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**MAINTAINING A LOVING VIGIL:
PARENTS' LIVED EXPERIENCE OF HAVING A PRETERM
BABY IN A NEONATAL UNIT**

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for the degree
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ABSTRACT

Technological aspects of preterm birth and the care of preterm infants are continually examined, yet the impact of the event on families, and particularly parents, has not received the same attention.

A review of the nursing literature illustrated that there are very few published articles examining parents' experiences in a Neonatal Intensive Care Unit, and in particular the effect this has on parents as a couple. Most studies focus on the mother, and there are a small number specifically focusing on the father. This study sought to elicit the experience of both parents as a couple.

This research used phenomenology to examine five couples' experiences following the births of their preterm infants and their subsequent care in a Neonatal Intensive Care Unit. Semistructured interviews were conducted with the parents as a couple. While each couple viewed the experience through their special lens, this study identified themes experienced by all the couples. They described a struggling-within-themselves in an attempt to face and survive the experience. The parents were living through a time-of-uncertainty, and talked about the factors that helped them, and those that made the ordeal more difficult. The three relationships the parents described as being essential were: with each other, with their baby and with significant others. Although their concern for their babies never left them, eventually the parents were able to move-from-fear and feel increasingly comfortable with their experience as they participated more and more fully in the care of their baby.

The research examined the parents' loving vigil with their baby and demonstrated the need for neonatal nurses to provide supportive intervention to influence positively the parents' struggle through the ordeal.

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KEY TO TRANSCRIPTS

The following abbreviations and conventions have been used in the presentation of research findings:

Int.	interview
<i>italics</i>	the words used by the study participants themselves
names	all study participants are identified by the use of pseudonyms
p (pp)	page (pages)
[square brackets]	comments added by the researcher to provide explanation or clarity
...//...	material edited out

CHAPTER ONE

INTRODUCTION

This phenomenological research focused on the impact that the experience of having a preterm baby and the subsequent care in a Neonatal Intensive Care Unit (hereafter called NICU) had on five New Zealand couples. Neonatal intensive care is an exciting, developing sector of the health care field. In no other area is so much human potential at stake. The challenge of helping an infant struggle for survival is awe-inspiring, and there are many rewards.

Medical and technological advances in neonatology have progressed rapidly and steadily improved the outcome for high-risk preterm infants. Many infants, who would not have survived a few years ago or who would have lived with major disabilities, are now living through the critical period with fewer residual effects of prematurity. In New Zealand over the past thirty years there has been a steady drop in perinatal mortality rate by 50% from 21 in 1000 births to 10 in 1000. In the same period, late fetal death rates have also decreased by 50% from 11 in 1000 births to 5 in 1000, and early neonatal mortality rates decreased from 10 in 1000 births to 4 in 1000 (Mortality and Demographic Data Statistics New Zealand, 1993).

Early identification of risk factors for neonates has contributed to the prevention of problems or recognition and treatment of those problems when they can not be prevented. Admissions to the NICU are usually as a result of preterm birth. Sometimes full-term babies are admitted and reasons for this include birth asphyxia or problems requiring surgical intervention, for example, abdominal wall defects. Many of the preterm babies require respiratory support and this may continue for some weeks. Complications due to the barotrauma from the ventilator are recognised, and although every attempt is made to prevent this, some babies are left with complications such as chronic lung disease. Parents need to also face other possible complications of prematurity such as retinopathy of prematurity and periventricular haemorrhage.

Technology such as intrauterine intervention, or air transport for the mother and her unborn baby to be transferred to facilities equipped to manage the situation has led to regionalization of expensive perinatal care. There are currently five hospitals in New Zealand with the ability to nurse neonates requiring level three care; that is, with facilities for providing intensive, life-saving care for preterm and/or critically sick newborn babies. This includes care of babies requiring respiratory support, blood pressure support and post-operative care for neonates until physically stable.

While there is widespread recognition of what technology can do for the preterm infant, so far little research has focused on parents. Examination of the effects of the experience on New Zealand families of high-risk newborns is an area where major advances in understanding could be made. With increased understanding, those caring for neonates in a NICU may have more insight into helpful ways of supporting the parents through their ordeal.

The few studies on parents' experience that already exist originate from Britain and North America. I assumed that parents' experiences of the care received in a NICU in New Zealand might be similar to parents' experiences in a NICU in other countries because of the increasing networking among medical staff working in NICUs throughout the world. There is also increasing networking of neonatal nurses throughout the world. Each year neonatal nurses from New Zealand attend Neonatal Nursing conferences in Australia and North America. This year some are also attending the Neonatal Nurses conference in Singapore. Despite these world-wide exchanging of ideas I could find no literature to support my assumption that parents' experiences are the same in New Zealand as in other countries.

This study aims to understand more about parents' experience of having a baby in a NICU. Through this understanding health care professionals, particularly nurses, may have an increased awareness and acceptance of parental feelings and of nursing practice that meets the parents' needs.

Nurses working in the NICU interact with parents who are visiting their babies and view teaching, explaining, reassuring, comforting and listening to the parents as part of their role. As a neonatal nurse working with parents and with other nurses in the NICU, I became aware that as nurses interacted with parents they felt that they understood how the parents were feeling. Exposed to parents for most of their working day, nurses saw how parents reacted and discussions among nurses often referred to parents' reactions. I wondered how much of our discussions about parents were based on assumptions. I began to listen to the parents' communication with nurses when they talked about their experience of having a preterm baby, and my awareness of the parents' responses (both verbal and non-verbal) increased. I became more aware of how frightening and overwhelming parents found this experience. I watched their facial expressions and their body movements when they visited the NICU, as they cared for their baby and when they left the unit. I decided that gaining more insight into parents' reactions through listening to their stories could have valuable implications for neonatal nursing practice. I was interested to know how the experience affected not only the individual parent, but the couple together.

Throughout the study my focus was on the parental experience. As a nurse working in a NICU, I am aware that there are other people whose experiences of working with parents and preterm babies also deserve to be told. These further studies, the stories of nursing and medical personnel, would complement the parents' experiences, and enhance our understanding of the human response to the birth of a preterm infant.

A phenomenological research method was chosen as the most appropriate method for this study. Walters (1994) pointed out that phenomenology, as a philosophy, has application for nursing, particularly when the study focuses on the phenomena of the everyday lives of people, coping with distress or some form of illness. The phenomenological perspective can help to increase the nurse's understanding of the life worlds of those s/he is helping by emphasising the meaning of the lived experience (Crotty, 1996). This study followed van Manen's (1984) interpretation of phenomenology. His belief is that other people's experiences, and reflections on their experiences, are 'borrowed' so that the researcher will be better able to understand a

new meaning, a deeper meaning or a significant aspect of human experience. The stories of the parents in this study illustrate the everyday experience of having a baby in a NICU.

