsibility is visualized by a rhombus to accentuate the development of their relationship. Parents' and nurses' change in responsibility (marked in grey colour) is initiated through the acute critical phase, increases dramatically as the infant's recovery facilitates increased parental involvement during the stabilizing phase, and decreases as discharge is approaching and parents' and nurses' roles are clarified. The peak in the adjustment process during the stabilizing phase, caused by crossing responsibility and unclear roles, may explain why this point is experienced as demanding regarding collaboration and development of a mutually beneficial relationship.

The decision to label the middle phase 'stabilizing' may be questioned as it appear to focus on the infant's condition rather than on parents' needs. I will suggest that the family's need for nursing intervention is – roughly speaking – a 'constant', as it is neither possible nor desirable to separate parents and infants when implementing FCC. When the infant's

condition is critical and heavy intervention is needed, parents receive less attention, and when the infant is stabilizing parents' needs may become more prominent and evident.

FCC in the future

Parents' participation and involvement in their infant's care appeal to neonatal nurses as well as scholars/researchers. We no longer accept that parents are deprived of contact with their newborn baby, or that professionals may perform their professional duty without involving parents. Despite this consensus the criticism of FCC is increasing, and scholars' query why embrace a philosophy unsupported by evidence is a just one (Carter 2008, Shields 2008). My question is whether there at present exist an alternative to FCC? As far as I am concerned, there is no alternative to parental involvement and collaboration with nurses. Even so, implementation of FCC needs further exploration. Based on findings from this study I would like to point out three issues concerning parents' and nurses' relationship which need further exploration: gender, responsibility or roles, and emotional involvement. I would also like to add some comments concerning FCC and education.

Gender

FCC emphasizes the individual family member's needs as important. This study's focus on mothers' and fathers' individual experiences has confirmed the importance of individualisation; however this issue needs to be explored further. The differences found in the attachment process immediately after birth need to be studied both during hospitalization and after discharge from hospital. Fathers' experiences of involvement need further attention to support their crucial contribution to the infant's care and to make their voices heard concerning parenting in a NICU. It would be interesting to compare fathers who become involved early and fathers who are less involved. My findings of mothers' ambivalent experiences concerning the early attachment process calls for follow-up studies, for instance research studies explicitly focusing on the mother-infant interaction. A comparison between parents of healthy infants and of prematurely born infants would also be interesting, particularly whether the different introduction to parenthood the two sets of situations entail, influence the ensuing attachment process.

In a study of gender there is also a need to focus on cultural differences, for instance to study variations in mothers' and fathers' ability to be present and spend time with the infant and how such issues influence the attachment process. As many of the published studies have been carried out in Scandinavia, studies outside Northern Europe are needed.

Responsibility and roles

The progress of neonatal care entails efficiency and new technical knowledge. These days the increased focus on the entire family and their participation add to the constantly increasing complexity of neonatal nursing. My findings support previous studies which reveal the demanding aspects of parental involvement and collaboration. Studies on neonatal nurses' experiences and needs seem however to be in short supply. To avoid burnout or increased turnover of staff there is furthermore a need to study the influences of changes in neonatal care on nurses' roles. One suggestion is to study how early discharge and shorter hospital stays influence nurses' ability to care for parents' needs as well as those of the infants. Nurses' experiences of combining instrumental competence and interpersonal competence, and how this influences their nursing role is another interesting issue to study.

The mutuality aspect supposed to characterize the parent-nurse relationship also needs attention. Several studies point at parents' and nurses' divergent understanding of what is mutually beneficial. I would suggest that the difference between being 'equally valued' and 'equal' ought to be focused, as there seems to be a discrepancy between parents' and nurses' understanding of what is mutually beneficial. Several studies have pointed out that parents express a need to perform different tasks than the nurses, and follow-up studies on this issue may help clarify what this means would be useful.

Emotional involvement

While one endeavours to achieve a close parent-nurse relationship, the emotional burden of this relationship on the involved parties needs further attention. Previous studies have focused on the *patient-nurse* relationship. Now the *parent-nurse* relationship in the NICU needs to be explored. The issues of closeness and detachment as well as the balance between a professional and a personal relationship need to be focused in various settings where parents and nurses collaborate. Issues concerning parents of chronically ill children

inside or outside institutions need to be studied as these children's parents probably receive less attention than those with acutely and critically ill infants. Also their relationships with nurses most certainly are challenging, perhaps in ways which could increase our general understanding of close and lasting parent-professional relationships.

A particular challenge is the balance between surveillance and privacy in the NICU setting. Some recent studies have focused on the physical environment's influence on parents' experiences. These studies show that further research on the physical environment's influence on the parent-nurse relationship is needed. Research on optimal design for new NICUs in collaboration with architects m be highly beneficial to facilitate implementation of FCC.

Education

Parental involvement and collaboration greatly influence both neonatal and paediatric care, and the vast body of research on FCC provides students and nurses with plenty of literature on this issue. It does not necessarily follow, however, that Norwegian nurses and students are acquainted with the philosophy of FCC. While English language Master level textbooks tend to advocate the FCC approach, bachelor level textbooks in nursing tend to allot only a few pages to the patients family, and nothing at all about the concept of FCC. This lack of focus on the family is worrying as collaboration with families is perhaps the most complex part of neonatal nursing. There is an obvious need to improve nursing education regarding the various aspects of a family centred approach.

This research project have more than ever made me realize how strongly the nurses' approach to the family influence parents' experiences of the first weeks as parents to a prematurely born infant. I have also learned a lot about nurses' experiences; their untiring efforts to provide optimal care to both the critically ill infant and its parents in a vulnerable situation. While I have embraced the philosophy of FCC during this process, I have also critically discussed its implementation in practical nursing. There is a need to explore further how participants in various contexts may negotiate their respective roles to achieve mutually beneficial relationships, and to focus on all the participants' views in order to grasp the multifaceted aspects of these relationships.

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Table 3: Data collection

Week / Year	44 2003	45	46	47	48	49	50	51	52	1 2004	2	3	4	5	6	7	8	9	10	38	39	40	41	42	43	44	45
Child 1 32 weeks, twins	In																										
Child 2 32 weeks			In				Out																				
Child 3 28 weeks				In		Out																					
Child 4 29 weeks							In											Out									
Child 5 30 weeks									In						Out												
Child 6 31 weeks																				In							Out
Observations			d	dkk	dd	ddd	dd	dd	d		dd	d	dd	ddk	d?	d	ddd	dd		dd	dd	dd	dk	dd	d	dd	
Interviews																											
Nurse 1		X																									
Nurse 2			X																								
Nurse 3					X																						
Nurse 4								X																			
Nurse 5																			X								
Nurse 6																											X
Mother 1						X																					
Mother 2							X																				
Mother 3														X													
Mother 4																X											
Mother 5																		X									
Mother 6																										X	
Father 1						X																					
Father 2							X																				
Father 3														X													
Father 4																X											
Father 5																		X									
Father 6																										X	

ATTACHMENTS

Norsk samfunnsvitenskapelig datatjeneste AS
NORWEGIAN SOCIAL SCIENCE DATA SERVICES

NSD

Liv Fegran
Institutt for sykepleiefag
Høgskolen i Agder

Serviceboks 422
4604 KRISTIANSAND S

Vår dato: 26.08.2003   Vår ref: 200300747 LT /RH   Deres dato: Deres ref:

KVITTERING FRA PERSONVERNOMBUDET

Vi viser til melding om behandling av personopplysninger, mottatt 25.08.2003. Meldingen gjelder prosjektet:

10244   Møte mellom mødre, fedre og sykepleiere ved en nyfødtpost

Norsk samfunnsvitenskapelig datatjeneste AS er utpekt som personvernombud av Høgskolen i Agder, jf. personopplysningsforskriften § 7-12. Ordningen innebærer at meldeplikten til Datatilsynet er erstattet av meldeplikt til personvernombudet.

Personvernombudets vurdering

Etter gjennomgang av meldeskjema og dokumentasjon finner personvernombudet at behandlingen av personopplysningene vil være regulert av § 7-25 i personopplysningsforskriften. Dette betyr at behandlingen av personopplysningene vil være unntatt fra konsesjonsplikt etter personopplysningsloven § 33 første ledd, men underlagt meldeplikt etter personopplysningsloven § 31 første ledd, jf. personopplysningsforskriften § 7-20.

Unntak fra konsesjonsplikten etter § 7-25 gjelder bare dersom vilkårene i punktene a) – e) alle er oppfylt:

a)   førstegangskontakt opprettes på grunnlag av offentlig tilgjengelige registre eller gjennom en faglig ansvarlig person ved virksomheten der respondenten er registrert,

b)   respondenten, eller dennes verge dersom vedkommende er umyndig, har samtykket i alle deler av undersøkelsen,

c)   prosjektet skal avsluttes på et tidspunkt som er fastsatt før prosjektet settes i gang,

d)   det innsamlede materialet anonymiseres eller slettes ved prosjektavslutning,

e)   prosjektet ikke gjør bruk av elektronisk sammenstilling av personregistre.

Personvernombudets vurdering forutsetter at prosjektet gjennomføres slik det er beskrevet i vedlegget.

Behandlingen av personopplysninger kan settes i gang.

Ny melding

Det skal gis ny melding dersom behandlingen endres i forhold til de punktene som ligger til grunn for personvernombudets vurdering.

Selv om det ikke skjer endringer i behandlingsopplegget, skal det gis ny melding tre år etter at forrige melding ble gitt dersom prosjektet fortsatt pågår.

Ny melding skal skje skriftlig til personvernombudet.

Offentlig register

Personvernombudet har lagt ut meldingen i et offentlig register, www.nsd.uib.no/personvern/register/

Ny kontakt

Personvernombudet vil ved prosjektets avslutning, 31.12.2007, rette en henvendelse angående status for prosjektet.

Vennlig hilsen

Atle Alvheim   Lis Tenold

Kontaktperson: Lis Tenold tlf: 55583377

Vedlegg: Prosjektbeskrivelse

Endringsskjema

for endringer i forsknings- og studentprosjekt som medfører meldeplikt eller konsesjonsplikt

(jf. personopplysningsloven og helseregisterloven med forskrifter)

Meldeskjema sendes per post, e-post eller faks, i ett eksemplar, til: Norsk samfunnsvitenskapelig datatjeneste AS
Personvernombudet for forskning
Harald Hårfagres gate 29
5007 BERGEN

personvernombudet@nsd.uib.no / Telefaks: 55 58 96 50 / Telefon: 55 58 21 17

Vennligst les veiledning bakerst

1. BEHANDLINGSANSVARLIG [i]

Institusjon:	Dato for innsending:	
Universitetet i Oslo, Medisinsk fakultet, Seksjon for sykepleievitenskap	11.12.07	
Adresse:	Postnr.:	Poststed:
Postboks 1153 Blindern	**0318**	**Oslo**

2. DAGLIG ANSVAR [ii]

Navn (fornavn - etternavn):		
Sølvi Helseth		
Arbeidssted (avdeling/seksjon/institutt):	Stilling/grad:	
Høgskolen i Oslo, SU, Masterstudium i klinisk sykepleievitenskap	Professor	
Adresse – arbeidssted:	Postnr.:	Poststed:
Stensberggaten 27	0170	Oslo

Telefon:	Telefaks:	Mobil:	E-postadresse:
22 45 37 73	22 45 37 99		Solvi.Helseth@su.hio.no

3. VED STUDENTPROSJEKT [iii]

Navn (fornavn - etternavn) på studenten:		
Liv Fegran		
	Grad:	
Universitetet i Agder (Høgskolen i Agder til sept. 2007)	Kandidat i sykepleievitenskap	
	Postnr.:	Poststed:
Serviceboks 422, Bygg I	4604	Kristiansand

Telefon:	Telefaks:	Mobil:	E-postadresse:
38141894		99248832	liv.fegrania.no

4. PROSJEKTNUMMER OG PROSJEKTTITTEL

Nummer:
10244

Tittel:
Møte mellom mødre, fedre og sykepleiere ved en nyfødtpost

5. ENDRING

Etter transkribering av data fra intervjuer og observasjoner er data registrert ved at deltakerne benevnes (se vedlegg 1);
Mor 1, mor 2, 3 osv.. Far 1, 2 osv, og sykepleiers fornavn. Barna er registrert med fornavn og fødselsdato for å kunne registrere antall uker innleggelse på posten. Data er lagret på mitt personlige område på universitetets nettverk, alle dokumenter er passordbeskyttet.

Datasamlingen er gjennomført ifølge fremdriftsplanen (avsluttet november 2004), men analyse og skriving i etterkant har overskredet planlagte tidsrammen. Jeg er nå i en avsluttende fase av mitt arbeid, planlagt innlevering er høsten 2008. Data må oppbevares til avhandlingen er forsvart. Tidsbruken fra innlevering til forsvar av avhandling kan være lite forutsigbar. For å være på den sikre siden søkes det derfor om tillatelse til å oppbevare data til forsvar av avhandling er fullført, eller maksimum til utgangen av 2009.

Er det spørsmål i forbindelse med utfylling av skjemaet, ta gjerne kontakt med Personvernombudet hos NSD, telefon 55 58 21 17

6. SPESIELLE TILLATELSER[iv]

Er endringen meldt til Regional komité for medisinsk forskningsetikk?I	☐ Ja ☒ Nei	Hvis ja, legg ved eller ettersend kopi av tilråding
Gjør endringen at prosjektet nå blir fremleggelsespliktig for Regional komité for medisinsk forskningsetikk (inkludert melding om forskningsbiobank)?	☐ Ja ☒ Nei	Hvis ja, legg ved eller ettersend kopi av tilråding
Gjør endringen det nødvendig å søke om dispensasjon fra taushetsplikt for å få tilgang til data?	☐ Ja ☒ Nei	Hvis ja, legg ved eller ettersend dispensasjon

7. TILLEGGSOPPLYSNINGER

8. ANTALL VEDLEGG

Legg ved eventuelle nye vedlegg (forespørsel, intervjuguide, registreringsskjema, spørreskjema, tillatelser og lignende).	Registreringsskjema for datasamling.

Regional komite for medisinsk forskningsetikk
Sør-Norge (REK Sør)

Førsteamanuensis, dr.polit. Sølvi Helseth
Høgskolen i Oslo
Falbes gate 5
0170 Oslo

Deres ref.: **Vår ref.:** S-03152 **Dato:** 01.07.03

Møte mellom mødre, fedre og sykepleiere ved en nyfødtpost
Prosjektleder: Førsteamanuensis dr.polit. Sølvi Helseth, Høgskolen i Oslo

Komiteen behandlet prosjektet i sitt møte torsdag 19. juni 2003.

"Komiteen har ingen forskningsetiske innvendinger mot prosjektet.

Komiteen har følgende kommentarer til pasientinformasjonen spesielt:

1. Informasjonsskrivene bør starte med en forespørsel om å delta i en studie og tittelen på denne.
2. Før forskeren presenterer seg, bør studien presenteres og forklares på en grei og forståelig måte.
3. Det bør informeres om at bruk av Minidisc og lydbånd er frivillig, og om det evt. er noe alternativ til dette.
4. Det bør gjøres oppmerksom på at mor og far intervjues enkeltvis og ikke sammen.
5. En endelig dato for sletting/makulering av lydbånd/materiale bør settes.