The research design required recruitment of a purposive sample of parents who had a preterm infant in a NICU. The data were expressively their data about this experience, and the findings cannot be generalized to the general population. Nevertheless, the stories of the five couples who were interviewed yielded rich data that provided insights for neonatal nurses to examine and develop their nursing practice.

OVERVIEW OF THE STUDY

Chapter One gives an introduction to the study and describes the assumptions that prompted the project to examine the parents' experiences of having a preterm baby in a NICU.

Chapter Two reviews the literature on parents who have had a preterm baby in a NICU. Most of the literature relating to the care of a baby in a NICU concerns the medical and technological aspects. Comparatively little research has examined the parents' experiences.

Chapter Three examines the use of the phenomenological method for the research and in particular, van Manen's (1990) method. The study design, methodology and ethical issues relating to the study are outlined.

Chapters Four, Five, Six and Seven use van Manen's thematic analysis to describe the parents' experiences. The four major themes that develop from the data chapter illuminate for me the path taken by the parents in their **loving vigil** with their baby.

In **Chapter Four** the parents vividly describe their reactions and feelings in their struggle-within as they attempt to live through the ordeal.

Chapter Five examines how the parents lived day by day, not knowing the outcome for their baby or for themselves as a couple and/or as a family and ways that helped them live-with-their-uncertainty.

Chapter Six demonstrates the importance parents placed on support from others and their reliance on their relationship with each other, with their own parents, friends, work mates, other parents in the unit and with the unit staff. The significance of the new relationship - that of becoming a parent for their new baby, is also evident as the parents related their stories.

In **Chapter Seven** the parents discuss how they grow to feel more at home in the unfamiliar environment of the NICU. The anxiety, which was always with them, became less acute. The confidence they were gaining in caring for their baby was the most important factor in helping them to feel more at ease as they gradually prepared to take their baby home.

Chapter Eight relates the parents' experiences to the literature in a discussion of the implications of the findings for neonatal nursing practice, education and research.

The research shows that parents, with a tiny sick infant, face an existence that is reliant on hospital staff for their baby's every need, in an environment that is foreign to them. Themes and issues experienced by the parents as they lived through a time of a loving vigil with their baby are illuminated.

CHAPTER TWO

LITERATURE REVIEW

This chapter provides an overview of the published literature relating to parents' experiences of having an infant in a neonatal unit. Most of the literature was authored by nurses and about 90% of the research reviewed was written from a psychological, educational, medical or sociological framework. Apart from the work carried out by McHaffie (1990), there is little published research written from a nursing perspective. North American research dominated the literature reviewed although about 10% did come from Britain. Disappointingly, New Zealand or Australia have not been in the forefront in researching the nursing processes for babies in a NICU and the impact this has on their parents. I did not find any published research in this area from New Zealand nurses. This review is on the major literature over the last thirty-five years. The focus is on the content, although the methodology is also examined. The following three headings provide the framework for the review:

The parental experience of preterm birth

The parent-infant relationship

The parents' relationship with staff and others.

THE PARENTAL EXPERIENCE OF PRETERM BIRTH

According to Bogden, Brown and Foster (1982), having a baby in a NICU is a highly stressful event. Unprepared for the hospitalization, and unsure of its outcome, parents face severe threats to their psychological well-being. This stressful time in the parents' lives has also been researched by Dohrenwend, Krasnoff, Askenasy and Dohrenwend (1978), Holdroyd and Lazarus (1982), McGrath (1970), Merenstein and Gardner (1993), and Silcock (1984).

Parents' emotional reaction to the crisis of having a preterm birth

Christensen (1977), Johnson (1979), Merenstein and Gardner (1993), and Shosenberg (1980) and have summarized parental feelings associated with the birth of a preterm baby. These included shock and denial at the time of the baby's birth and later, feelings of anger, depression, insomnia, irritability and guilt. Parents were fearful that their preterm baby would die or develop major medical, physical and/or mental disabilities. Miles, Funk and Kasper's (1992) study which was part of Miles and Funk's (1987) larger study exploring parental responses to the hospitalization of a preterm infant, found that both parents are distressed by the admission of a preterm baby to a NICU. Their data support Affleck, Tennen and Rowe (1991), Benfield, Lieb and Reuter (1976), Gennaro (1988), Jeffcoate, Humphrey and Lloyd (1979), Philipp (1983), and Trause and Kramer (1983), who showed that feelings of disappointment, fears regarding the baby's survival and altered parental experiences, including separation and reduced opportunities to interact with the baby, are all difficult for parents.

Individuals approach a crisis in ways that reflect their personality, and past and present experiences. A key feature of the crisis of neonatal intensive care is that it violates parents' cherished assumptions about themselves. Behaviours of parents show disorganization, a sense of helplessness and lack of equilibrium of thought when they are confronted with the birth of their preterm infant (Caplan, 1964; Halpern, 1973; Miles, 1985; Seligman, 1975). Merenstein and Gardner (1993) using a psychological framework describe a number of nonverbal and verbal signs that indicate parents are struggling to gain a sense of security in the NICU.

It is important that health professionals assist families in using their experience of the preterm birth of their baby to maximise their growth, adaptation and reorganisation during this period (Goldson, 1992; Minde, 1984; Solnit & Stark, 1961; Thorne & Robinson, 1988; Woolley, 1990). Robert's (1983) research which used a psychological framework examined infant behaviour and the parents' transition into parenthood. A more difficult transition into parenthood for these families was identified by Fanaroff, Kennell and Klaus (1972) and Lynch (1975) and a greater incidence of failure to thrive

and child abuse in the infants was noted.

Gennaro (1991), Griffin (1990) and Siegal (1982) have described several situational factors affecting parental coping. These include the behaviours and attitudes of the hospital staff, the sensitivity used in the process of 'separation' and transfer of the baby to the intensive care nursery and the flexibility of hospital policy concerning parental and sibling involvement and visitation in the nursery. The above researchers also found other significant factors which affect parental coping. These are the instruction of parents in their baby's individual behaviours and characteristics, the staff's comprehension and appreciation of the psychosocial functioning of families and the family's response and adaptation to stress and crisis, the employment of emotionally supportive intervention programs for parents within the nursery setting, and the development of appropriate discharge planning to provide adequate follow-up care to the baby and family.