Vedtak:
Under forutsetning av at prosjektleder tar hensyn til merknadene ovenfor, tilrår komiteen at prosjektet gjennomføres. Revidert pasientinformasjon sendes komiteen til orientering."

Vi ønsker lykke til med prosjektet.

Med vennlig hilsen

Sigurd Nitter-Hauge (sign)
Professor dr.med.
Leder

Ola P. Hole
Avdelingsleder
Sekretær

Kopi: Liv Fegran

Regional komité for medisinsk forskningsetikk, Sør-Norge
v/ avdelingsleder Ola P. Hole
Postboks 1130, Blindern
0318 Oslo

MOTTATT

15 AUG 2003

REK II

Inst. for sykepleiefag
Gimlemoen 25 I, Serviceboks 604
4809 ARENDAL
Telefon: 38 14 18 50
Telefaks: 38 14 18 51
Org.nr.: 970 546 200 MVA

Deres ref.: S-03152   Vår ref.:   Dato: 14. august 2003

Revidert pasientinformasjon - til orientering

Takk for positiv tilbakemelding på søknad om gjennomføring av prosjektet *Møte mellom mødre, fedre og sykepleiere ved en nyfødtpost,* behandlet i deres møte 19. juni 2003.

Vedlagt sendes revidert pasientinformasjon til orientering ifølge vedtak av samme dato.

Tatt til etterretning
20-08-03

Med hilsen

Liv Fegran

Liv Fegran
Høgskolelektor

Regional komité for
medisinsk forskningsetikk
Sør-Norge

Vedlegg
1. Informasjon til foreldre
2. Informasjon til sykepleiere

Avd. administrasjonen	Sykehusveien 4, Serviceboks 604	4809 Arendal	Tlf 37 00 40 00	Faks 37 00 40 01
Inst. for sykepleiefag	Gimlemoen 25 I, Serviceboks 604	4809 Arendal	Tlf 38 14 10 00	Faks 38 14 13 01
Inst. for sykepleiefag	Sykehusveien 4, Serviceboks 604	4809 Arendal	Tlf 37 00 40 00	Faks 37 00 40 01
Inst. for idrettsfag	Gimlemoen 25 I, Serviceboks 604	4809 Arendal	Tlf 38 14 10 00	Faks 38 14 13 01
Inst. for helsefag	Gimlemoen 25 I, Serviceboks 604	4809 Arendal	Tlf 38 14 10 00	Faks 38 14 13 01
Inst. for helsefag	Sykehusveien 4, Serviceboks 604	4809 Arendal	Tlf 37 00 40 00	Faks 37 00 40 01

Informasjon til foreldre

Som mor eller far til et barn ved nyfødtposten ønsker jeg å forespørre deg om å delta i forskningsprosjektet *'Møte mellom mødre, fedre og sykepleiere ved en nyfødtavdeling'*.

Hensikten med prosjektet er å beskrive hvordan mødre, fedre og sykepleiere på en nyfødtavdeling opplever møter med hverandre. Jeg vil sammenligne mødres og fedres opplevelser av møtene, og undersøke om det eksisterer en felles oppfatning blant sykepleierne om hvordan man møter foreldre. I tillegg ønsker jeg å få deltakernes beskrivelse av hvordan dette samarbeidet utvikler seg over tid når barnet er innlagt. Undersøkelsen gjennomføres ved Sørlandet sykehus HF, Kristiansand.

Du som mor eller far er bedt om å delta i dette prosjektet ut fra at du er vurdert av lege som i stand til å delta i undersøkelsen, ditt barn er født prematurt med en gestasjonsalder på maksimum 32 uker, og at dere begge foreldre sammen har omsorgen for barnet mens det er innlagt på sykehuset.
Sykepleiere som deltar i prosjektet er valgt ut fordi de har vært ansatt i avdelingen minimum et år i minimum 50 % stilling.

Dersom du velger å delta i dette prosjektet sier du ja til følgende:
1. Du vil bli observert i møter med sykepleiere ved nyfødtposten. Under noen av observasjonene vil sykepleier bære en Voice recorder (lydopptaker), og det som blir sagt i møter mellom deg og sykepleier blir tapet. I etterkant utgjør opptaket et muntlig materiale som blir en del av mine data. Bruk av lydbånd i tillegg til feltnotater vil gi en fyldig beskrivelse av situasjonen. Jeg vil unngå å sile ut data som for meg ikke synes viktige der og da, men som i etterkant kan vise seg å være av betydning. Opptak av det som blir sagt under observasjonene er frivillig. Dersom du ikke ønsker at opptak benyttes i enkelte situasjoner vil dette ikke bli gjennomført.

2. Som deltaker i prosjektet vil du bli intervjuet individuelt (mødre og fedre hver for seg) om hvordan du opplevde å få et kritisk sykt nyfødt barn, og dine møter med sykepleier fra innleggelse til utskrivelse. Intervjuet vil foregå når tiden for utskrivelse nærmer seg. Jeg vil intervjue mor og far hver for seg, fordi jeg ønsker å se på om det er forskjeller i deres opplevelser av møter med sykepleier. Av personlig opplysninger ønsker jeg å vite noe om din alder, kjønn, sivil status, yrke, bosted og eventuelt andre barn og deres alder.

Jeg er som forsker underlagt taushetsplikt. Alle data vil bli behandlet konfidensielt og anonymisert, og vil ikke kunne føres tilbake til deg som person. Alle disketter og notater med personlige opplysninger vil bli oppbevart utilgjengelig for andre enn mine veiledere og meg under hele prosessen, og de vil bli makulert når forskningsarbeidet er fullført, senest 31.12.2007. Prosjektet resultater kan, i tillegg til avhandlingen, publiseres i aktuelle tidsskrifter og presenteres på konferanser.
Du vil som deltaker ikke få noen direkte goder av å delta i prosjektet. Jeg håper imidlertid at ditt bidrag vil være med på å gi økt kunnskap om temaet, og komme både foreldre og sykepleiere til gode i framtiden.

Mitt navn er Liv Fegran. Jeg er sykepleier og doktorgradsstudent ved Det medisinske fakultet, Universitetet i Oslo, og prosjektet er en del av mitt doktorgradsarbeid. Ønsker du ytterligere informasjon om prosjektet kan du ta kontakt med min veileder 1. amanuensis Sølvi Helseth ved Høgskolen i Oslo, eller undertegnede.
Regional komite for medisinsk forskningsetikk har tilrådd gjennomføring av prosjektet. Prosjektet er også meldt til Personvernombudet for forskning, Norsk samfunnsvitenskapelig datatjeneste AS.

| Liv Fegran | Tlf. **38 14 18 94** (arbeid) | Sølvi Helseth | Tlf. **22 45 37 73** (arbeid) |
| | Tlf. **99 24 88 32** (mobil) | | Tlf. **90 02 02 78** (mobil) |

Med vennlig hilsen

Liv Fegran

Informasjon til sykepleiere

Jeg ønsker å forespørre deg som sykepleier ved nyfødtposten om å delta i forskningsprosjektet *'Møte mellom mødre, fedre og sykepleiere ved en nyfødtavdeling'*.

Prosjektet er en del av mitt doktorgradsarbeid. Hensikten med prosjektet er å beskrive hvordan mødre, fedre og sykepleiere på en nyfødtavdeling opplever møter med hverandre. Jeg vil sammenligne mødres og fedres opplevelser av møtene, og undersøke om det eksisterer en felles oppfatning blant sykepleierne om hvordan man møter foreldre. I tillegg ønsker jeg å få deltakernes beskrivelse av hvordan dette samarbeidet utvikler seg over tid når barnet er innlagt. Undersøkelsen gjennomføres ved Sørlandet sykehus HF, Kristiansand.

Du som sykepleier er bedt om å delta i dette prosjektet fordi du har vært ansatt i avdelingen minimum et år i minimum 50 % stilling.
Foreldre som deltar i undersøkelsen er valgt ut fordi de er vurdert av lege som i stand til å delta i undersøkelsen, deres barn er født prematurt med en gestasjonsalder på maksimum 32 uker, og at begge foreldre har sammen omsorgen for barnet mens det er innlagt på sykehuset.

Dersom du velger å delta i prosjektet sier du ja til følgende:
1. Du vil bli observert i møter med foreldre ved nyfødtposten. Under noen av observasjonene vil du bære en Minidisc, og det som blir sagt i møter mellom deg og foreldre blir tapet. I etterkant utgjør opptaket et muntlig materiale som blir en del av mine data. Bruk av lydbånd i tillegg til feltnotater vil gi en fyldig beskrivelse av situasjonen. Jeg vil unngå å sile ut data som for meg ikke synes viktige der og da, men som i etterkant kan vise seg å være av betydning. Opptak av det som blir sagt under observasjonene er frivillig. Dersom du ikke ønsker at opptak benyttes i enkelte situasjoner vil dette ikke bli gjennomført.

2. Du vil også bli intervjuet om hvordan du opplever møter med mødre og fedre. Jeg ønsker at du forteller litt om det å være sykepleier på en nyfødtavdeling, og utvikling av ditt samarbeid med foreldre fra barnets fødsel og fram til utskrivelse. Av personlig opplysninger ønsker jeg å vite noe om din alder, når ble du utdannet sykepleier, hvor lenge har du jobbet på denne avdelingen/type avdeling, og om du har noen spesialutdanning og/eller videreutdanning. Intervjuet vil ha en åpen form, og vil i stor grad ha preg av en samtale. Hvert intervju vil vare cirka 1-1 ½ time, og vil bli tapet.

Jeg er som forsker underlagt taushetsplikt. Alle data vil bli behandlet konfidensielt og anonymisert, og vil ikke kunne føres tilbake til deg som person. Disketter og notater med personlige opplysninger vil bli oppbevart utilgjengelig for andre enn mine veiledere og meg under hele prosessen, og de vil bli makulert når forskningsarbeidet er fullført , senest 31.12.2007. Prosjektets resultater kan, i tillegg til avhandlingen, publiseres i aktuelle tidsskrifter og presenteres på konferanser.
Du vil som deltaker ikke få noen direkte goder av å delta i prosjektet. Jeg håper imidlertid at ditt bidrag vil være med på å gi økt kunnskap om temaet, og komme både foreldre og sykepleiere til gode i framtiden. Avdelingen du er ansatt på vil motta et eksemplar av avhandlingen.

Mitt navn er Liv Fegran. Jeg er sykepleier og doktorgradsstudent ved Det medisinske fakultet, Universitetet i Oslo, og prosjektet er en del av mitt doktorgradsarbeid. Ønsker du ytterligere informasjon om prosjektet kan du ta kontakt med min veileder 1. amanuensis Sølvi Helseth ved Høgskolen i Oslo, eller undertegnede.
Regional komite for medisinsk forskningsetikk har tilrådd gjennomføring av prosjektet. Prosjektet er også meldt til Personvernombudet for forskning, Norsk samfunnsvitenskapelig datatjeneste AS.

Liv Fegran	Tlf. **38 14 18 94** (arbeid)	Sølvi Helseth	Tlf. **22 45 37 73** (arbeid)
	Tlf. **99 24 88 32** (mobil)		Tlf. **90 02 02 78** (mobil)

Med vennlig hilsen

Liv Fegran

Skriftlig informert samtykke fra foreldre om deltakelse i doktorgradsprosjektet
'Møte mellom foreldre og sykepleiere ved en nyfødtpost'

Mitt navn er Liv Fegran. Jeg er sykepleier og doktorgradsstudent ved Det medisinske fakultet, Universitetet i Oslo.

Doktorgradsprosjektets hensikt er todelt; for det første å beskrive hvordan mødre, fedre og sykepleiere på nyfødtposten opplever og beskriver møter med hverandre, og for det andre hvordan forholdet utvikler seg i løpet av den tiden barnet er innlagt.

Dersom du velger å delta i studien sier du ja til å bli observert i samhandling/møter med sykepleiere ved nyfødtposten. Under noen av observasjonene vil sykepleier bære en Minidisc, og det som blir sagt i møter mellom deg og sykepleier blir tapet. I etterkant utgjør opptaket et muntlig materiale som blir en del av mine data.
Du vil også bli intervjuet om hvordan du opplever møter med sykepleiere. Intervjuet vil ha en åpen form, og vil i stor grad ha preg av en samtale. Et intervju vil vare cirka 1-1 ½ time, og vil bli tapet.

Alle data vil bli behandlet konfidensielt og anonymisert, og vil ikke kunne føres tilbake til deg som person. Alle disketter og notater med personlige opplysninger vil bli oppbevart innelåst, og bli makulert innen et år etter at avhandlingen er avsluttet.

Det gis ingen økonomisk dispensasjon for deltakelse i studien. Studiens resultater kan, i tillegg til avhandlingen, publiseres i aktuelle tidsskrifter og presenteres på konferanser.

Ønsker du ytterligere informasjon kan du ta kontakt med min veileder 1. amanuensis Sølvi Helseth ved Høgskolen i Oslo, eller undertegnede.

Liv Fegran   Tlf. **38 14 18 94** (arbeid)   Sølvi Helseth   Tlf. **22 45 37 73** (arbeid)
              Tlf. **38 04 34 98** (privat)   Tlf. **90 02 02 78** (mobil)
              Tlf. **99 24 88 32** (mobil)

Jeg har lest informasjonsskrivet om forskningsprosjektet, og forstår at deltakelse er frivillig. Jeg kan si nei til å delta, eller på hvilket som helst tidspunkt i prosjektet trekke mitt samtykke uten grunn. Velger jeg ikke å delta i prosjektet vil dette ikke få noen innvirkning på mitt forhold til leger eller sykepleiere ved avdelingen.

Sted og dato

-----------------------------------   -----------------------------------
Underskrift mor/far   Underskrift prosjektansvarlig

Skriftlig informert samtykke fra sykepleiere om deltakelse i doktorgradsprosjektet
'Møte mellom foreldre og sykepleiere ved en nyfødtpost'

Mitt navn er Liv Fegran. Jeg er sykepleier og doktorgradsstudent ved Det medisinske fakultet, Universitetet i Oslo.

Doktorgradsprosjektets hensikt er todelt; for det første å beskrive hvordan mødre, fedre og sykepleiere på nyfødtposten opplever og beskriver møter med hverandre, og for det andre hvordan forholdet utvikler seg i løpet av den tiden barnet er innlagt.

Dersom du velger å delta i studien sier du ja til å bli observert i samhandling/møter med foreldre som har barnet sitt innlagt ved nyfødtposten. Under noen av observasjonene vil du bære en Minidisc, og det som blir sagt i møter mellom deg og foreldre blir tapet. I etterkant utgjør opptaket et muntlig materiale som blir en del av mine data.
Du vil også bli intervjuet om hvordan du opplever møter med mødre og fedre. Intervjuet vil ha en åpen form, og vil i stor grad ha preg av en samtale. Et intervju vil vare cirka 1-1 ½ time, og vil bli tapet.

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Ønsker du ytterligere informasjon kan du ta kontakt med min veileder 1. amanuensis Sølvi Helseth ved Høgskolen i Oslo, eller undertegnede.