The guilt felt by the parents

There is overwhelming evidence, based on research, that following a preterm birth some parents experience guilt for a variety of reasons. Grant and Siegal (1978) whose work examines families in crisis following the birth of a sick infant, state that guilt is one of the primary, and often the most intense, reactions of parents after the birth of a preterm baby. Merenstein and Gardner (1993) illustrate the many behaviours that parents demonstrate which indicate they are struggling with guilt and failure. Some parents directly verbalize these feelings, and attempt to obtain helpful answers from the staff. Others exhibit an overwhelming sense of helplessness, and because they feel responsible for causing their baby's prematurity, and helpless to remedy the situation, they become highly anxious about their ability to handle their baby and cannot tolerate visiting their baby. Their guilt feelings can cause them to be self-deprecating and angry at themselves, a state that may result in depression.

Merenstein and Gardner (1993) also point out that parents search for reasons because they need to find a cause for such an event happening to them. For some parents it is

more difficult to feel out of control and helpless than to feel guilty. Some parents place responsibility on themselves, but others shift the blame to their spouse, extended family, doctor or nurses. Often both parents are concerned with the disappointment that they have caused their partner, and may withdraw from each other at a time when they both need acceptance and support.

Whetsell and Larrabee's (1988) work examines the causes of guilt in parents of preterm infants. They discuss both destructive and constructive cycles of behaviour that arise from guilt, and describe an affirmation model or process nurses can use to guide parents to an awareness of the destructive guilt cycle and to a mastery of the constructive guilt cycle.

Grief for the loss of the anticipated baby

A survey conducted by Nance (1982) revealed that parents of preterm babies in a NICU had an overwhelming concern about illness and the development of their baby. Parents typically respond to the birth of a preterm, sick baby with intense feelings and a grief similar to that occurring at the death of a loved one. McHaffie's (1990) prospective study examined anticipatory grief as the first phase the mothers of very low birth weight [VLBW] babies passed through. Anticipatory grief, also described by Benfield et al. (1976), Edwards and Allen (1988) and Fraley (1986) is dominated by fear both of death of the infant and of other traumatic sequelae to the preterm delivery. The data from Fraley's (1986) descriptive survey indicated that the parents experienced feelings of loss, grief and fear when their preterm baby experienced illness, surgery or medical problems. While mourning the loss of the hoped for perfect baby, mothers begin to assimilate facts about their baby, and in many cases also anticipate his/her death. In grieving they tend to hold themselves emotionally distant from the baby in an attempt to lessen the loss in the event the baby should die.

Merenstein and Gardner (1993) point out that it is important to keep in mind that withdrawal and grieving is a necessary and natural process. A psychoanalytical study of Solnit and Stark (1961) demonstrated that for parents to develop an attachment to and

accept the reality of their baby's condition, they must experience their feelings over the loss of the expected child. This grieving serves to free the parents' emotional energy so that they can interact with and become attuned to their baby. Samrall's (1987) psychological study shows that failure to successfully resolve the grief which accompanies the birth of a critically ill baby is linked to later parenting difficulties, marital disruption, an increased incidence of child abuse and neglect, and nonorganic failure to thrive in the baby.

Both parents are distressed by the admission of a preterm baby to a NICU. Samrall (1987) outlined the grief process with particular emphasis on the ways men and women differ in their adjustment to grieving. Benfield et al's. (1976) psychological study of 101 mother - father pairs whose critically ill newborns were admitted to a NICU, identified seven grief responses. They found that mothers of critically ill infants reported more sadness, loss of appetite, guilt, anger, disbelief, depression and crying than fathers. Philipp's (1983) psychological study found that mothers retrospectively recalled more anxiety than fathers. Merenstein and Gardner (1993) identified that differences are fostered in part by different cultural expectations, especially stereotypical roles which allow mothers to cry and express their fears, but expect fathers to remain stoic and control their emotions.

Three articles reviewed make recommendations for specific interventions nurses could use to help families to manage their grief. Edwards and Allen's (1988) practical article briefly reviews factors found that contribute to successful resolution of grief. Maelick's sociological study (1984) advocated nursing interventions to assist parents in expressing their feelings of anxiety and anger. In a case study, Kruger (1992) has set out a summary of the general principles to consider when assisting the parents and points out that many of the interventions presented require the nurse to have basic counselling skills.

Ways parents cope with their preterm babies' hospitalization

Affleck and Tennen (1991) carried out a research program to examine how parents adapt to the crisis of neonatal intensive care and what this may mean for them and for their child's future wellbeing. Each of the studies composing this program was longitudinal. These researchers administered Lazarus and Folkman's (1984) Ways of Coping Checklist. They describe five strategies of coping with the hospitalization - taking instrumental actions, mobilizing social support, seeking meaning, escaping, and minimizing the situation. Affleck and Tennen (1991) and Merentein and Gardner (1993) found that seeing the infant helps to facilitate attachment, decrease exaggerated fantasies, decrease withdrawal from the baby and enhance the parents' ability to grasp the reality of the situation. Stress may be reduced by factors such as personality strength (Haan, 1982; Hobfoll & Lieberman, 1987; Holroyd & Lazarus, 1982; Janis, 1982; Kobasa & Pucetti, 1983; Pearlin, Lieberman, Menaghan & Mullan, 1981) social support (Brown, 1981; Broadhead, Kaplan, James, Wagner, Schoenbeck, Grimson, Heydren, Tibblen & Gehlbeck, 1983; Cronenwett, 1985; Mercer & Ferketich, 1988); prior experience with the stressor (Kadner, 1989); and preparation for the stressors through education (McGrath, 1970).

McHaffie (1990) described the phase of anxious waiting as "when the baby's survival was reasonably assured." The focus of concern now changed to the quality of life the child could expect. Numerous anxieties often focused on relatively trivial behaviours, which to an extent masked fears too great to be addressed in full. Gradually, the mothers in McHaffie's study began to allow themselves to attach to the baby, and to perceive the baby in more positive terms. Throughout this phase they continued to be emotionally labile, showing mood fluctuations with the changing fortunes of the child. Positive perceptions were reinforced by the baby's responses. Increasingly the mothers welcomed opportunities to perform basic caretaking tasks, and their confidence grew with their involvement with their baby's care and the pleasure they took in their performance.