Liv Fegran	Tlf. **38 14 18 94** (arbeid)	Sølvi Helseth	Tlf. **22 45 37 73** (arbeid)
	Tlf. **38 04 34 98** (privat)		Tlf. **90 02 02 78** (mobil)
	Tlf. **99 24 88 32** (mobil)		

Jeg har lest informasjonsskrivet om forskningsprosjektet, og forstår at deltakelse er frivillig. Jeg kan si nei til å delta, eller på hvilket som helst tidspunkt i prosjektet trekke mitt samtykke uten grunn. Velger jeg ikke å delta i prosjektet vil dette ikke få noen innvirkning på mitt forhold til leger eller sykepleiere ved avdelingen.

Sted og dato

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Underskrift sykepleier   Underskrift prosjektansvarlig

Paper I

Fegran L., Helseth S. and Slettebø Å.

Nurses as moral practitioners encountering parents in neonatal intensive care units.

Nurses as Moral Practitioners Encountering Parents in Neonatal Intensive Care Units

Liv Fegran, Sølvi Helseth and Åshild Slettebø

Key words: Løgstrup; moral practice; NICU; nurses; parents

Historically, the care of hospitalized children has evolved from being performed in isolation from parents to a situation where the parents and the child are regarded as a unit, and parents and nurses as equal partners in the child's care. Parents are totally dependent on professionals' knowledge and expertise, while nurses are dependent on the children's emotional connection with their parents in order to provide optimal care. Even when interdependency exists, nurses as professionals hold the power to decide whether and to what extent parents should be involved in their child's care. This article focuses on nurses' responsibility to act ethically and reflectively in a collaborative partnership with parents. To illuminate the issue of nurses as moral practitioners, we present an observation of contemporary child care, and discuss it from the perspective of the Danish moral philosopher KE Løgstrup and his book *The ethical demand*.

Introduction

The role of parents in neonatal intensive care units (NICUs) has changed dramatically over the last century. A historical review (Table 1) shows a shift from nurses having a paternalistic attitude towards parents to regarding them as partners in caring for their child. Today, family-centred care is considered 'best practice' in NICUs, with a collaborative partnership as the foundation of the encounter between nurses and parents. In this collaborative partnership, parents are supposed to be invited to participate actively to the extent that they take part in the assessment, planning, implementation and evaluation of care. They are, however, totally unprepared and inexperienced in parenting a critically ill newborn child, while nurses are prepared, educated in care and experienced. Parents also have a strong emotional involvement in the situation, while the nurses' involvement is professional. Despite this asymmetrical basis, there is an element of interdependency in the child's care, because, just as parents are dependent on the professionals' knowledge and expertise, the professionals are dependent on the child's emotional and physical connection with the

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Table 1 A synthesis of four models of care[6] and international and national legislation influencing Norwegian neonatal care, and the historical development of neonatal care

Date and type of care	Models of care				Acts and regulations
	Medical	Child focused	Family focused	Family centred	
1900–1940	Focus on basic physical needs: Temperature, Prevention of infection, Breast milk, Oxygen therapy was introduced				Personal individual freedom was being discussed, but not according to the patient's role. Patient participation was not an ethical issue
1941–1960 Parental involvement	Focus on unforeseen physical complications from treatment procedures	Cleanliness and sterility excluded active maternal involvement. Mothers encouraged in providing breast milk for their infants	Parents primarily cared for premature infants after discharge		1948: UN's Declaration of Human Rights[18]. 1953: ICN Code of Ethics for nurses[19]
1961–1970		The view that children adjusted best to hospitalization without receiving family visits was starting to change	The hospitalized child was isolated from the parents. Research was initiated on parent–infant interaction and mother/infant bonding		1964: World Medical Association Declaration of Helsinki[20]
1971–1980 Participation	Neonatology emerged as a recognized medical specialty	Parents were allowed into NICUs, but just as visitors. Incubated children were not to be held by their parents	Acknowledgement of the family's role in the care of premature children. Increased research on parent–infant interaction and mother/infant bonding. Husbands/partners allowed to act as 'labour coaches'		Caring and feminist ethics stressing relationships became more accepted

Table 1 (*Continued*)

Date and type of care	Models of care				Acts and regulations
	Medical	Child focused	Family focused	Family centred	
1981–1995 Partnership in care	Development of sophisticated technology and treatment Critique of the power of professionals 'Care' stressed in addition to 'cure' Ethical discussions	Increased research on infants' physical and emotional behaviour Skin-to-skin holding became routine	Rooming-in. Increased involvement of family Siblings and family were allowed access to the ward Family involvement was increasing, but with little focus on the needs of individual family members		1983: The Norwegian nurses' professional code of ethics 1988: Regulations concerning children in Norwegian hospitals[35] 1999: Norwegian Act concerning patients' rights[36] 1994: Declaration on the promotion of patients' rights in Europe[37]
1995–2004 Family-centred care	Continuous technological development, e.g.: Pain relief Ventilation Medical examinations	The environment was adjusted to the child's needs by individualized developmental care (NIDCAP)		Parents are their child's advocates, and active participants in the decision-making process Increased involvement of parents/individual and family members' needs Focus on fathers' individual needs	1997: Convention on human rights and biomedicine[38] 1999: Several acts concerning patients' and professionals' rights[39-41] 2000: Revision of World Medical Association Declaration of Helsinki 2000: Latest revision of the ICN's and the Norwegian nurses' codes of ethics

parents. This interdependency can however become a power-dependency situation if nurses, by their professional authority, exclude parents from being involved in their child's care. The relationship between parents and nurses therefore constitutes an ethical challenge for nurses: to be moral practitioners who act ethically and reflectively when encountering parents in an NICU.

Literature review

The published literature was systematically searched using a snowball method. A search of CINAHL and MEDLINE to the year 2004, using the keywords 'NICU', 'parents', 'nurses' and 'history', revealed the historical development of neonatal care (Table 1). For greater understanding of the concept of family-centred care, a further search of CINAHL, ISI and MEDLINE was conducted using the keywords 'family-centred care', 'NICU' and 'evaluation' to the year 2005. This search highlighted parents' pivotal role in their children's care. However, there seemed to be a discrepancy between the theoretical foundation of family-centred care and its implementation in NICUs. This discrepancy was explained variously: a lack of consensus in the meaning of the concept of family-centred care,[1-6] questioning the feasibility of family-centred care in NICUs,[1,7–9] or parents' and nurses' different experiences with the approach.[7–15]

Learning about these aspects of neonatal care prompted us to deepen our under-standing of the relationship between parents and nurses, especially the aspect of nurses' responsibility as professionals when encountering parents. The view of nurses as moral practitioners is presented here from the perspective of the Danish moral philosopher KE Løgstrup, specifically addressing issues surrounding the concept of 'ethical demand' as presented in his similarly titled book, *The ethical demand.*[16] Finally, an observation originating from a Norwegian NICU in 2004, illustrating how nurses may reflectively encounter the parents of a critically ill child, is discussed.

Neonatal care: from autocracy to partnership (Table 1)

Until 1940, neonatal care was dominated by professionalization and institutionaliza-tion, and contact between these children and their parents was almost nonexistent.[17] Health care professionals treated hospitalized children autocratically, and the family and other relatives had no influence on the children's care.

During the 1940s and 1950s, a child's functioning was supposedly independent of context.[6] Professionals widely believed that children adjusted best to hospitalization without family visits, and the family was expected to comply with treatment recommendations. However, the general view that hospitalized individuals had no right to influence their situation was beginning to change.[18–20] This change in perspective on human life also influenced the care of hospitalized children, and a child-focused approach, emphasizing hospitalized children's individual needs, became more dominant.

Changing perceptions of the family's contribution, especially the mother's role, began with the work of Bowlby during the 1950s.[21,22] Emotional problems in infants

who were separated from their parents were described for the first time.[23,24] The work of early authors on the topic coincided with new knowledge about cross-infection, which had been one of the factors excluding parents from hospital wards. This new knowledge led to a significant reconfiguration of hospital design, policy and practice. By the end of the 1960s, parents were finally permitted to enter the nursery.[25] However, it took decades before Bowlby's research resulted in changes enabling parents to participate actively in their children's care.

By 1970, neonatology was recognized as a medical specialty, and relationships based on caring, feminist ethics became more accepted.[26] This new ethical awareness influenced neonatal care and attitudes towards parents and families,[27] but despite this, parents were still regarded as visitors in the NICU. It was the professionals' assessment, and the professionals' perception of the family's needs, that formed the basis of interventions. The focus was the mother, sometimes both parents, but rarely other individual family members such as the father.[28–33]

In 1984, the first Norwegian code of nursing ethics[34] was accepted, followed by several regulations and acts concerning children's and patients' rights.[35–37] Acknowledgement of the importance of close contact between parents and their child grew steadily,[25,27] and by the end of the 1980s parents were allowed to live with their child in hospital (rooming-in). There was also an expectation that parents would become actively involved in the care and decision making concerning their child.

From the mid-1990s, further acts and conventions concerning hospitalization were accepted.[36,38–41] Revisions of the Helsinki declaration, and of the ICN and Norwegian codes of ethics, demonstrated a strong awareness of ethical standards in professional health care. These all contributed to strengthening the rights of hospitalized persons by providing ethical standards and legal rights regarding research, treatment and care. Parents today are an integrated part of their child's care in hospital. The principles of individualized developmental care of newborns as promoted by the Newborn Individualized Developmental Care and Assessment Program (NIDCAP®) strongly influence nursing in NICUs.[42–44] Family-centred care, based on the principles of respect, information sharing, collaboration and confidence building, is today considered 'best practice' in NICUs.[1,5,45–48]

Family-centred care

The literature on family-centred care was first developed in the context of children with special educational needs, and was adapted later to provide a framework of care for critically and chronically ill children.[5,10,49] Despite today's acceptance of family-centred care as a central element of paediatric nursing, there seems to be a discrepancy between the theoretical foundation of the concept and its implementation in practical life.[1,3,9,10,45,50–52]

According to Hutchfield,[5] family-centred care can be seen as a hierarchy that may be applied to all children and families, and which assumes various levels of parental involvement. The hierarchy begins with parental involvement, proceeds to parental participation, then to partnership, and finishes as family-centred care. The lowest level (parental involvement) is said to represent the minimum that any family could expect of the nursing profession, whereas family-centred care in its fullest sense may be implemented only in some cases.

Cahill[53] supports the hierarchical view of the relational concepts and compares the meaning of patient participation with patient partnership, patient collaboration and patient involvement. Patient collaboration and involvement form the base, and are the precursors to patient participation, which in turn is the precursor to patient partnership. The highest level is an ideal goal, but may not necessarily be achieved in practice.

Nethercott[46] believes that family-centred care can be detrimental to a child in some instances. This view is shared by Cahill,[53] who states that, despite recognizing the parents' need to be involved in planning and evaluating care, family-centred care is not always attainable or desirable.

Letourneau and Elliott[9] explain the discrepancy between perceptions and practices by what they call 'the dilemma of helping'. The medical model of helping directs professionals to assume the role of evaluator and controller of treatment interventions, which results in parental dependence. In contrast, family-centred care is intended to empower parents. Influence on the level of care given by the 'helping model' position is in direct conflict with the conditions needed for more active parental involvement.

MacKean *et al.*[10] argue for a critical reflection of the evolution of family-centred care, and strongly advocate moving beyond conceptualizing and operationalizing family-centred care as simply training parents to assume more responsibility for their child's care and care management. Rather, their research supports the development of a collaborative relationship between families and health care providers, in which the respective roles are jointly determined rather than being dictated by health care providers.

According to Trivette *et al.*,[52] further advances require the next generation of family-centred care issues to move beyond conceptual considerations towards translation of the philosophy into concrete practice indicators. One contribution to this effort could be our discussion of parental involvement on admission of a newborn infant to an NICU. This thesis discusses the encounter between parents and nurses from the viewpoint expressed in Løgstrup's book, *The ethical demand.*[16]

The ethical angle: 'We are each other's life and destiny'

Parents and nurses in an NICU have a common concern, namely a critically ill newborn child, hospitalized sometimes for weeks and months. This prolonged relationship is demanding for both parties, and the experiences of parents and nurses are crucial in determining how both cope with the situation. Here, we use Løgstrup's[16] ethics to illuminate this parent–nurse relationship.

Løgstrup was a Danish philosopher and theologian who developed his theories of ethics from the early 1950s to the mid 1970s. He was a phenomenologist, inspired mainly by German philosophers. Løgstrup criticized traditional views of human beings as independent and autonomous, existing in their own world and excluding others. According to Løgstrup, the basic ontological fact about human existence is that we are always intertwined with and in the lives of other human beings. This entanglement of our lives is ontologically present prior to our constitution as individual persons. In this relationship the consequences are clear: the other person's life is dependent on how one acts in a situation.

Being intertwined with other human beings, our life is characterized by encountering one another with natural trust. To trust is to lay oneself open to the other person.

Abused trust is not only deeply hurtful, but is made worse by the trust being scorned by the other person. Trust is related to the interdependence that exists between people and is guided by the ethical 'demand' that human beings should protect another's life when it is entrusted to them. However, trust is not always an idyllic phenomenon; it may also serve as a context in which power is exercised. One person's exposure is the other person's control, as Løgstrup states: 'Out of this basic dependence and direct power arises the demand that we take care of that in the other person's life which is dependent upon us and which we have in our power' (p. 28).[16] Løgstrup goes on to say that this same demand, however, 'forbids that we ever attempt', even for other people's sake, to rob them of their independence; responsibility never consists of assuming the other person's responsibility (p. 28).

The encounter between parents and nurses in an NICU could comprise a typical power and dependency context. It is very important to make visible the underlying and inevitable power relationships in hospital settings (that is, to ensure these situations are not concealed) so as to allow meaningful relationships between parents and nurses.

How do human beings appear to one another? In his book Løgstrup describes sovereign and spontaneous life manifestations as the way in which human beings express themselves to each other.[16] These life manifestations include trust, hope, shame, openness of speech and compassion. According to Løgstrup, they are prereflective and spontaneous because they are the way we naturally meet the other person, unless we actively decide to act differently. The demand implicit in every encounter is silent, not vocal. Therefore the individual, to whom the demand is directed in each relationship, must decide the nature of the demand. When we approach the other person, we are exposing something of our lives; we are making ourselves vulnerable.

Parents in an NICU are placing their precious child in the hands of nurses, and trust is a fundamental aspect of their relationship with these nurses. Parents are frightened, vulnerable and strongly emotionally involved in the situation. They do not have a choice about whether they should give responsibility to the health care professionals; they are obliged to deliver the child into their care. This ethical demand means that nurses have a great responsibility in caring for the premature child and the child's family.

From a field observation in a Norwegian NICU in 2004, we now provide an example of how nurses, by recognizing the ethical demand in caring for children whose parents have entrusted them into their hands, can help to create a collaborative partnership.

Nurses as moral practitioners

MacKean *et al.*'s research showed that when family-centred care is operationalized the collaborative process often disappears.[10] To discuss the collaborative process by focusing on nurses as moral practitioners, we describe an encounter between nurses and a newborn premature child and the parents. The observation was conducted one morning in February 2004, when a newborn child with a gestation age of 29 weeks had just arrived in the NICU. The child had been delivered by caesarean section, and the mother was in an intensive care unit still asleep following anaesthesia. The father had

accompanied the mother until the surgical procedure commenced and had not yet entered the NICU. The child was accompanied to the unit by doctors and nurses.

The dependent child in the hands of the professionals

The admission of a newborn premature child to the NICU is one of the most stressful moments for the child, the parents and the professionals. The following observation notes capture the scene:

> The two incubator rooms are divided by a wall of glass; there are no parents present. In one of the rooms there is a resuscitation table in the corner, surrounded by monitoring equipment. When looking into the incubator room I can see two doctors working intensively and concentrating on a tiny newborn child. There is hectic activity around the table. A third doctor is observing, standing secluded in the background. The doctors are assisted by a nurse, while another nurse is documenting the child's treatment.

The newborn child has been delivered into the hands of the professionals. According to legislation and codes of ethics (Table 1) doctors and nurses are committed to save lives, and they are doing their utmost to fulfil this obligation. The care is founded on accumulated knowledge, and the child is given the best treatment regardless of social status, ethnicity or financial status. The nurse's responsibility at this time is to care for the child on behalf of the parents, thereby initiating a mutually trusting relationship. The parents, for their part, are trying to cope with their experiences in relation to the dramatic birth, and they are usually not willing or able to be active collaborators at this time. Rather than assessing whether care should be provided by the family, family-centred care stresses the importance of assuming this to be true.[46] Because parents are not familiar with their newborn child's needs, or do not have professional knowledge about acute care, it could be difficult to anticipate the level of parental participation. At this time, parental involvement (the lowest level of participation[5]) is based primarily on nurse-led care of the newborn child.

Focusing on the child's needs

After the acute phase, when stabilizing the child is critical, attention is focused on the child's need for protection against sensory overstimulation:

> There is a hectic atmosphere with a lot of professionals present, but hardly any noise or talking. The nurses avoid walking through the incubator room if not necessary. A trolley with an unfolded surgical kit is standing in the middle of the room; the gauze pads on the table are blood-stained. How could a tiny child lose such an amount of blood and still be okay? After a while the doctors straighten their backs while taking off their face masks, and the room is being tidied up. The nurse places the child in a 'nest' for comfort.

There has been a strong movement towards a humanistic view of hospitalized children, recognizing their physical and emotional needs.[21] Research stressing the importance of minimizing sensory impressions such as pain, noise and light is obliging nurses to put this new knowledge into practice, thus sheltering the dependent child.[43] In the above observation, if the nurses had not responded to the child's spontaneous life-manifestations as indicated by body language, facial expressions, crying or apathy, they would not have acted in the child's best interests, perhaps because of inadequate knowledge, will or time to focus on the child's specific needs. The business discourse

dominating today's health care, which emphasizes efficiency and cost-effectiveness, may also restrict individualized care. Individualized care may appear to be more time consuming and expensive than routine care, although in the long term it can provide a better outcome, both physical and emotional, for the child. Child-centred care therefore calls for nurses at all levels of the organization constantly to reflect on and improve the care according to current knowledge about the needs of hospitalized children.

Alertness and respect

Historically, there have been many reasons not to involve fathers in their child's care: the danger of contagion, questions about whether the father has a role in a newborn child's life, giving the nurses extra work, and so on. The major issue for today's nurses is not the question of whether to include fathers, but how to do so.[33] In this situation, a nurse initiates a relationship by inviting the father into the NICU to meet his daughter for the first time:

> The nurse who has assisted the doctors looks into the corridor to see if the father is out there. He is sitting in the parents' corner, and the nurse invites him into the room. For the first time the father is allowed to meet his child. The nurse congratulates him on a beautiful baby girl.

The father's experience of the encounter will be influenced by the nurse's awareness of how emotionally demanding and maybe frightening the situation could be for him. Focusing on positive aspects, for instance that the baby girl is 'beautiful' could help the father to cope with the situation. The nurse congratulating the father could also create a sense of hope and normality in a situation that is so abnormal and frightening. According to Løgstrup,[16] a nurse's attitude and response in such an encounter is pivotal; it helps to determine whether the other individual's world is experienced as large or small, bright or drab, rich or dull, threatening or secure. If the nurse is not aware of how crucial this encounter is, and the necessity of responding to the father's reactions, it could have a negative impact on their future relationship.

To lay oneself open

The first contact between father and child is a very special moment. It is a situation with which the father is unfamiliar; he has to rely on the professionals. How can the nurse help to create contact between the father and his child, who is placed in an incubator and connected to a lot of technical equipment?

> She tells the father that he can touch the child gently, if he would like to. 'She is so beautiful,' the nurse said. The father gently touches his daughter's tiny hand, and comments that her hand is no bigger than his own thumbnail.

There has been a tendency for nurses, as experts, to define the roles that parents are expected to play, instead of developing a collaborative relationship based on open communication, trust and negotiation.[10] This situation describes the father being encouraged to touch his little girl's hand for the first time. If the nurse lets the father decide whether he wants to approach his child or not by asking him, the father will not experience that the nurse is forcing him to do something he is not ready for, robbing

him of his independence. If the nurse respects the father's ability and willingness to be involved, he is invited into a relationship based on trust, respect and mutuality.

Initiating a partnership

The relationship between father, nurse and child has been established, but how can the mother also be involved? Mothers often grieve when they are deprived of the possibility of holding, smelling and cuddling their newborn child.[54] How can the nurse help to relieve this experience of loss of control and emotional contact?

> The nurse takes a picture of the girl, and a copy of her footprint.

The nurse is now visualizing the child to her parents; the child is being transformed from a fetus into a living person. The baby girl in the photograph looks exactly like herself, and the footprint shows the parents that, yes, she is tiny, but she is like nobody else! She has become a living person and she is linked to them as parents. This demonstrates how the nurse transfers power to the parents, identifying her as their progeny. This view differs from that held until the 1970s, when parents were not acknowledged as having a role in the care of hospitalized premature children (Table 1). Today, nurses acknowledge the importance of connecting children with their parents as early as possible, and the father's role is becoming more obvious.

> Together with the photo, footprint and a nice card, the father is asked to take these items to the mother, who is recovering from the general anaesthetic. The father is now the connecting link between mother and child. The nurse tells the father that both he and the mother are most welcome to visit their child in the NICU. The father leaves the unit.

The parents' involvement in the care of their infant is gradually evolving from involvement to participation.[5] Their presence is sought and there is an expectation that they should be with their child in the NICU. However, the parents' roller-coaster life between the NICU and their home highlights a more complicated aspect of the encounter. It is important to acknowledge the different levels of parental participation by discussing to what extent and in which situations parents are able and willing to participate.[5,46,53] The nature of the parents' and the child's unique roles and the evolving nature of the health care provider–family relationship need to be determined jointly.[10]

Interdependency

A relationship has now been created where the participants are dependent on each other. Both parents and nurses are unique human beings with individual needs, experience and knowledge. From this point, the encounter will progress depending on how the parents cope with their new role.

> After a couple of hours the parents enter the NICU; the mother still in a bed. The nurse welcomes them, and accompanies them to the incubator to meet their child. The father remains in the background, giving the mother the opportunity to meet and touch their newborn girl.

The father stands in the background, giving his wife the opportunity to experience the unique moment of meeting her newborn baby girl for the first time. The mother is the focus; the nurse and the father appear secluded. This sharing of responsibility also

makes the mother an important contributor to the relationship, and helps her to feel valued as a parent. However, this entails the nurse being willing to give parents the responsibility of becoming partners, in a way and to the degree they desire. Family-centred care emphasizes collaboration between parents and nurses, and this situation illustrates how parents can be contributors despite an asymmetrical relationship. Developing a relationship based on trust and openness empowers parents and helps them to achieve the highest possible level of involvement in their child's care, which, in some cases, may involve family-centred care.[5,9]

This story is an example from the initial phases of developing the parents' role in an NICU, and illustrates the responsibility of nurses in involving parents in their child's care. Nurses' experiences and attitudes, the atmosphere in the NICU context, the parents' emotional and physical condition and, not least, the child's condition, will strongly influence the relationship. Trust is a fundamental element in the encounter between parents and nurses, and can influence parents' experiences from feeling great satisfaction to a feeling of encroachment on their independence.[55]

Concluding remarks

Nurses caring for hospitalized premature children have experienced a radical change in the philosophy of care. From being concerned primarily with a child's physiological condition, nurses today are strongly aware of a child's various and complex needs, not least the importance of child–parent attachment. However, many parents experience their encounter with health professionals as a struggle characterized by the uncertainty of their roles.[10] The ethical demand for nurses is to reflect on their competence and willingness to involve parents in the care of their child to an extent and in areas jointly determined by both parents and professionals.

The mother of a premature girl born at 29 weeks wrote the following on a greetings card to the nurses after discharge from a Norwegian NICU: 'We treasure you as angels – you held me in your sheltered hands, and carried me into life.' This quotation could be an example of how parents are vulnerable and dependent but, despite this, their encounter with nurses can be a positive struggle if experienced as meaningful, or, as Løgstrup could have said, the nurses took care of those things for which parents and child were dependent upon them, and which they had in their power, but without robbing the parents of their independence. By focusing on nurses as moral practitioners in their encounters with parents, this thesis contributes to discussion of the collaborative process between parents and nurses in an NICU.

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Paper II

Fegran L., Helseth S. and Fagermoen M.S.

A comparison of mothers' and fathers' experiences of the attachment process in a neonatal intensive care unit.

A comparison of mothers' and fathers' experiences of the attachment process in a neonatal intensive care unit

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A comparison of mothers' and fathers' experiences of the attachment process in a neonatal intensive care unit

Aim. To compare mothers' and fathers' individual views and experiences of the attachment process in a neonatal intensive care unit within the first week after a premature birth.

Background. The attachment between parents and children is a precursor to the consolidation of parenting skills, the growth and development of the infant and the establishment of a bond between parent and child. Premature birth and the resultant hospitalization disrupt the normal attachment process between parent and child. Most of the litteraure on attachment theory focuses on the mother–child connection and is being criticised for regarding the father's role as supportive and peripheral.

Methods. The design of this study was descriptive with a hermeneutic approach. Twelve parents (six mothers and six fathers) in a 13-bed neonatal intensive care unit in a Norwegian regional hospital participated in a field study addressing the encounter between parents and nurses. This paper is based on the semi-structured interviews with the parents at discharge.

Results. The interview analysis revealed two main categories. (a) *Taken by surprise*: For mothers, the premature birth created a feeling of powerlessness and they experienced the immediate postnatal period as surreal and strange. The fathers experienced the birth as a shock, but were ready to be involved immediately. (b) *Building a relationship*: Mothers experienced a need to regain the temporarily lost relationship with their child, whereas the fathers experienced the beginning of a new relationship.

Conclusion. Comparing parents' experiences of the attachment process within the first days after a premature birth reveals a striking contrast between the mother's

experience of surrealism and the father's ability to be involved immediately after birth.

Relevance to clinical practice. Parents' of premature children's different starting points should be acknowledged as professionals encourage parents to have early skin-to-skin contact with their premature infant.

Key words: attachment, midwifery, nurses, nursing, premature birth, parents

Introduction

Premature birth and the first few days of life disrupt the relationship between the child and his or her parents and restoring this disrupted relationship poses a challenge in the neonatal intensive care unit (NICU) (Gay 1981, Billings 1995, Anderson 1996, Goulet *et al.* 1998, Lau & Morse 1998, Fegran *et al.* 2006). Supporting the attachment process between parents and their child may promote the consolidation of parenting skills, the social and psychological development of the child and the establishment of a bond between parents and child (Gay 1981, Anderson 1996).

Bowlby's (1969) attachment theory explains the fundamental impact of the emotional connection between a caregiver and a child on the child's emotional and psychological development. He states that children are born with a biological predisposition to seek proximity and contact and develop signalling mechanisms that make up an instinctual response system. Recent evidence from neuroscience supports Bowlby's assertions that the attachment theory explains instinctive behaviour as a biological function (Schore 2000, Feldman *et al.* 2003). Gay (1981) described the biological and affective aspects of attachment as a gradually developing process from the stimulus–response level to the acquaintance level. Bowlby (1969) positioned the first six months after birth as crucial in establishing an affective tie between mother and infant, whereas Klaus and Kennell (1976) hypothesised that the first hour after birth is crucial to this relationship. Despite the difference in time frame, it is obvious that the close contact between parent and child is important from the very start of life (Brody 1981, Tessier *et al.* 1998). Although the early theories focused on the attachment process after birth, later research has shown that the mother–foetal attachment grows stronger as pregnancy progresses (Cranley 1993, Cannella 2005). According to Goulet *et al.* (1998), the central characteristics of the attachment process between parents and child in a natural setting are proximity, reciprocity and commitment. Proximity through touch and visual contact are the most powerful communication tools parents utilize to interact with their infant. *Reciprocity*

involves the child as an active partner in the process of interaction and requires parents to be able to decode their infant's language to develop an attachment. Commitment refers to the enduring nature of the relationship.

Optimising the close contact between parents and child is an important issue in neonatal care. According to Sajaniemi *et al.* (2001) the cues tend to be disorganised and of lower intensity in premature infants rather than in full-term infants and are therefore more difficult for parents to respond adequately. An infant may be rejected by parents because the child is critically ill and tiny and may not survive. The rejecting parent may send inconsistent messages that may influence the attachment process negatively. Placing the naked baby prone on the parent's bare chest kangaroo mother care (KMC) has a positive influence on both the infants' and the parents' health (Brody 1981, Tessier *et al.* 1998, Charpak *et al.* 2001, Engler *et al.* 2002, Feldman *et al.* 2002, 2003, Anderson *et al.* 2003, Browne 2004, Browne *et al.* 2004, Carter *et al.* 2005, Conde-Agudelo *et al.* 2005). Tessier *et al.*'s (1998) study showed, however, that some mothers experience isolation and too much responsibility when practicing KMC 24 hours a day. The major barriers to the practice of KMC in hospitals are nurses' concern for infant safety and family or staff reluctance (Engler *et al.* 2002, Petersen *et al.* 2004).

Most of the literature on attachment theory focuses on the mother–child connection, even if the affective component of the relationship is comparable in mothers and fathers (Gay 1981, Billings 1995, Anderson 1996). Moehn and Rossetti (1996) found significant differences in the experiences of mothers and fathers. Mothers were more emotional than fathers were and fathers had significantly greater difficulty than mothers interacting with their infant because of the child's fragility. Others have reported that, the earlier fathers held their baby and were active participants in their child's care, the sooner they reported feelings of warmth and love for him or her (Moehn & Rossetti 1996, Lundqvist & Jakobsson 2003). The frequency of parental visits to the NICU is a significant predictor of the father's later relationship with the infant and the quality of the infant's development (Gloppestad 1995, Sullivan 1999).

Aim

In the present study of encounters between parents and nurses in a Norwegian (NICU), a crucial issue for parents was parent–child attachment. In the interviews, mothers and fathers described the challenging early bonding process, but their experiences immediately after birth seemed to be quite different. These findings led to further reading on attachment theory and the attachment process in parents of premature newborns was compared with that experienced by parents of healthy newborns. The aim of this study was to obtain in depth knowledge of and to compare parents' individual experiences of the attachment process immediately after a premature birth.

Methods

This study involved a descriptive design with a hermeneutic approach using a fieldwork method to obtain in-depth knowledge about the encounter between parents and nurses in an NICU. This article is based on the interviews of mothers and fathers in connection with discharge from hospital. The study protocol was approved by the Regional Committee for Medical Research Ethics, the Ombudsman for Privacy in Research at the Norwegian Social Science Data Services and the hospital's research department.