The parents' vulnerability

Affleck and Tennen (1991) showed that major life stressors can have positive as well as negative effects on psychological well-being. These researchers found that the way the mothers appraised a threatening event influenced their coping efforts and well-being. The women evaluated their babies selectively on dimensions that made their own baby's condition seem relatively less serious. Mothers of the smallest babies tended to compare their baby with those who needed more technological support to survive. Conversely, mothers of infants who were larger, but in some way more ill, compared their baby with the smaller babies. Mothers in both groups thought their own baby better off.

Growing through the experience

Several psychological studies examined how parents responded to the crisis of preterm birth. Successful resolution of the crisis according to Caplan (1960) and Mason (1963) is determined by the family's cognitive grasp of the situation, their ability to handle feelings, and the help provided with learning mothercraft. Kaplan and Mason (1965) identified four essential psychological tasks for the mother to assist resolution of the crisis. These were preparation for possible loss of the baby, acknowledgement of maternal failure to deliver a normal full-term baby, resumption of the process of relating to the baby by the mother, and maternal understanding of how the growth and development of a preterm baby differs from that of a normal baby. Anderson (1981) and Barbarin and Chesler (1984) have also examined ways that parents use to maintain a sense of mastery over having a preterm baby. Affleck and Tennen (1991) describe benefits from overcoming the crisis of having a preterm infant. Edwards and Allan (1988) found that a positive outcome of the preterm birth experience was the parents' enhanced confidence in their ability to parent.

THE PARENT-INFANT RELATIONSHIP

As Samrall (1987) has pointed out, if the pregnancy has ended prematurely, parents have not had the full nine months' time span to resolve conflicting feelings and prepare for the role of parenting.

Parents' perception of the baby

Preterm babies have different body proportions from the full-term baby that the parents expected. Klaus and Kennell (1982) in their work on parent-infant bonding documented that parental fantasies about their infant's problems are usually worse than the reality. Kennell's (1978) article states that it was not uncommon for a mother to describe her baby in terms such as "rat-like." In some parents this leads to the question of whether the baby will ever grow up to look like a normal human being. Many mothers of preterm babies feel alien to their infants, making it easier to have feelings of rejection toward the baby. In addition to feeling inadequate about the ability to deliver an infant at term, they feel empty inside, as if something is missing (Kennell, 1978; Merenstein & Gardner, 1993).

Few studies have attempted to discover if the preterm baby's appearance causes the mother to have maternal perceptions which are more negative than those of full term infant mothers. The reviewed research showed conflicting outcomes. Leonard, Scott and Erpestad's (1992) quasi experimental study showed that mothers of preterm babies had a more positive perception of their babies than mothers of babies born fullterm. Jeffcoate et al's. (1979) sociological study found that mothers of preterm babies rated their babies significantly less positively than did full-term mothers. Watt's (1987) psychological study supported this finding. Robert's research (1983) identified a more difficult transition into parenthood for these families, and a greater incidence of failure to thrive and child abuse of the preterm infant.

Alteration of the parenting role

The ability to parent is influenced by a multitude of factors that occur before, during, and after the birth of the baby. Previous life events including genetic endowment, cultural practices, being parented, previous pregnancies and interpersonal relationships affect the experience of pregnancy and parenting (Jordan, 1978; Kadner, 1989; Kaplan & Mason, 1960; Klaus & Kennell, 1982; Mead & Newton, 1967). The events of the current pregnancy, their significance to the parent and the availability of support and assistance influence parenting ability (Merenstein & Gardner, 1993). After birth, infant characteristics, behaviour of health professionals, separation from the infant and hospital practices may positively or negatively influence parents (Barnett, Leiderman, Grobstein & Klaus, 1970; DeChateau, 1977; Gardner, 1978; Griffin, 1990; Klaus & Kennell, 1982; Leifer, Leiderman, Barnett & Williams, 1972; Sugarman, 1977).

Younger's (1991) cross-sectional study discovered that the most stressful aspect of the NICU environment for the parents was alteration in the parental role. Miles et al. (1992) found that mothers were more distressed than fathers by the parental role alteration and discuss examples such as separation from the baby, feelings of helplessness in the parental role, and limitations on their ability to give care as aspects of the situation that the nurse must address with the parents. Kennell's (1978) article states that these parents are not psychologically ready, that they need an extended period of time to think about and plan for the birth of their baby, and although the necessary studies have not been performed, possibly the mother is not hormonally prepared for attachment to her preterm baby. Daley's (1984) article examining the perceived immediate needs of families with relatives in the intensive care situation, found that parents need to see their baby as an individual and be able to interpret/perceive his/her reactions and needs.

Several articles have described development of the maternal role (Mercer, 1981, 1985, 1986; Rubin, 1967; Walker, Crain & Thompson, 1986) but literature on the paternal role is limited. Jeffcoate et al. (1979), Marton, Minde and Ogilvie (1981), Parke and Anderson (1987) and Yogman (1987) have examined the responses of fathers to the

birth and care of preterm infants. Brown, Rustia and Schappert (1991) used role theory concepts to investigate factors related to infant care behaviours of fathers of high-risk infants but generalizations from the findings are limited because of the non-random, small, homogeneous sample. They did show that failure of the father to adjust to fatherhood and take on the paternal role may influence the well-being of the entire family. In general, the fathers had originally thought they would do more for the baby than they actually achieved. This is consistent with the findings of Humenick and Bugen (1987) and Rustia and Abbott (1990).

Confidence in caring for their baby

Several factors have been found to be positively related to maternal confidence such as parity, prior experience, social support, self-esteem and education (Gibaud-Wallston, 1978; Gross, Rocissaro & Roncoli, 1989; Jordan, 1973; Rutledge & Pridham, 1987;) and negatively related to stressful situations such as preterm birth, lack of social support, separation from the infant and temperamentally difficult infants (Brown, 1967; Cutrona & Troutman, 1986; Greenberg, Rosenberg & Lind, 1973; Jeffcoate et al. 1979; Kenner & Lot, 1990; Leifer, Liederman, Barnett & Williams, 1972; Liederman & Seashore, 1975; McHaffie, 1990). The purpose of Zahr's (1991) study which utilized a psychological framework, was to investigate the relationship between maternal confidence in mothers of preterm infants, maternal behaviours and skills and infant temperament. The results revealed that maternal confidence was related to education, income and parity as well as the presence and severity of intraventricular bleed which results in insult to the brain depending on the severity of the bleed. Infants with an intraventricular bleed are likely to be sicker and less alert than their counterparts in the early months. There was no relationship between observed maternal behaviours and skills and perceived confidence by mothers.

Curry's (1983) psychological study noted that the mother-infant relationship is adversely affected if the mother feels she is not confident in her parenting role. Involvement in caretaking lessened the feelings of helplessness and frustration and facilitated identification with the role of a parent. A longitudinal study by Williams, Joy, Travis,

Sotowiew, Blumsteele, Aitken, Painter and Davidson (1987) revealed that parental confidence is the driving force for a healthy parent-child relationship. However, Zahr (1991) points out that despite the importance of maternal confidence in caring for the baby, few researchers have attempted to measure it, or determine its relation to maternal characteristics and infant temperament especially with preterm infants.

Parents' interaction with their baby

Gottwald and Thurman's (1990) work based on a psychological framework examined the literature on variables such as factors in the physical environment of the NICU and factors related to the status of the infant and the emotional state of the parents that could affect interactions of parents and their infants in a NICU.

Als, Lester and Brazelton's (1979) behavioural study showed that among the factors that may contribute to altering mother-infant interactions with preterm infants are delayed maternal tactile contact, maternal and/or infant health status, alteration in infant state, and the infant's decreased responsiveness to social stimuli. Preterm infants are less alert and responsive than full-term babies, vocalize less, achieve less eye-to-eye contact and have more limited responses to stimuli (Davis & Calhoun, 1989; Goldberg, 1978; Holditch-Davis, 1990; Klaus & Kennell, 1976; Klaus, Kennell, Plumb & Zuchlke, 1970; Leonard, Scott & Erpestad, 1992; Linn, Horowitz, Buddin, Leake & Fox, 1985). These behaviours are usually unexpected by parents, and difficult for them to interpret (McGehee & Eckerman, 1983). Greeg, Haffner and Korner (1976), Rose, Schmidt, Riese and Bridger (1980) and Solkoff, Yaffe, Weintraub and Blase (1969), have found that preterm infants are deprived of appropriate stimulation. As compared to parents of full-term newborns, parents of preterm infants interact less intimately with their baby (Gottwald & Thurman, 1990; Leifer et al. 1972; Seashore, Leifer, Barnett & Leiderman, 1973). Jones (1982) reports that only about 10% of the contact experienced by infants during their stay in the NICU came from parents. Parents may also be reluctant to form close attachments to a sick preterm baby because of fear that the baby might die (Pederson, Bento, Chance, Evans & Fox, 1987). However there is research showing the advantages of parents persisting with the care of their babies in the NICU.

Miller and Holditch-Davis (1992) studied interactions of parents and nurses with high risk infants and found that preterm infants responded to maternal care with increased eye opening and alertness, suggesting that social stimulation led to an increase in infant social behaviours. Olson, Edwards and Hunter (1987) found that parent and staff interaction lay the foundations for the parents' satisfactory adjustment to their baby.

Another source of stress for parents which may affect the nature of parent-child interactions is the environment of the NICU such as the sights and sounds of the unit the infant's physical appearance, the equipment and relationships with health care personnel in the unit (Gottwald & Thurmann, 1990; Jones, 1982; Linn et al. 1985; Miles, 1989; Miles, Funk & Kasper, 1991; Paludetto, Faggiano-Perfetto, Asprea, De Curtis & Magara-Paludetto, 1981; Yu, Jamieson & Astbury, 1981).

Slaikeu (1984) examined nursing interventions focusing on assisting and supporting parents to integrate the experience of having a preterm infant in a NICU into their lives. Fostering realistic hope, creating an atmosphere of trust and encouraging questions that otherwise would go unasked and unanswered, help parents to be open instead of closed to the future.

Most studies have examined mothers' interactions with their baby. Less is known about how fathers interact with their babies in the NICU or how their interaction differs from that of mothers. In an attempt to discover more about paternal responding in the NICU, Marton et al. (1981) conducted a study that compared the patterns of interactions of mothers and fathers with their infants in the NICU. The results indicated that mothers talked to their babies more than fathers and that infants behaved differently when fathers rather than mothers were present. Brown et al. (1991), Gottwald and Thurman (1990), Levy-Shiff, Sharir and Mogilner (1989), and Miles et al. (1992) found that mothers visited more and engaged in more caregiving, talking and holding behaviours during initial hospitalization than fathers. However, with the exception of caretaking, differences between maternal and paternal interactions decreased with time (Miles et al. 1992).

Opportunities for parenting

Brown, York, Jacobsen, Gennaro and Brooten's (1989) study which examined parental visiting and telephoning during initial infant hospitalization showed that mothers were the primary visitors and telephone callers during their infants' hospitalization in the NICU. Kaplan and Mason (1960), and Merenstein and Gardner (1993) found that parents struggling with their fears may resist seeing, touching, or visiting the baby. If they do visit the baby in the NICU, they may remain distant by having little or no eye contact with the baby, refusing to touch, standing away from the baby, and asking few or no questions of the staff.

In a study reported by Gottwald and Thurman (1990), mothers appeared to be less confident and more passive with their infants during early parent visits to the NICU which were described as infrequent and tenuous, preferring to look at the infants rather than interact more actively. Those mothers who visited more frequently and for longer periods were also those mothers who interacted more dynamically. Kennell (1978) has provided evidence that mothers who visited fewer than three times each week had a remarkably high incidence of mothering disorders.

Learning to parent in an unusual environment

For many parents of preterm infants, the first site of involvement with their infant is the NICU. Siegel's (1982) sociological study found that they must learn a new language, establish trust in new relationships, and accept their role in the NICU setting. The number of hospital personnel who have contact with infants in the NICU may also affect parent-infant interaction (Gottwald & Thurman, 1990). The intense and sometimes disorganised appearance of a high-risk nursery makes it a frightening experience that serves to increase parental feelings of helplessness and anxiety. Evidence has been provided by Easterbrooks (1988), Goldberg (1978), Gottwald and Thurman (1990), Harrison (1990) Jeffcoate et al. (1979), Jones (1982), Kennell (1978), Linn et al. (1985), Miles (1989), Miles et al. (1991), Paludetto et al. (1981), Trause and Kramer (1983), Yogman (1987) and Yu, Jamieson and Bajuk (1981) that the NICU

environment is highly technical, bright, noisy and chaotic. It also lacks the privacy that could be conducive to the most optimal parent-infant interaction. Miles et al. (1992) stated that the sights and sounds of the unit were moderately stressful for both mothers and fathers, and this did not change over time.