Research context and participants

The study was conducted in a 13-bed NICU in a regional Norwegian hospital. A convenience sample of parents was established using the following inclusion criteria: (a) their infant's gestation age was 32 weeks or less; (b) their infants stayed at the same hospital from birth until they were ready for discharge to home; (c) a family of a mother and father and (d) both parents agreed to participate in the study. The total number of children admitted to the unit during the 27-week field research period was 95 and 12 of the 95 children were 32 weeks or younger. Parents who met the inclusion criteria were consecutively asked to participate in the study. The inclusion process continued until the desired number of six couples was reached; two of the screened couples did not want to be included in the study. Table 1 presents the demographics of the sample.

Data collection

The study's 27-week field research period lasted from October 2003 until March 2004 and from September until November 2004. The interviews addressed the parents'

Table 1 Demographic data

Mother's age	Father's age	Previous births	Type of birth	Child's gestation age (weeks)	Hospitalization (weeks)
42	59	2	Cesarean	32	3
29	30	0	Cesarean	28	10
34	34	1	Cesarean	29	11
25	30	0	Cesarean	31	6
26	27	1	Vaginal	30	6
32	37	2	Vaginal	32	5

experiences of becoming mother or father to a premature child. Parents were interviewed separately so each could speak freely and to facilitate a comparison of their views and experiences. Both parents were interviewed in a separate room in the NICU and there was no specific sequence as to which parent was interviewed first. Each interview lasted about 40 minutes and was audiotaped.

Data analysis

The interviews were transcribed verbatim to create a text for analysis. The first analytical step was meaning condensation (Kvale 1996). The birth and perinatal period had a great emotional impact on both mothers and fathers.

The next analytical step was meaning categorisation, which involved the systematic coding of the text. The NUD*IST computer software QSR (N6 Full version © QSR International Pty Ltd 1999–2002) was used for this purpose. This process included two steps. Firstly, the meaning units (free nodes) in the text were identified and secondly, the free nodes were grouped into an index tree where the tree nodes outlined hierarchically all levels of categories. The authors' discussion on the analysis led to adjustment of the model to provide coherence between the text (raw data), free nodes and tree nodes.

This structured text was then analysed according to Kvale's (1996) contexts of interpreting qualitative data. The first context, self-understanding, reflects a condensed form of the meanings parents attached to their experiences and their understanding of the situation, as interpreted by the researcher. The second context, common sense understanding, involves a more critical reading and interpretation within a broader framework. In this analysis, dissimilarities and inconsistencies in mothers' and fathers' views and experiences were uncovered and used to identify different subcategories for the two parents. In the third context of interpretation, the results are interpreted within a theoretical perspective; in this study, the attachment theory provided new insights.

Results

Two main categories emerged during the analysis of the parents' experiences of the attachment process during the first days in their child's life: (a) *Taken by surprise* and (b) *Building a relationship*. The responses of the mothers and fathers are presented separately to reflect their different experiences.

Taken by surprise

This category contains descriptions of the unexpected and unpredictable aspects of becoming parents of a premature child:

Mothers: I didn't really understand what was happening until it was over.

The mothers' strong emotional reactions to the pregnancy and premature birth and their descriptions, were many and lengthy. Three of the mothers described a lack of coherence between their bodily experience and professionals assessments during pregnancy, for example one mother feeling healthy despite the doctor telling her she was ill:

In the beginning of the pregnancy, I felt healthy, but the doctor said I had to calm down because of the high blood pressure. I didn't listen to him because I felt healthy. (Mother 1)

Conversely another mother illustrated how she struggled to convince the doctor about something being wrong and she described how this effort made her feel like a 'hysterical person'.

Even if two of the mothers had been prepared for a possible premature birth, all of them experienced the birth as unpredictable when happening. They described their experience of going into labour as a sense of powerlessness. They felt that their bodies had not responded as they wanted and that they were dragged into a situation without the opportunity to take control. One mother even compared her birth experience to a helpless animal being slaughtered. This surreal experience made them feel like outsiders to their own labour:

It took some time for me to understand what had happened, I think. First, there was no normal birth, instead there was a cesarean. Then the anesthetic did not work and they gave me general anesthesia. So then I just woke up afterwards and did not understand anything… everything was over and that was very peculiar. (Mother 6)

One of the mothers giving birth to her second premature child said she expected the professionals to prevent the premature birth because they were able to do so for her previous child. The unexpected and sudden birth was perceived as physically momentous, but mentally the mothers felt they were outsiders. The normal birth, where a mother actively delivers her child and immediately afterward holds her child, was, for these mothers, replaced by a frightening emergency delivery after which the child was taken away and cared for by professionals.

Fathers: You get a shock no matter what.

One of the fathers was present during delivery, one chose not to be present and the four others were excluded from the delivery room because they were emergency deliveries. These four fathers indicated that they would not have wanted to be present because the outcome was so unpredictable, but they were very aware of what was happening as they waited outside the operating room. They interpreted the health professionals' behaviour to gauge the gravity of the situation:

It was quite peculiar when I was sitting there; I could see everybody passing by… of course they were dressed in green clothes, everybody was dressed the same. They looked at me, but nobody batted an eyelid… so I did not know what to think. But when they returned everybody was just a big smile. (Father 3)

After birth, the fathers were concerned for the child's as well as the mother's health. Assured that the mothers would be all right, the fathers directed their attention towards the child. From the very beginning, professionals encouraged fathers to have skin-to-skin contact with the child. All but one chose to be present at the hospital and the close encounter between these fathers and their children seemed to accelerate their familiarity with the infant:

In the beginning I was afraid of touching him, but after the first time it became less scary; in fact, after a couple of times it was quite okay (Father 5).

The child's appearance appealed to the fathers and two of the fathers described their newborn children as 'insanely small'.

Building a relationship

This category describes the parents' experience of making bonds with their infant after birth:

Mothers: I need to be allowed to feel that he is mine.

Mothers were encouraged to become involved in their child's care as soon as possible after the birth. However, it took quite a few hours before four of the mothers were able to be with their child because of their health condition (e.g. anaesthetics, high blood pressure and surgery) and the two who had visited

and touched their child during the first hours said they hardly remembered anything from this encounter. Being deprived of the normal relationship with their child after delivery, all of the mothers expressed the importance of being involved in their child's care, thereby regaining the position of being a significant person in their child's life. The most significant issue for the mothers was to be physically close to their child, as one mother expressed:

I have been here for her to give her closeness and contact, to make a bond with her. I felt the maternal feeling immediately, because I could be close to her. (Mother 3)

Despite the need to be close, three of the mothers described experiencing ambivalent feelings such as wanting to hold their infant but ending up crying all the time when they did so, or expressing a need to have skin-to-skin contact with their child but not daring to touch him or her. Being involved also confronted them with the burden of not being able to take care of their child. One mother described how she was overwhelmed by impressions:

And then there was a period we didn't feel like visiting him. Because we expected just more bad news (mother crying)… It was right of them to inform us… It was more like, 'Oh God, do we have the strength?. (Mother 4)

Acknowledging the lack of ability to care for their infant, the professionals' competence and attentiveness towards their child became very important to the mothers:

Fathers: I felt I did a good deed and it was a great feeling.

Acknowledging their distant position during birth, the fathers talked about how satisfactory it was to be accompanied to the NICU immediately after birth and encouraged to touch or hold their stabilized infant. Being reluctant to have skin-to-skin contact in the beginning, they described a momentous experience when the close encounter transformed their relationship:

When you see that tiny child you think, 'Oh God, can I really touch this (the child)?' You are afraid of breaking every bone in her body you know. Then the nurse told me that you don't, they are much stronger than you think. I suggested that I would try and it was just splendid, it was a very special feeling. I somewhat feel that she is mine, I have to take good care of her and it is a strong feeling. You are supposed to protect her, it is strange. (Father 2)

The close father–child contact affected the fathers and made them feel as important contributors of care. This was true for the first-time fathers as well as the ones with previous experience. Their relationship changed from being impersonal to a relationship of belonging and protection.

The father–child contact also relieved the fathers' worries about the child's situation. It was as if they experienced an exchange of power initiated by the skin-to-skin contact, which made both father and child relaxed:

In the beginning, I couldn't sleep during the nights and then sometimes I went up to the NICU in the middle of the night. But whenever I got there, they took him out of the incubator, I did not dare to take him out myself then… It felt so good; I was sitting in the chair sleeping while he was lying on my chest… They tried to help me bond with him as early as possible, so that I would not keep my distance from him because he was inside the incubator and this made me feel more confident, it did. (Father 4)

The close relationship between father and child was described as having a positive effect on the fathers' self-esteem and coping ability, whereas exclusion from their child's care contributed to creating uncertainty and distress. Little difference in the attachment process was found between the couple who had a previous premature child and the first time parents of premature children. The experienced couple described the current birth as incomparable with the previous one, because the present child was unique and more critically ill. The only relief was that they were more acquainted with the context and the routines in the NICU, but the attachment challenge was the same.

Discussion

Parents' descriptions of the challenging attachment process during the first days in the NICU revealed an emotional complexity and the mothers' and fathers' different experiences when approaching their infant immediately after birth. This discussion addresses the parents' individual starting points according to physical proximity and reciprocity and the potential influence on the commitment that follows.

Proximity

Physical proximity (Goulet *et al.* 1998) is required to develop bonds between parent and child and the amount and timing of contact may explain why these parents experienced the early bonding process differently (Gay 1981, Schore 2000, Feldman *et al.* 2002). The mothers' who were deprived of contact with their infants possibly inhibited the physical stimulation and therefore delayed the attachment process. This may have contributed to their ambivalent feelings alternating between a need to be close, but still experiencing the close encounter as painful and difficult. These findings are supported by research describing physical contact as an antecedent to attachment (Bowlby 1969, Goulet *et al.* 1998) and the mother's strong

emotional reactions in connection with a premature birth (Moehn & Rossetti 1996, Wigert *et al.* 2006).

The fathers who were able to have early skin-to-skin contact with their infant described this as a very positive experience. Physical contact transformed the infant from being something impersonal to becoming a child with whom they emotionally and physically identified with. These findings support previous research showing that the stimulus–response reaction may be an important precursor to the induction and evolution of the attachment process (Gay 1981, Schore 2000, Feldman *et al.* 2002). This may also explain why each father's relationship with their child was experienced as more positive than the mothers' relationships.

Reciprocity

The ability to communicate is needed by both parent and child to build a good relationship (Goulet *et al.* 1998). Mothers faced two challenges with regard to their relationship with their infant: firstly, the intrauterine mother–infant attachment was less developed because of the premature birth (Cannella 2005) and secondly, the mother's emotional and physical experiences in connection with the unexpected and traumatic birth may make her feel helpless, reducing her confidence in interacting with the infant. These aspects may curtail the attentiveness of the mother's towards the infant whilst her attentiveness should be sharpened to balance the reduced signals of the infant (Moehn & Rossetti 1996, Jackson *et al.* 2003). We suggest that the mother–infant bonding process is more demanding in the case of a premature birth than with a normal birth of a full-term healthy infant.

The fathers who were immediately involved in their child's care expressed a feeling of being important contributors and this positive feedback seemed to accelerate their desire to be close to their infant (Gloppestad 1995, Sullivan 1999, Lundqvist & Jakobsson 2003). Their involvement was encouraged by both professionals and the mothers and this seemed to positively influence their feeling of being valuable contributors and they became more confident in interacting with their infant. These findings contrast with research reporting that fathers are more reluctant to interact physically with their children than are mothers, but underscore the importance of the connection between early father and child contact and the fathers' feelings of affection (Lundqvist & Jakobsson 2003, Latva *et al.* 2004).

Commitment

Commitment (Goulet *et al.* 1998) refers to the enduring nature of the relationship, where parents develop a sense of confidence in their actions and feelings towards their infant. The parents' ability to interact with their child became more equal after some days. Fathers' early involvement seemed to be strengthened by their positive skin-to-skin experiences and by the mothers' encouraging them as important contributors to the child's care. The mothers' early involvement was influenced by their emotional condition and they experienced the first days as challenging. Professionals should be aware of the mothers' approach to their infants because reluctant behavior may indicate a prolonged complicated reaction (Carter *et al.* 2005). These parents' shared responsibility may explain why only one of the mothers felt she had too much responsibility. This was described earlier as a possible negative effect from mothers staying with their infant in hospital (Tessier *et al.* 1998).

Conclusion

The small number of parents interviewed is a limitation of this study; however, our intention was to obtain in-depth knowledge of these parents' experiences instead of drawing general conclusions. This study contributes new understanding of mothers' and fathers' experiences of the attachment process immediately after a premature birth. The mothers wanted to be close even though the encounter also involved negative emotions, whereas the fathers were reluctant to be close but experienced the contact as more positive than expected. The mothers' emotional and physical condition may inhibit the mother–child attachment, whereas the fathers' early involvement may positively influence the attachment process and support the mother. Professionals should encourage both mothers and fathers to be involved in skin-to-skin contact from the very beginning, but should also recognize the parents' different starting points and needs. Acknowledging both as cocontributors could optimise the bonding process and contribute to a shared responsibility between parents when a premature child is hospitalised for a longer period.

Clinical implications

The evolution of parent's role while their child is hospitalised has been an important issue for centuries (Alsop-Shields & Mohay 2001, Fegran *et al.* 2006). Despite the acknowledgement of parents' involvement, the attachment process in a NICU is still a challenge. Although this is a qualitative study with no statistical generalisable findings, these results can be utilized in care of parents in NICU by emphasizing the importance of acknowledging mothers' and fathers' different

starting points and its impact on the resulting attachment process.

Contributions

Study design: LF, SH, MSF; data collection: LF, analysis: LF, SH, MSF and manuscript preparation: LF, SH, MSF.

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Paper III

Fegran L., Fagermoen M.S. and Helseth S.

Development of parent–nurse relationships in neonatal intensive care units – from closeness to detachment.

JAN ORIGINAL RESEARCH

Development of parent–nurse relationships in neonatal intensive care units – from closeness to detachment

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Abstract

Title. Development of parent–nurse relationships in neonatal intensive care units – from closeness to detachment.

Aim. This paper is a report of a study to explore the development of relationships between parents and nurses in a neonatal intensive care unit.

Background. As increasingly smaller premature babies survive, the prolonged hospitalization that follows makes relationships between parents and nurses crucial. A collaborative partnership in which all the family members' needs are acknowledged is suggested as the best approach.

Method. A hermeneutic approach was adopted, using overt participant observation (160 hours) and in-depth interviews to study interactions between parents and nurses. The participants were six mothers, six fathers, and six nurses from a 13-bed Norwegian neonatal intensive care unit. Data were obtained over 27 weeks from 2003 until 2004.

Findings. A partnership between parents and nurses developed in three phases: the acute critical phase, the stabilizing phase, and the discharge phase. The stabilizing phase seemed the most challenging. As exhausted parents expressed the importance of maintaining the trusting relationship with their primary nurses to become confident when assuming more responsibility and adjusting to the new situation, nurses purposely withdrew and reduced their contact with parents, facilitating their independence and confidence as caretakers. Parents and nurses rarely seemed to discuss with each other the discrepancy in their understanding of the detachment process.

Conclusion. Acknowledging the need for parents and nurses to discuss the processes of involvement and detachment may contribute positively to the development of family-centred care in neonatal intensive care units.