Breast-feeding the preterm infant

Regardless of eventual success, the mother should be encouraged to try to breast-feed if she has an interest (Merenstein & Gardner, 1993). Mothers of preterm infants might especially benefit from a support program designed to assist with day to day lactational problem solving. The physical conditions of both mother and baby, the neonatal intensive care environment, and mother-infant separation may contribute to maternal psychological stress and inhibition of lactation (Richards, 1982). A positive association between breast-feeding and social network support has been widely reported (Baranowski, Bec, Rassin, Richardson, Brown, Guenther & Nader, 1983; Bryant, 1982; Entwisle, Doering and Kaufman & Hall, 1989; Reilly, 1982; Wright & Walker, 1983). Kaufman and Hall (1989) conducted a prospective analytic study to examine the influences of the social network on the choice and duration of breast-feeding among 125 mothers of preterm infants. The supports reported by the mothers included family, especially partners, friends and health care professionals. The amount of support was an influential factor for both the choice to breast-feed and for the duration of breast-feeding.

THE PARENTS' RELATIONSHIP WITH STAFF AND OTHERS

Since the initial NICU hospitalization may be complicated by a series of events which constitute a continuing crisis state for the parents, Gottwald and Thurman (1990) and Samrall (1987) point out that there is a high need for social support. Samrall (1987) has provided evidence that availability of social support during the preterm baby's hospitalization and ability of parents to use that support was significantly related to final emotional outcome for the parents. The provision of social support leads to an enhancement of parental coping abilities, increased self-esteem, reduced parental anxiety and increased feeling of control and mastery of the situation. Therefore, point out McKim (1993), Sameroff and Chandler (1975) and Schraeder (1986), social support is a factor that enhances the possibility of a positive outcome for high-risk preterm infants.

Finding social support

The implications that the experience of having a preterm baby have for the marital relationship have been extensively studied. Murphy's (1990) grounded theory study looked at the way both parents responded to the birth of their preterm baby and the effect of this on the parents' relationship. Aguilera and Messick (1978) conceptualized the stress impact on a family when the preterm birth of an infant occurs. They found that when the relationship between the husband and wife was unstable, a crisis state was observed. Borg and Lasker (1981), Clyman, Green, Rowe and Ataide (1980), Cook (1983), Gardner and Merenstein (1986), Schiff (1978), Williams and Nikolaisen (1982), and Wilson, Witzke, Fenton and Soule (1985) discuss the extent to which discrepant coping efforts serve as a source of conflict between the couple. A related source of conflict identified by Helmrath and Steinitz (1978) and Miles, Spicher and Hassenein (1984) was the expectation that the response of one's partner should be identical to one's own response. Gardner and Merenstein (1986), Helmrath and Steinitz (1978), Peppers and Knapp (1980), Rando (1985) and Wilson, Fenton, Stevens and Soule (1982) found that women described a sense of confusion over their husbands' behaviours, and expressed difficulty in understanding why their partners did not seem to be experiencing the same degree of emotional intensity that they were experiencing.

Crnic and Greenberg (1987) and Mercer and Ferketich (1988) indicated that the mother's perceived satisfaction with her support may be more important than the actual amount or availability of support. Affleck and Tennen (1991) found that husbands expressed greater satisfaction with their support network than did their wives. The primary source of support for mothers was found to be the baby's father (Adams, 1963; Sherwen, 1986), with their mother as the secondary source of support (Crockenburg, 1987). For those women whose partners do not provide the needed resources, Younger (1991) found no evidence suggesting that other resources could be substituted. Parents who have successfully dealt with and resolved the crisis of the preterm birth of their baby, can be extremely valuable by providing support to new parents of a preterm baby through sharing common feelings, reactions and experiences, and guiding them on aspects of having a hospitalized baby in a NICU (Katz, 1983; Martin, 1983).

The mothers of VLBW infants, in Rajan and Oakely's (1990) study expressed a need for more support, reassurance and information, for recognition of economic hardships caused by the birth of the baby, and for more attention to the parents' feelings and opinions from health professionals. Katz (1983) and Martin (1983) have commented on how important it is for nurses and other health professionals to be an integral part of the parents' support network.

The needs of the baby's siblings

When the baby is born seriously ill and is hospitalized in the NICU, siblings may experience confusion about the situation, irrational guilt feelings that they caused the baby's illness, and fears for their own security and health, and that of their parents (Samrall, 1987). They suffer from being somewhat isolated from their parents, and may feel disappointment, sadness and anger that their baby has not come home as they had expected. Newman and McSweeney (1990) in their descriptive study of sibling visitation in the NICU, discuss how parents are often unsure about what to tell the other children, and whether or not the children should see the baby. Their study found that children tended to invent an explanation for the baby's illness if no explanation was given to them.

The parents' need for information

One method parents used to deal with the crisis was to seek information (Bull & Lawrence, 1985; Golas & Parks, 1986; Hall, 1983; Harrison & Hicks, 1983; Hiser, 1987; Moss, 1981; Smith, 1989; Sumner & Fritsh, 1983). Samrall (1987) indicated that parents want particular information about the diagnosis and treatment, expected outcome and causes of the infant's condition. Initial concerns are related to cause while the more specific questions about treatment and outcome arise later in the NICU stay. McKim's (1993) descriptive study found that mothers of preterm babies wanted more information on problems related to the prematurity of their baby. The mothers who did not receive this information were more anxious and less confident in caring for their infant. The mothers also reported lack of confidence and the need for reassurance. Uncertainty about the infant's survival, the baby ceasing to breathe while asleep, and apprehension about an infant's condition have been discussed by Goodman and Suave (1985), Jeffcoate et al. (1979), and McKim (1993).

Getting the information

The unit staff and the parents need to build up a relationship which ensures that the parents receive the information they require. Able-Boone, Docecki and Shelton Smith's (1989) ethnographic study investigated parents' and health care providers' interactions when the parents had a baby in the NICU. They found that the parents had concerns regarding the medical information provided, the lack of time that health care workers had to spend interacting with parents, and the possibility that the parents' emotional involvement interfered with their understanding of the baby's condition. Parents prefer that staff are direct and honest with them and want to be involved in the treatment decision-making for their baby. Cave, Johnson, Komar, Meaker and Patton (1985) and Holloway (1988) suggest group meetings between health professionals and families as a way to meet families information needs.

Daley's (1984) work found that seeing a family member amidst highly technical equipment can cause an emotional crisis. The two main expressed wishes of families in Daley's study were to be informed truthfully of the patient's condition, and to know

the best care is being offered. This places a considerable onus on staff to provide sufficient explanation and information, and to repeat it, as most parents in a shocked state cannot readily assimilate it initially. Samrall (1987) stated that since people in crisis hear and understand information at varying rates, talking to parents promptly, preferably at the same time increased the chance that they will receive adequate information and decreases the possibility of overprotection of one parent by the other with resulting communication problems and marital disruption.