Keywords: closeness, detachment, family care, interviews, neonatal care, neonatal intensive care unit, nursing, participant observation

Introduction

The technological and medical development of neonatal care has dramatically influenced premature babies' survival and their subsequent prolonged hospitalization. There has been a shift from concentrating exclusively on the baby's physiological needs in early neonatal care to today's additional emphasis on emotional and developmental issues

(O'Donnell 1990, Ahmann 1998, Connell & Bradley 2000, Davis *et al.* 2003, Fegran *et al.* 2006). At the same time, parents' role has changed from being outsiders to being regarded as collaborative partners in family-centred care (FCC) (Griffin 2006).

Most of the literature about therapeutic relationships has focused on nurse–patient relationships (Graber & Mitcham 2004, Faugier 2006). In neonatal intensive care units (NICUs) parents and nurses are brought together in a caring team relationship, and creating such a relation seems to be physically and emotionally challenging for both (Espezel & Canam 2003, Graber & Mitcham 2004, MacKean *et al.* 2005, Malusky 2005, Corlett & Twycross 2006, Dowling 2006, McAllister & Dionne 2006).

Background

The birth of a premature baby precipitates a crisis for the parents, leading to intense and confusing emotions. During this period, they attempt to acquaint themselves with a baby who did not meet their expectations of a healthy baby. In addition, they have to redefine their parenting roles to meet the expectations of parenting in a NICU. To meet these parents' needs FCC, the theoretical framework of this study, has gradually been developed and acknowledged as 'the best way' of caring (Shields *et al.* 2006).

The literature on FCC was first developed for children with special educational needs, and was later adapted to provide a framework of care for critically and chronically ill children (Hutchfield 1999, Irlam & Bruce 2002). While several definitions of FCC exist, we chose to present The Institute for Family Centred Care's definition, which encapsulates the family, child and professionals: 'family centred care is a way of caring for children and their families within health services which ensures that care is planned around the whole family, not just the individual child/person, and in which all the family members are recognized as care recipients' (Shields *et al.* 2006, p. 1318). Unrestricted parental presence in the NICU, parental involvement in caring for the baby, and open communication with parents are basic tenets of the mutually beneficial partnership that characterizes FCC (Griffin 2006).

The elements of FCC were developed in both the UK and USA (Hutchfield 1999). However, Norwegian neonatal care is characterized by a similar approach governed by regulations (Ministry of Health and Social Affairs 1997). The regulations encompass parents' rights to be present in the hospital, to be informed and to participate in any decision concerning their baby's treatment and care. In addition, Norwegian regulations provide parents with economic security. Mothers have paid maternity leave (43 weeks with 100% compensation or up to 53 weeks with 80% compensation), starting when the baby is discharged from hospital. Financial compensation is available for fathers who are present in the unit when the baby is critically ill, and accommodation, catering and travel between home and hospital are also provided.

Despite today's acceptance of FCC as a central aspect of paediatric nursing, there appears to be some discrepancy between its theoretical foundation and its practical implementation (Galvin *et al.* 2000, Coyne *et al.* 2007). FCC is criticized for simply training parents to assume more responsibility for their child's care rather than developing a collaborative relationship between parents and nurses (MacKean *et al.* 2005, Shields *et al.* 2007). A lack of effective communication and professional expectations, as well as issues of power and control, frequently inhibits open and mutual negotiation between families and nurses (Carmack 1997, Kirk 2001, Espezel & Canam 2003, MacKean *et al.* 2005, Corlett & Twycross 2006).

Professionals' unrealistic view of FCC may also explain the discrepancy between theory and practice (Cahill 1996). Instead of regarding FCC as implemented immediately after the child has been hospitalized, it should rather be the ultimate goal of any relationship that develops gradually during the child's hospitalization. The development of the process starts with *parental involvement*, develops further to *parental participation*, then to a *partnership with parents*, and ending up with *FCC*. FCC is based on mutual respect, and the parents are seen as experts in their child's care while the nurses assume a consultative role (Hutchfield 1999).

The study

Aim

The aim of this study was to explore the development of relationships between parents and nurses in an NICU.

Design

The study was philosophically grounded in Gadamer's hermeneutics emphasizing prior understandings and prejudices as essential for the interpretive process (Gadamer 1989, Denzin & Lincoln 2005). Fieldwork with observations and semi-structured interviews was used to obtain in-depth knowledge of the development of a relationship between parents and nurses in an NICU (Hammersley & Atkinson 2007).

Setting

The study was conducted in a 13-bed NICU in Norway. The unit is a regional centre for the treatment of premature babies with a gestation period of 26 weeks or longer. The average annual number of admissions to this unit is 340, and the majority of babies are admitted directly from the maternity ward. The unit consists of two intensive care rooms and two smaller bedrooms for babies in a more stable condition. Care for each baby in the NICU is organized by a primary care team consisting of two Registered Nurses, a paediatric nursing auxiliary (education at high-school level similar to a nursing auxiliary, but with a paediatric focus), and a doctor, all of whom are responsible for the baby's care.

Participants

A convenience sample of parents was obtained using the following criteria: (1) the baby's gestation period was a maximum of 32 weeks; (2) the baby stayed at the same hospital from birth until ready to go home; (3) each family contained a mother and a father; and (4) both parents agreed to participate in the study. The total number of babies admitted to the unit during the field research period was 95, and 12 of these were 32 weeks or younger. Parents who met the inclusion criteria were asked consecutively to participate in the study, and the recruitment process continued until the desired number of six couples was reached. Two of the screened couples did not want to be included.

A convenience sample was obtained of Registered Nurses who: (1) were one of the family's primary nurses; (2) had been employed in the unit for at least 1 year; and (3) held at least a half-time position in the unit. The nurses were informed about the project and their role as potential participants in a meeting at the NICU. After the field research started, nurses who met the inclusion criteria were asked by the researcher to participate.

Three factors are considered in decisions on sampling in fieldwork: time, people and context (Hammersley & Atkinson 2007). The inclusion process continued until redundancy of information was reached (Erlandson *et al.* 1993), and this was achieved with 18 participants and extensive observation from the baby's birth to discharge to obtain in-depth knowledge of the encounter.

Data collection

The 27-week fieldwork period lasted from October 2003 until March 2004 and from September 2004 until November 2004, during which 160 hours of observations and 18 in-depth interviews were conducted.

Observations

The data collector was an RN who had worked in the NICU. Although knowledge of the field could facilitate access to information from participants, it also created a need to consider thoroughly the observer role. Acting as an RN would have been ethically inappropriate because this nurse no longer had the necessary skills to hold such a position. It would also make objective reflection more difficult. These considerations led us to choose assuming a peripheral-member-researcher role (PMR) (Adler & Adler 1994). When holding a PMR, the researcher seeks to obtain an insider's perspective on the participants and their situation by observing but not assuming functional roles within the group (Hammersley & Atkinson 2007). Following agreement with the head nurse, the PMR used the same uniform and identification as other staff members.

The observations were made during both the day and evening shifts. The main focus of the observations was the interaction between parents and their primary nurses, and the most common observation situations were when parents were participating in the infant's nursing care and feeding. The researcher sat at the perimeter of the room observing and writing field notes. This position was chosen to avoid interrupting the collaboration between parents and nurses. However, the small size of the rooms still allowed her to observe and hear what was going on.

Field notes comprising descriptive and reflexive notes as well as methodological reflections were transcribed verbatim after every observation. Different ways of organizing the field notes were explored (Emerson *et al.* 1995) but, to capture the development of the relationship, writing observations in chronological order was chosen.

Interviews

Individual retrospective interviews with parents were conducted at the time of their baby's discharge from hospital. Initially, parents were asked about their experiences of becoming the mother or father of a premature baby. Further, their roles in the NICU were addressed, as were their personal dealings with each professional and the development of their relationship with nurses during the hospitalization.

Interviews with the nurses addressed their general experiences with parents in the NICU, but not specifically those parents who were included in this study. Initially, they were asked what characterized their role as a nurse in an NICU. Questions also focused on nurses' experiences of their role, as well as their need to be both professional and personal when

dealing with parents. Further, the development of the relationship with parents during the period from hospitalization until discharge was addressed. The audiotaped interviews were conducted in a separate room in the NICU.

Ethical considerations

The study complied with the ethical principles of the Declaration of Helsinki (World Medical Association 2004) and the study protocol was approved by a medical research ethics committee, the Ombudsman for Privacy in Research at the Norwegian Social Science Data Services, and the hospital's research department. Written consent was obtained from parents and nurses before they were included in the study.

Data analysis

Field research is characterized by a dialectic interaction between data collection and analysis, formally by the use of analytic notes and memoranda and informally by being embodied in the researcher's ideas and hunches (Hammersley & Atkinson 2007). To have time for reflection and to make decisions about further data collection, the observer's presence in the NICU was limited to 2–3 days a week. The time between observations was used to transcribe and to reflect upon the collected data, and this initially open approach was narrowed as the data collection progressed. Some issues became prominent, such as the parents' indefatigable efforts to nurse and bond with their infants and the nurses' close support of them in this effort. This narrowing of the focus resulted in further reflections concerning parents' and nurses' experiences of being in these enduring and close relationships. In the interviews, these issues were further elaborated and subjected to validation.

After finishing the data collection, the transcribed data from interviews and observations were read thoroughly several times and discussed by the authors to gain an impression of what characterized the interaction. Data were condensed and concepts that might make sense of the interaction's purpose were identified: involvement, trust, unpredictability, emotions, strain and attitude.

Systematic coding of the transcribed raw data was performed using NUD*IST QSR software (N6 Full version Copyright © QSR International Pty Ltd 1999–2002). This process involved two steps. First, the meaning units (free nodes) in the text were identified. Second, the free nodes were grouped into an index tree, the nodes of which provided a hierarchical outline of all the category levels. The analysis continued until there was a stable set of categories with coherence between the text (raw data), free nodes and tree nodes. The two main categories, *interaction* (with subcategories *anticipations, role, and increased responsibility*) and *trust building* (with subcategories *respect and taking care of*) gave an overall picture of the interaction.

After having structured the great amount of data, there was a need to withdraw and look beyond or above the structured categories to see the wholeness of parent–nurse encounter (Gadamer 1989, Nyström & Dahlberg 2001). We therefore moved back and forth between the concepts identified through the initial reading, raw text (transcribed interviews and field notes) and node tree to deepen our understanding of the parent–nurse encounter. The evolution of the relationship became obvious, and this made us go deeper into the data to explore how the relationship developed; to achieve this, data from both categories, interaction and trust building, were used.

Rigour

Prolonged engagement and persistent observations, combined with thick descriptions, reflexive journal, peer debriefing and member checking, were used to increase the study's trustworthiness. Thorough descriptions of the setting, inclusion process, data collection and analyses increase the study's confirmability (Erlandson *et al.* 1993).

Findings

The mean age of the fathers (36·1 years) was higher than that of the mothers (31·3 years), and the average age of the nurses (34·5 years) was approximately the same as those of the parents. Fathers' educational level was lower than the mothers. The mean length of hospitalization was 7 weeks, and one of the mothers gave birth to twins. An overview of the participants is presented in Table 1.

Three distinct phases in the development of parent–nurse relationship were uncovered: (1) the first acute phase, including the birth and the immediate time-period, when the nurses were the primary caregivers and the parents were mainly spectators; (2) the stabilizing phase, during which the baby's condition gradually improved and the parents' involvement started to increase while the nurses gradually withdrew, thus entrusting the parents with more responsibility; and (3) the discharge phase, encompassing the period associated with discharge from hospital, when the parents became the primary caregivers while the nurses offered their support.

Acute critical phase

During the acute critical phase, parents viewed themselves as spectators of their baby's care. However, they never felt

Table 1 Participant demographics

Nurses (n = 6)	
Age range	29–44 years (mean = 34·5)
Length of time qualified	2–12 years (mean = 5·75)
Gender	
Female	6
Male	0
Further education	
Paediatric nursing	2
NIDCAP®*	1
Supervision pedagogy	1
None	2
Parents (mothers n = 6, fathers n = 6)	
Mothers' age range	25–42 years (mean = 31·3)
Fathers' age range	27–59 years (mean = 36·1)
Mothers' education	
High school	2
College/university	4
Fathers' education	
Elementary school	4
High school	2
College/university	0
Babies (n = 7)	
Gestation period range (weeks)	28–32 (mean = 30)
Birth	
Caesarean	4
Vaginal	3
Hospitalization range	4–12 weeks (mean = 7)
Gender	
Female	4
Male	3

*Newborn Individualized Developmental Care and Assessment Program.

excluded because they were informed and encouraged to give their baby physical contact. The baby was in the hands of professionals, and knowing that the baby was being cared for was the most important issue for parents:

I was the first one to see the infants, and when I saw the collaboration between our nurse and doctor…saying that 'She must have this and that' and the other answering, 'Yes, she has', there was just no discussion. Everything went so quick and easy…it was just great to see that they were competent professionals (Father).

Although the nurses considered the baby to be their primary responsibility during the critical phase, it was also crucial to develop the parents' confidence in them as professionals:

I strongly emphasize that I am in control of everything around, so they can focus on the child. …I talk very little in the beginning. I think parents experience me as being very calm. …I very seldom become stressed, and I think that makes parents feel safe (Nurse).

During this early critical phase, building a trusting relationship occurs. The nurses feel confident in their professional role and parents trust the professionals' competence.

Stabilizing phase

During the stabilizing phase, parents' adaptation to life in the NICU and to their new parenting role was essential. To empower parents, nurses acted as role models and gradually entrusted more responsibility to them by normalizing and familiarizing their interaction with the child. Nurses needed to feel confident when putting the baby in the parents' hands, while parents needed nurses' confirmation of their ability to take care of the baby:

The father arranges with the nurse what he wants to do. He is given a washbowl, and the nurse asks whether he is familiar with the required water temperature. Then she gives him a diaper, and he asks if it should be warmed in the incubator before being used on the child. The nurse confirms this. The nurse sits down some distance away, as if she wants the parents to manage themselves. However, the nurse is close enough to be available when needed. The alarm goes off. Both parents stop and look at the monitor. The nurse enters immediately and turns off the alarm. The parents continue. The baby has to be turned over, and the nurse asks whether they have done this before. They answer, 'No', and then she shows them how they should protect the baby's head and shoulders. Then the baby has to be weighed, and the parents are asked whether they want to hold her skin-to-skin afterwards. The mother wants to hold her, and the father lifts the baby out of the incubator. The nurse says he is doing great, but asks him whether he is afraid. He answers, 'No', but that he has to get used to it…and that it feels good (observation).

Even if the baby's condition was stabilizing, progress was sometimes slow, and parents put a great deal of energy into making their daily lives manageable. Combining caring for their premature baby with care for their other children, and dealing with their jobs and homes were experienced as exhausting. When parents were interviewed about their experiences of this 'exhausting phase', many of them started to cry. One of the mothers felt that she was living on 'a merry-go-round', while one father described this period as follows:

Never getting our daily life organized was frustrating. It was top speed all the time…we had to drive back and forth…and the days just passed by. Being in the NICU and having a lot to do at home and never getting into a routine frustrated me. I am looking forward to returning to work, to get back into some routine. …I was exhausted. I was tired to the bone (Father).

During this stressful period when parents spent a lot of time in the unit, the close relationship with their primary nurses meant a lot, and expressions such as 'It was almost as if we became friends' were used. Similarly, nurses experienced this closeness as being crucial for creating a trusting relationship. However, they also talked about the challenging and demanding aspects of being close:

It can be very difficult to help parents cope with the situation, especially if we are busy. Having time…or maybe the issue of time pressure is just an excuse, because when things have calmed down I sometimes still choose to avoid close relationships. The more you talk to parents, the closer you get (Nurse).

As the baby's condition stabilized and the parents' involvement increased, the primary nurses gradually adopted a more secluded position. A consequence of their withdrawal was that other, frequently unfamiliar nurses and auxiliary personnel cared for the family. Unfamiliar nurses and divergent instructions appeared to confuse parents and made them less confident, while a continuing relationship with their primary nurse(s) seemed to strengthen parents' confidence in assuming responsibility for their baby:

I don't like it when we have to encounter unfamiliar nurses…even up to our last day in the unit we have encountered new nurses. We just feel safe with the ones we know. Different nurses do things differently (Father).

While encountering familiar nurses meant a great deal to parents during this demanding period, nurses withdrew from parents in an attempt to enhance their independence:

She (the mother) usually wants to talk a lot, and maybe she needs to. I don't know why she wants to talk so much to all of us…it's not supposed to be like that. I expect that we shouldn't talk so much, because they will soon be going home (Nurse).

Despite the routine of leaving parents to do more of the caring themselves, some nurses reflected on a possible paradox of reducing contact while, perhaps, parents needed to maintain close contact with nurses whom they trusted:

This (stabilizing phase) is a time for all the questions: what really did happen in the very beginning, and what will the future bring? Parents move on from taking one day at a time to thinking about the future: will things be OK? They start reflecting on the consequences…and it is important to talk about these things, adapting…asking for our opinions (Nurse).

This stabilizing phase, during which responsibility was gradually transferred from nurses to parents, was described as the most demanding period for parents. There seemed to be a discrepancy between parents' and nurses' understanding of their relationship.

Discharge phase

Despite parents longing to return home, the discharge phase was characterized by joy mixed with dread. Leaving the professionals and the safe surroundings of the NICU seemed to be challenging:

When they said I could take her home on leave I became extremely stressed. Immediately after they told me we could go home my milk disappeared; I was pumping and pumping and only a few drops appeared. I wondered what was going on. I did want to take her home, didn't I? (Mother).

Taking a premature infant home was different and unfamiliar. One of the mothers who had previously had a premature baby described how her experience enabled her to prepare herself this time:

Even if it was early, I was completely ready to go home. I used the weeks in hospital to prepare everything at home. It was just like therapy for me, washing clothes, blankets and toys…preparing different things. Yes, I was prepared for the practical issues and very much looking forward to this day (Mother).

All the families were encouraged to take their babies on leave, either in a hospital apartment or at home, before they were finally discharged. This break between hospital and home seemed to increase their confidence, as they were able to determine whether they could handle the baby on their own. Parents were also given the opportunity to contact the unit if they felt insecure either on leaving or after discharge:

I think it is important that parents look forward to discharge, that this day does not become a day of horror. I think it is important that they are prepared, but at the same time they shouldn't handle everything at home by themselves if they feel afraid and unsure of themselves. …They can always phone us if they have questions (Nurse).

The nurses closely supported parents as they prepared for discharge and, despite much excitement and insecurity, parents experienced the discharge phase as a positive experience.

Discussion

Study limitations

As the study was conducted in a Norwegian NICU, the homogeneity of the participants could be a limitation. Norwegian regulations facilitating parents' presence could

make the parent–nurse relationship especially close, and thereby increase the need to focus on the detachment process. However, making parents independent caregivers following discharge is a general issue in neonatal care.

The small number of participants is also a limitation. However, our intention was to obtain in-depth knowledge of these parents' and nurses' experiences rather than to draw a general picture. The in-depth knowledge we gained of the detachment process, as a crucial part of the development of enduring parent–nurse relationships, could be transferred to similar contexts, thereby contributing to the development of FCC theory.

The use of observations and individual interviews with mothers, fathers and nurses was one of the study's strengths. This approach added richness and depth to the interpretation of the development of a relationship from the point of view of all participants.

Discussion of findings

Family-centred care is defined as a method for caring for children that focuses on the baby, family and professionals. A caring team consisting of parents and nurses based on collaboration and mutuality is fundamental to this approach (Shields *et al.* 2006). While parents' main contribution is to give their infant skin-to-skin contact and daily care, nurses have the expertise and experience to give the baby nursing care and to act as role models for parents.

Our findings support research on FCC showing that both parents' and nurses' contributions to the relationship evolve during hospitalization (Cahill 1996, Hutchfield 1999). There is an interchange of roles and responsibility, nurses being in control and parents being spectators in the beginning, and parents acting as independent caregivers supported by nurses at discharge. The development of the participants' roles, beginning with the acute critical phase, moving on to the stabilizing phase, and finally ending with the discharge phase, is illustrated by the model shown in Figure 1.

Acute critical phase

During the acute critical phase, nurses expressed how their main responsibility is the baby's care, whereas attending to the parents' needs becomes secondary. The parents' contribution is their being available to give their baby skin-to-skin contact, while they trust nurses to be the main caretakers. Open and honest information, combined with respect for the family's needs, allows the parents' and nurses' contributions to be made in accordance with the initial *parental involvement phase* which initiates the development
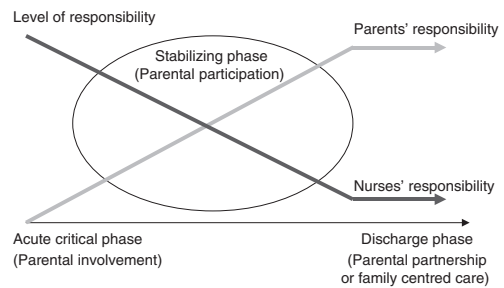

Figure 1 Development of parents' and nurses' responsibilities during the baby's hospitalization.

of FCC (Hutchfield 1999). The acute critical phase is demanding for both parents and nurses. However, their collaboration seems to be unproblematic, as there is general agreement on prioritizing the needs of the critically ill baby.

Stabilizing phase

As the baby's condition stabilizes, the parent–nurse relationship develops from parental involvement to *parental participation* (Hutchfield 1999). Parents gradually take over the normal care that was provided previously by the nurses. Maintaining a close relationship with their primary nurses becomes vital for parents in meeting the demands of increased participation, and in normalizing their lives both inside and outside the NICU. This is in accordance with research showing that support from familiar nurses whom parents trust eases their burden in the NICU (Cescutti-Butler & Galvin 2003, Hall 2005, Lee 2007). Our finding that parents need to gradually build a closer relationship might nevertheless seem to be contrary to the goal of nursing in the NICU, which is to help parents become independent caretakers. This could explain why there is a discrepancy between parents' and nurses' understandings of the detachment process. Parents experience their primary nurses as withdrawing when they need a trusting relationship, while the nurses anticipate the parents' independence and so question their need to remain in close contact. Although the parents' presence is expected in current neonatal care, the presence of scant negotiation about the detachment process does not support a collaborative relationship (Espezel & Canam 2003, MacKean *et al.* 2005, Corlett & Twycross 2006).

Our findings revealed the extensive presence of parents in the NICU, which could be a result of the parents' rights established by Norwegian regulations (Ministry of Health and Social Affairs 1997). Although parents' presence is desired, the longer and more intense a caregiver's involvement, the more

What is already known about this topic

- Family-centred care is widely acknowledged as the best way of caring for premature children and their families.
- The process of implementing the theory of family-centred care is unclear.
- Lack of effective communication, professional expectations, and issues of power and control seem to inhibit implementation of family-centred care.

What this paper adds

- There appears to be a discrepancy between parents' and nurses' expectations of the development of their partnership.
- Parents express a need to maintain a close relationship with their primary nurses throughout the hospitalization period, while nurses withdraw as the baby's condition stabilizes and parents gradually take over the care.
- Nurses need to acknowledge the emotions involved in the detachment process and what has happened during the hospitalization in order to facilitate closing the parent–nurse relationship.

important it is to learn to balance closeness and detachment (Carmack 1997). Nurses in our study expressed a need to create some distance from parents, which is supported by research that characterizes a collaborative nursing approach as shifting between closeness and distance (Söderbäck 1999). FCC theory seems to focus on building a relationship, but scarcely discusses the challenges of being involved in such enduring and demanding relationships. Nurses' focus on detachment in our study could be caused by their need to make parents independent but also to limit their own involvement (Dowling 2006). The fact that the stabilizing phase was experienced as the most challenging could be explained by the enduring and close relationship, combined with differences in how parents and nurses understand the evolving detachment process.

Discharge phase

At the time of discharge, parents are the primary caregivers, with nurses serving as supporters in a manner comparable to a *parental partnership* (Hutchfield 1999). Our findings showed that bringing the baby home is a significant event: parents experience this phase as being frightening, but remain

positive as a result of the nurses collaborating with them when planning the baby's discharge. The nurses' gradual letting go of the parents could be an example of how the individual family's needs are met. Such an approach increases parents' influence and makes them feel like collaborators in the caring relationship (Shields *et al.* 2006). However, our findings support the idea that FCC, defined as parent-led care with nurses serving as consultants, might be difficult to achieve during hospitalization in an NICU (Hutchfield 1999, McAllister & Dionne 2006, Lee 2007). As the parent–nurse relationship in an NICU will always be a power-dependence one, we suggest that parent–nurse interdependency be emphasized as well as equality and mutuality (Fegran *et al.* 2006).

Conclusion

Family-centred care is internationally acknowledged as the best way of working with families in paediatric care; however, further exploration of experiences of this approach in different contexts is needed. Although the parent–nurse relation in NICUs is time limited, it appears that a focus on how to close this relationship is rare. Nurses need to acknowledge the emotions involved in the detachment process and what has happened during the hospitalization to facilitate closing the parent–nurse relationship.

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Paper IV

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The parent–nurse relationship in the neonatal intensive care unit context – closeness and emotional involvement.

The parent–nurse relationship in the neonatal intensive care unit context – closeness and emotional involvement

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The parent–nurse relationship in the neonatal intensive care unit context – closeness and emotional involvement

Aim and background: Family-centred care, which acknowledges parents as partners in care, is a desirable and essential part of neonatal nursing. There has been extensive research on parents' experiences of parenting in neonatal intensive care units (NICU), but there is little research on nurses' experiences of being in these enduring close relationships. The aim of this paper is to explore parents' and nurses' experiences of the close parent–nurse relationship when a premature child is hospitalized.
Method: The design was exploratory with a hermeneutic approach. The methods used were participant observation and in-depth interviews with six mothers, six fathers and six nurses in a Norwegian 13-bed NICU. Eighteen individual interviews and 160 hours of observations were conducted over 27 weeks from 2003 to 2004. This study complies with the principles of the Declaration of Helsinki. The Regional Committee for Medical Research Ethics, the Ombudsman for Privacy in Research at the Norwegian Social Science Data Services and the hospital's research department approved the study protocol.

Results: The NICU context is a technological environment where human interaction is a crucial issue. The character of the context and the ongoing interactions drive parents and nurses into close relationships. Closeness increases the emotional involvement and the boundary between the professional and the personal approach is threatened. The commitment of being close, combined with the emotional involvement, can be an emotional burden to both parents and nurses.
Conclusion: Parent–nurse closeness in NICU is desirable; however, the emotional burden of this closeness seems to be seldom problematized. Awareness about the need to strike a balance between closeness and distance can positively influence parents' independence and nurses' ability to maintain professional relationships with their primary care parents.

Keywords: nurse, parents, closeness, emotional involvement, neonatal intensive care unit, hermeneutics, interviews and observations, ethnography.

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Introduction

Nowadays, parents in neonatal intensive care units (NICU) are regarded as important contributors to the caring team, providing care to the premature child. Consequently, providing support to parents has become a crucial part of nurses' responsibilities (1–5). The role of a neonatal intensive care nurse is diverse and demanding, both technically and interpersonally (6–9). Even if close parent–nurse collaboration is desirable, parents' presence and

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involvement seems to challenge the professional relationship (6, 10–18). The aim of this article is to obtain in-depth knowledge of parents' and nurses' experiences of this close parent–nurse relationship in an NICU.

Background

A professional relationship is different from a social relationship: the professional initiates it; there are time and space limits; interactions are confined to a particular setting; and most of all it is formed with a focus on one of the participants only, the patient (19).

Professionals interact with patients at several levels and striking a balance between these is one of the core concepts of building professional relationships (15, 20, 21). The longer and the more intense the relationship, the greater is

the need to balance engagement with detachment (16, 22). Nurses should be capable of being sufficiently involved to participate emotionally, spiritually and intellectually, while retaining adequate distance to maintain control and use their involvement to assist patients (19, 23, 24). If the relationship changes from professional to one of friendship, maintaining professionalism may become more difficult (25). A posture of detached concern may not be desirable however; instead, the compassionate clinician should operate effectively while maintaining close relationships with patients (15). In a study of paediatric oncology nurse–parent relationships, Bignold (26) found that even if the relationship contained elements of friendship, it was not friendship in the conventional sense of the term. The enduring relationship between parents and nurses was characterized instead by *befriending,* a relationship where formal professional–client barriers were replaced by a reciprocal partnership. Befriending facilitates partnership but at the same time it increases emotional labour for nurses. By far the most frequent personal trigger leading to compassion fatigue is becoming overly involved or crossing professional boundaries (27). The ability of caregivers to balance closeness with detachment seems to increase with experience (4, 28, 29).

The context influences relationships, and the open rooms in the NICU that are designed to accommodate technical equipment and facilitate surveillance can make the environment incomprehensible and stressful (28, 30). The hospital room is a small world, a space within space, a physical context but also a place where people meet and interact (31). Professionals' behaviour has a great impact on parents' experiences of the encounter, and their approach can support or worsen parents' coping with the situation. Writers have highlighted the distinction between the physical presence *being there* and the mutual exchange of *being with* someone (29, 32–35). *Being there* is a limited intersubjectivity grounded in nurses' and patients' respective roles. *Being with* is an intersubjectivity grounded in mutuality, where the nurse and the patient (parent) are present not only according to their respective roles, but also as whole persons (35).

Focusing on both parents' and nurses' experiences of the close relation endeavoured in NICU could be a contribution to understand the desired, but at the same time challenging aspects of this relation.

Method

Research design

The study involved an exploratory design with a hermeneutic approach, philosophically grounded in Gadamer's hermeneutics. This approach emphasizes that prior understandings and biases are essential for the interpretative process (36, 37). Ethnographic fieldwork with semi-

structured interviews and observations was used to obtain in-depth knowledge of the development of a relationship between parents and nurses in an NICU (37).

Setting and participants

The study was conducted in a Norwegian NICU, which is a regional centre for treating premature infants with gestation ages of 26 weeks and above, with the majority of babies admitted directly from the maternity ward. A convenience sample of mothers, fathers and primary care nurses was chosen. The inclusion criteria for parents were: (i) infant had a gestation age of 32 weeks or less; (ii) the infant stayed at the same hospital from birth until ready for discharge home; (iii) the family consisted of a mother and father; and (iv) both parents agreed to be included in the study. All parents meeting the inclusion criteria were asked to participate in the study, and informed consent was obtained. Registered Nurses were included according to the following inclusion criteria: the nurse was one of the family's primary nurse caregivers and had been employed in the unit for a minimum of 1 year in a position that was at least 50% full time. As parents were included in the study, their primary care nurses who met the inclusion criteria were asked to participate, and informed consent was obtained. The inclusion process continued until data saturation occurred (38). Six mothers, six fathers and six primary care nurses were included in the study.