Preparation for discharge

As the time for discharge from the NICU nears, preparation of the family is important. McHaffie (1990) and Samrall (1987) note that this is a time of mixed emotions for most parents including happiness that the baby is now well enough for discharge, anxiety at the prospect of caring for a baby who so recently required intensive medical care, qualms about the future of the baby, and resentment or jealousy that the staff shared in their baby's first days to a greater extent than they did themselves. Able-Boone et al. (1989) and Olson et al. (1987) point out that although survival of the baby is the primary goal of the NICU, the integration of the baby into a well-functioning family is also of paramount importance.

SUMMARY:

This chapter has reviewed the North American and British literature that relates to parents' experience of having a baby in a NICU. The literature review revealed no published nursing research on parental experiences of having a preterm infant in a NICU in New Zealand. Most of the research reviewed discussed the traumatic effect of having a baby born preterm admitted to a NICU. For the most part, researchers have focused on one aspect of this event. For example they have examined the guilt or the sorrow of the parents, or parents interaction with their baby in a NICU. McHaffie's (1990) prospective study was the only documented research I found which aimed at finding out how mothers of very low birth weight babies adjusted. No study has asked both parents what the experience was like for them.

Although the methodology of the reviewed research is noted, the main focus for the literature review was on the outcomes. Most of the research utilized sociological or psychological models, no researcher used phenomenology as their research method. This study asked five couples to talk about what the experience of having a preterm baby in a New Zealand NICU was like for them. Phenomenology was used as this method was the most appropriate to elicit these parents' experiences.

Chapter Three focuses on phenomenology as the method used to explore parents' reality of having a baby in a New Zealand NICU and the impact this has on the parents' lives. The research process used for this study is fully described.

CHAPTER THREE

RESEARCH METHODOLOGY AND DESIGN

Understanding of the impact on families has not kept pace with the technological advances [in neonatology] and there is a paucity of information in parent perception of events related to the birth and subsequent progress of very small sick infants (McHaffie, 1990).

Introduction:

The purpose of this research was to listen to the stories of parents who have had a preterm baby in a NICU, and from these to learn about what this experience was like for them. Phenomenology was chosen as a way to reflect on these lived experiences and their practical applications for the parents. The phenomenological tradition seeks to understand the lived experience of individuals and their intention within their "life-world". For van Manen (1990) this method aims at gaining a deeper understanding of everyday experiences by asking "What is this or that kind of experience like?" (p. 9). Omery (1983) notes that it is a requisite of phenomenology that no preconceived notions, expectations or frameworks be present to guide the researchers as they gather and analyze the data. The goal of phenomenology is to describe accurately the experience of the phenomenon under study and not to generate theories or models, nor to develop general explanation (Morse & Field, 1996).

Van Manen states that phenomenology differs from almost every other science in that it attempts to gain insightful descriptions of the way the world is experienced pre-reflectively, without classifying or abstracting it. From a phenomenological point of view, to do research is always to question the way we experience the world in which we live as human beings, systematically attempting to uncover and describe the internal meaning of structures of lived experiences. Van Manen notes that a person cannot reflect on lived experience while living through the experience, and therefore phenomenology is always retrospective and recollective.

There are different terminologies and approaches to analysis. Van Manen (1990) and Benner (1994) talk more of ordering of themes and of acquiring an intuitive grasp of the textual data. Validity rests in the richness of the discussion. Does the description make sense to anyone else? Does it make sense within the context of nursing practice (Ray, 1994)? Phenomenological writing may be descriptive or interpretive but it is essentially written as text and open to varied interpretation depending on the experience of the reader (Morse & Field, 1996). This study will describe the experiences of parents who have had a preterm baby in the NICU.

Phenomenology claims to be scientific in a broad sense since it is a systematic explicit, self-critical and intersubjective study of its subject matter - lived human experience. It is systematic in that it uses specially practised modes of questioning, reflecting, focusing and intuiting. Phenomenological human science research is explicit in that it attempts to articulate through the content and form of text, the structures of meaning embedded in lived experience. It is self-critical in the sense that it continually examines its own goals and methods in an attempt to come to terms with the strengths and short-comings of its approach and achievements. Phenomenology is a human science since the subject matter of phenomenological research is always the structures of meaning of the lived human world (van Manen, 1990 p. 11).

This chapter outlines the history and assumptions of phenomenology. Van Manen's approach to phenomenological research is given particular emphasis as his method has guided this study. The discussion moves on to describe the value phenomenology has for a study with a nursing focus. Lastly, the selection procedure for participants, introduction to the participants, ethical considerations, data analysis and issues of reliability and validity are presented.

Growth and development of the phenomenological method

Wilkes (1991) states that historically the 'Phenomenological Movement' as described by Spiegelberg (1965) has three phases: the preparatory phase, the German phase, and

the French phase. Heideggerian hermeneutic phenomenology arose from the German phase dominated by Husserl, a German philosopher and the founder of phenomenology. Husserl was Heidegger's teacher and colleague, and authors Kockelmans (1967), Spiegelberg (1970, 1976), Sukale (1976) and Stapleton (1983) have elaborated on their personal and philosophical differences.

Sukale (1976) concluded that a basic difference between Husserl (1962) and Heidegger (1962) was their different interpretation of the concept of the world. Husserl introduced the concept of the 'life-world' or 'lived experience'. Studying using this method is to return to the taken-for-granted experiences and to re-examine these. The inquirer using Husserlian phenomenology always asks about the meaning of human experience. Reality is the life world (Koch, 1995).

Walters (1995) points out another difference between Husserl's and Heidegger's approaches is that Heidegger argued that it is not possible to bracket one's 'being-in-the-world' in the process of philosophical enquiry. Heidegger was concerned with being-in-the-world therefore, instead of trying to lay presuppositions to one side, he explored them as legitimate parts of Being. For Heidegger it is only possible to interpret something according to one's own lived experience. Walters (1995) states that hermeneutics presupposes prior understanding on the part of the interpreter. Hermeneutics or interpretation is Heidegger's phenomenological method for an analysis of 'being-in-the-world'.