Data collection

Data collection comprised 27 weeks of field research, from October 2003 until November 2004, during which 160 hours of observations and 18 in-depth interviews were conducted. Clarifying the researcher's preunderstanding and perspectives is a necessary and important part of the research process in qualitative studies, because the researcher is the research instrument (37, 38). In participant observation there is a need to balance the positions of being both participant and researcher, creating a distance so that the analytic work can be done (39). A peripheral-member-researcher role was chosen to obtain an insider's perspective on the participants and their situation but without assuming functional roles within the group (39, 40). The main focus for the observations was the encounter between parents and their primary care nurses. The most common observation situations were nursing and feeding times, where the researcher sat at the edge of the room observing and writing field notes. The field notes consisted of descriptive and reflexive notes in addition to methodological reflections, and were transcribed verbatim after every observation. The observations were written in chronological order to capture the development of the relationship (41).

Individual retrospective interviews with mothers and fathers were conducted in connection with their infant's

discharge from the hospital. The parents were asked about the parent–nurse relationship, their experiences of becoming a mother or father to a premature child and their roles in the NICU. The interviews with nurses addressed their experiences of working with parents in the NICU in general, what characterized being a nurse in an NICU and their experiences of their role as a nurse in the NICU. All interviews were audiotaped and conducted in a separate room in the unit. Each interview with the parents lasted for about 40 minutes and each interview with nurses lasted about 1 hour.

Data analysis

Field research is characterized by a dialectic interaction between data collection and data analysis (37). The observations were carried out over two or three days each week, and the time between observations was used to transcribe and reflect upon collected data. By openly observing and reflecting on the encounters between parents and nurses, their emotional aspects became obvious. The interviews allowed further elaboration and validation of these findings.

After transcribing data from interviews and observations the text was read thoroughly several times to gain an impression of what characterized the encounter. After condensing data, the following concepts were identified as aspects characterizing the encounter: involvement, trust, unpredictability, emotions, strain and attitude. To validate the initial analyses and to explore whether a computer programme would facilitate the handling of large amounts of data, a systematic coding of the same transcribed raw data was performed using NUD*IST computer software (QSR N6 full version, Copyright © QSR International Pty Ltd 1999–2002). The two main categories, *interaction* (with subcategories anticipation, roles and increased responsibility) and *building trust* (with subcategories 'being understood' and 'taking care of'), gave an overall picture of the encounter. After organizing the large amount of text data into categories there was a need to withdraw and look beyond, or above, the analytical categories to see the wholeness of the parent–nurse encounter (37, 42). By moving backwards and forwards between the concepts identified through the initial reading, the raw text (transcribed interviews and field notes), and the node tree generated by the computer programme, the challenge of being in close enduring relationships became obvious. This made us go deeper into the data to explore the issue of closeness, using data from both categories, interaction and building trust.

Ethical considerations

The Regional Committee for Medical Research Ethics, the Ombudsman for Privacy in Research at the Norwegian Social Science Data Services and the hospital's research department approved the study protocol. Written informed consent was obtained from all the participants before they were included in the study. The nurses were informed about the project and their role as potential participants in a meeting at the NICU in May 2003. Parents were informed as they were asked to participate in the study.

Although I had chosen a peripheral-member-researcher role, this role had to be reconfirmed during the fieldwork period. Sitting in the intensive care unit for weeks made me a familiar person to the participants. This familiarity, combined with my previous role as a practising nurse, created a need to emphasize my role as an observer. Observation without intervention was my intention; however, this point of view had to be counterbalanced against the issue of not causing harm to the participants. Observing for days and weeks gave me a profound insight into parents' experiences, and therefore I chose once to inform the head nurse about a parental behaviour that I believed required intervention from nurses, but which had not received it. Without involving me, the nurses adjusted their approach after receiving this information. This was one situation where ensuring that participants were not harmed took precedence over rigid design rules.

Findings

The sample

The sample consisted of six mothers, six fathers and the families' six primary care nurses. The mothers' mean age was 31.3 years and the fathers' mean age was 36.1 years. Mothers had a higher education level than fathers. There was one pair of twins among the seven children (four girls and three boys). Four of the children were delivered by Caesarean section, and the average time of hospitalization was 7 weeks. Nurses' mean age was 34.5 years, and four of the nurses had undertaken postgraduate education, two of them in paediatric nursing. The nurses had an average of 5.75 years of experience of working in an NICU.

The NICU environment

The NICU environment is a context where two worlds meet, the nurses' professional world and the lay parent world. The professionals' need for efficiency, visibility and access contrasted with the parents' and infants' need to experience privacy and individualized care. The following field observation gives an impression of the environment where parents and nurses must closely interact:

> Entering into the NICU is like coming into a different world: a world separated from the rest of the hospital, but also from the pulsating life outside the hospital. After passing through two corridors, washing my hands, and putting on a uniform while assuring

myself (and the note hanging on the wall) that I don't have any contagious infections, I enter the NICU. Having experienced the physical barriers before entering the unit, the disclosure and transparency inside the unit becomes striking. The visibility of the incubator rooms is strengthened by the glass walls. Each room contains from three to five incubators. Parents seem to be squeezed in between the technical equipment, sitting in chairs holding and nursing their infants, leaving little room for privacy. The noise is striking; alarms and sizzling sounds from the surveillance equipment are mixed with nurses' and parents' quiet talk. The air feels dense and warm; the room is crowded. Curtains patterned with pastel-coloured animals and colourful hand-knitted blankets in the incubators seem to attempt to normalize the abnormal surroundings for newborn children; however, the high-tech impression and lack of privacy is striking. This is the context where parents and nurses spend weeks and sometimes months interacting as a caring team providing care for children born prematurely.

Emotional involvement

Becoming parents to a premature child introduces parents to an alien world; their child is different, their parenting role is different and, not least, the caring context is different from what they would have anticipated and prepared for. Finding their way in this marginal situation makes support and respect from professionals important.

> What is important to me? … It is hard to express, but perhaps that they talk to me on my level, that they understand me, that … perhaps that I can relax … that I can be myself? And that I feel confident enough to … to cry if I need to? (mother).

Understanding parents' situations is also crucial to nurses; they express how they strive to support parents without being intrusive or prejudiced:

> I try to find out what is going on with these parents … Not just by asking them, but to find out who they really are. Because they are all different, like other people we know … some like to talk a lot, some are difficult, some are sceptical on meeting strangers. Even if we are nurses, we are strangers to them. Some open up immediately … some don't even like us and our nursing role (nurse).

Taking care of vulnerable parents is an important part of the nursing role and failing to build a relationship is experienced as painful. That nurses carry such memories with them shows how great an impact these experiences have professionally, but also emotionally and personally:

> That's what it is like with the so-called difficult ones (parents) … you get rejected, both verbally and you can see it in their bodies. You can see it quite clearly … I felt that her eyes, they told me that things were

not OK … and I wondered whether it was my fault, could it be the way I was behaving, because that could have been the reason, don't you see? (nurse).

One nurse describes the memory of a painful experience feeling like 'a bad lump' she has carried with her ever since. Enduring and emotional interactions can lead the parent–nurse relationship onto a more personal level, and this is increased by the open and visible surroundings:

> I am surprised how much we get to know about the families' lives, not just about their child, but also about their lives at home. Some things are too private … marriage problems or other problems at home. I think they become so exposed, we are together all the time, and they don't have any place to hide. They are in a crisis because of the child … And if you sit down and talk to them and show interest, I think these things appear when they feel confident (nurse).

Parents' presence and involvement make the quality of the relationship crucial, and the closer a relationship becomes the more strongly nurses feel committed to take care of the vulnerable parents.

Closeness obliges

Because parents and nurses are together in the NICU for weeks and months, they are forced into closeness, both emotionally and physically. Even if closeness is desirable, it can also be revealing, and nurses describe how the close collaboration makes some things apparent. Openness, honesty and acknowledgement of parents' experiences are described as fundamental:

> If I make a mistake I have to admit this, and explain to parents that if they want somebody else to take care of their infant that is OK with me. I have to respect this if they have lost confidence in me … We (nurses) are human beings like everybody else, I can also make a mistake … parents should not be afraid of me making mistakes, and if it happens I must admit it and apologize for it. I would do that even though it could be difficult (nurse).

For their part, parents also experience that the close relationship with nurses often creates a commitment to become involved. As nurses gradually trust parents to take more responsibility for their child's care, parents accept this responsibility. The open NICU environment can, however, be revealing, and sometimes parents feel responsible not only for themselves but also for what was the nurses' responsibility:

> I found that one of the nurses didn't take good care of our child. There were these small things … when I got there the CPAP was on his eye instead of the nose, and the nurse had gone to lunch, my feeling was that he wasn't taken care of ... When I leave the hospital I expect that he gets all the help he needs. And when I experience that this is not happening … I told

them how I felt, but the answer was that it didn't matter for the child (father).

Parents express a strong need to be respected both as parents and as collaborators, and the experience of their voice being neglected can be an extra burden. Involvement, however, can also be demanding and one mother described how she dreaded coming to the hospital because then she was confronted with reality.

Nurses describe finding the balance between a professional and a personal approach as a demanding but crucial journey. The open context can facilitate the development of a collaborative relationship but it can also influence the limits of a professional relationship. Closeness can create an obligation for nurses to be involved in issues that they believe are outside their professional role, and therefore they endeavour to limit their contact. The means they use to do this include avoiding being the primary contact for parents they are acquainted with, or not giving parents their home address or private telephone number. As one nurse stated, 'job is job'. Drawing a line between their nursing role and their private life is part of being professional. Nurses describe their professional role in the NICU as diverse and demanding at the instrumental, emotional and interpersonal levels. Creating a good relationship with parents will always put great demands on their personal aptitude and capacity:

> I think a great part of being a NICU nurse is to interact with people. That is, to understand signals, being sensitive towards what the parents you meet express, what they need ... do they want to interact or just be left alone, we have to balance this all the time (nurse).

Nurses also describe how interacting with parents can be difficult to explain and justify, and how it can even be the most demanding part of their job. Nurses gradually master technical and instrumental tasks and these become second nature to them, but many of the nurses found interaction with parents to be much more challenging and demanding.

Discussion

The study confirms closeness as an essential part of the interaction between parents and nurses in an NICU, and shows how the quality of the relationship has a great impact on both parents' and nurses' experiences of the encounter.

The professional relationship

The focus of nursing has traditionally been on the individual patient (43, 44, 45). However, theories about critically ill children emphasize that care is needed for both the child and close family members (46–49). Our study supports previous research (19) about the importance of interpersonal communication and the development of human relationships in parent–nurse encounters. However, the elements that characterize a professional relationship, namely time and space limits, the setting and the exclusive focus on the patient (parent), seem to be less obvious in the parent–nurse relationship in an NICU than in traditional patient–nurse relationships (19).

There are several possible reasons for this. First, interacting with parents as *partners* in care brings different challenges to interacting with patients (5, 50). The ideal of neonatal nursing care is to create a mutual parent–nurse caring team to provide care for the critically ill child. The combination of instrumental and relational competence makes the nursing role complex and demanding. Our findings reveal that nurses experience interaction with parents as perhaps the most challenging part of their job, and they support research showing that the quality of the interaction depends more on nurses' personal abilities than the instrumental aspects of their professional role do (22, 51).

Another issue which can influence the professional relationship is that parents and nurses are in a *similar age group* and *phase of life*, exemplified in our study by parents describing their relationship with their primary care nurse as 'almost like a friendship'. The positive aspect of this is that it can increase nurses' sensitivity to the parents' situation; however, it can make the maintenance of professional distance more difficult (26). Similarly, parents may feel that they can easily relate to their nurses; but over time, this closeness gives parents an insight into the professionals' weaknesses and strengths. This might transfer more responsibility to parents, which they could experience as positive, but which they might perceive as a burden (25). Although this emotional closeness can increase parents' and nurses' respect for each other, it can also reduce their confidence in the others' ability to fulfil their respective roles.

A third issue is the *NICU context*. Parents and nurses interact in an open environment with little room for seclusion, and the overcrowded rooms with windows instead of walls provide little privacy for either parents or nurses. This is different from traditional hospital units where patients are behind doors that nurses have to pass through before contact is established. The need to facilitate supervision of premature infants in the NICU makes parents' life visible to professionals and other parents, while nurses' work also becomes visible to parents (52). This lack of privacy can also contribute to the blurring of professional barriers (25).

Time span and emotional labour

Our findings strongly support the importance of close parent–nurse relationships in building trust. This is in accordance with the characteristics of family-centred care, which emphasizes the mutual character of the

parent–nurse relationship (53). The use of primary nursing care as a way of encountering parents in NICU is supposed to ease the parent–nurse interaction; however, the ongoing close relationship between them makes the issues of closeness and distance important (25, 54). Our findings show that parents describe their relationship with nurses as personal and close. They support research identifying 'befriending' as a way of interacting that is intermediate between a professional and a personal relationship. Even if this position facilitates partnership, it can make professional distance more difficult to attain and increase emotional labour for nurses. The ability to balance closeness with detachment increases with experience, which could explain the nurses' need to keep a professional distance not only to protect themselves as professionals, but also to protect parents' personal integrity (29). The issue of power in professional–patient/parent relationships is well documented (4), and our findings suggest that nurses choose to keep their distance to avoid becoming over-involved and intrusive towards parents (55). The appropriateness of befriending in professional relationships can be questioned; however, the possible increased labour of befriending can be relieved by the positive rewards of mutuality and an approach where the participants interact as individual unique persons (26, 33).

The challenging aspects of collaboration become more obvious as nurses describe the importance of closeness on the one hand, but at the same time talk about difficult or demanding relationships they had experienced. Creating a good relationship seemed to be an expected part of nurses' professional role, and it was difficult both personally and towards parents when nurses found that they failed to be a support to parents. Becoming over-involved with parents can make this professional obligation more personal and demanding, and this supports research that shows that becoming too involved can trigger compassion fatigue (27).

Ongoing relationships also put demands on parents in our study. Although they were acknowledged as collaborators, they had to adjust to the professionals' routines and decisions. These findings support research criticizing neonatal nurses for their use of power and lack of negotiation (18). Although closeness is important, the process of parent–nurse detachment is equally vital in making parents gradually more independent and able to take full responsibility for their child by discharge. The findings support research that identifies the need to explore and clarify closeness and distance in parent–nurse relations, and which suggests that nurses need a range of defences including detachment and objectification in order to cope with the needs of children and parents in a NICU (20, 22, 56).

Conclusion

Although closeness is desirable in family-centred care, the emotional burden of this closeness seems to be seldom problematized. The open and visible NICU environment and ongoing close relationships increase emotional involvement between parents and nurses. Nurses who are conscious of the need to strike a balance between closeness and distance can positively influence parents' independence and coping, as well as their own ability to manage close relationships with their primary care parents.

Author contributions

Liv Fegran was responsible for the study's conception and design, and the drafting of the manuscript. She performed data collection and analyses supervised by Sølvi Helseth, and Sølvi Helseth also made critical revisions to the paper.

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