Another fundamental difference between Husserl and Heidegger is their phenomenological view of the person. Husserl's view was based on Cartesian duality (Koch, 1995). Dreyfus (1987) states that Husserlian phenomenology is considered the culmination of the Cartesian tradition that thinks of man's relationship to the world in terms of 'subjects moving objects'. The phenomenology of Heidegger is based on an existential perspective which considers that an understanding of the person cannot occur in isolation from the person's world (Walters, 1995). Heidegger's phenomenology is a reaction to Cartesian subject-object dualism and to the notion of intentionality that is also evident in Husserl's phenomenology. Benner (1989) states that according to

Heidegger, "a person is a self-interpreting being...[with] an effortless and nonreflective understanding of the self in the world" (p. 41).

Crotty (1996) points out that there is a new phenomenology aimed at gathering people's subjective meanings, the sense they make of things. He states that no-one has embraced this new phenomenology with as much warmth as nurses. For Crotty, what phenomenology requires is a radical attempt to return to pre-reflective, pre-predictive experience, a return to the possibilities for our meaning which our experience offers.

This research utilises thematic analysis as described by van Manen (1990) to discover what was important in the experience of the parents I interviewed.

Van Manen's (1990) phenomenological method

Van Manen's method was the one chosen for this study as it provides a phenomenological framework which has an emphasis on an approach demanding a re-learning to look at the world as it is met in immediate experience. This is a form of hermeneutic phenomenology in the tradition of Heidegger. For van Manen, "phenomenology describes how one orients to lived experience, hermeneutics describes how one interprets the 'texts' of life" (p. 4), it does not produce empirical or theoretical observations or accounts; instead it "attempts to explicate the meanings as we live them in our everyday existence, our lifeworld" (p. 11). Hermeneutic phenomenology is a human science which studies persons, encourages a certain attentive awareness to the details and seemingly trivial dimensions of our everyday lives and makes us thoughtfully aware of the consequential in the inconsequential, the significant in the taken for granted. According to van Manen hermeneutic phenomenological research may be seen as a dynamic interplay among six research activities. These are turning to the nature of lived experience, investigating experience as it is lived, reflecting on essential themes, the art of writing and rewriting, maintaining a strong and oriented relation to the phenomenon and balancing the research context by considering parts and whole (pp. 30-33).

Van Manen states that a good phenomenological description collected by lived experience and which recollects lived experience, is validated by lived experience and it validates lived experience. Van Manen's method attests to the nature of being immersed within people's particular experience of being-in-the-world. He makes no attempt to bracket presuppositions (as found in Husserlian phenomenology) to find essences of things, rather he acknowledges the importance of people's lived experience by exploring the participants' world and the intersubjective meanings they find within them. In coming to grips with the structure of meaning of the text van Manen (1990) describes ways of uncovering or isolating thematic aspects of a phenomenon in a text:

The wholistic approach where the text is attended to as a whole in a search for the phrase that may capture the fundamental meaning or main significance of the text as a whole. The meaning is then expressed by formulating such a phrase.

The selective or highlighting approach where the text is read several times to determine what statements or phrases seem particularly essential or revealing about the phenomenon or experience being described. These statements are then underlined or highlighted.

The detailed reading approach where every single sentence is examined to determine the meaning of each sentence or sentence cluster about the phenomenon or experience being described. The art of the researcher in the hermeneutical interview is to keep the question open, to keep him/herself and the interviewee oriented to the substance of the thing being questioned (p. 93).

In discovering themes in my research, I used a combination of these methods. The text was examined as a whole and themes became evident. Examples of these themes were highlighted and further examples of these themes were isolated from the meaning of each sentence cluster about the phenomenon being described.

For van Manen, anecdotes are an important device in order to gain the reader's attention, to teach, and to aid in a reflective search for significance. In gathering anecdotes one needs to be rigorous and construct accounts that are trimmed of all

extraneous, possibly interesting but irrelevant aspects of the stories. As I chose anecdotes to record, I was aware that excerpts from the parents' stories spoke volumes as they allowed the reader to enter into their lived experiences.

At the beginning of my study it was not evident that there was a 'fit' between van Manen's (1990) framework and the data from the interviewed parents. As I became more familiar with the data it became clearer that van Manen's approach would be appropriate for this thesis. Van Manen's framework for phenomenological research (p. 39-51) of orienting to the phenomenon, formulating the phenomenological research question and explicating assumptions and pre-understandings have provided the basis for this study design. The parents' experiences discussed in this study were examined utilizing thematic analysis which van Manen describes as the process of recovering the themes embodied in the evolving meanings and imagery of the work. The word 'theme' in this context is used to describe "the structure of lived experience" (van Manen, 1984).

The ultimate aim of hermeneutic phenomenological reflection is to uncover the meaning of experience, and to this end, the notion of a theme gives direction and control to the research process (van Manen, 1990). Theme analysis in this research refers to the process of an insightful discovery of the underlying meaning of the parents' experience of having a baby in a neonatal unit. When the phenomena were analyzed, the themes were uncovered first and then the experiential structures that underlie the themes were explored. The study is set out as stated by van Manen - "The main body of the study is divided into chapters, parts or sections which elaborate an essential aspect of the phenomenon under study. Each section heading articulates the theme that is being described in that section" (p. 168).

Phenomenology and nursing

There is a growing acceptance by nurses of phenomenology as a research method to examine nursing practice. This trend is evident by the increasing numbers of publications on phenomenological research studies in nursing literature. In the 1970s

a trickle of phenomenological research studies were published in nursing journals. An upsurge of phenomenological studies appearing in the nursing literature occurred in the later 1980s, and this trend is continuing into the 1990s.

Davis (1978) states, that compared with quantitative research, phenomenology provides a different perspective that adds to the knowledge of nursing and a close fit, conceptually, with clinical nursing and with the types of research questions that emerge from clinical practice. In one of the first papers to promote phenomenological methodology in nursing research, Davis (1973) argues that phenomenological methodology is similar to actual nursing practice. According to Davis, clinical nursing stresses skills of observation, interpersonal relations, interviewing and interaction as part of nursing practice. These skills, and the skill of interpretation are highly relevant for phenomenological nursing researchers. Oiler (1982) asserts that phenomenology is a philosophy, an approach and a method, the aim of which is a better understanding of patients. I would also add that this method has value in aiming towards a better understanding of the patients' families. Understanding people through a phenomenological perspective offers nurse researchers the opportunity for understanding the meaningful rich and complex lived world of those human beings for whom nurses care (Leonard, 1994).

Beck (1994) points out that phenomenological research has been conducted with persons ranging from adolescents to the very old and in diverse clinical specialities of nursing. Haase (1987) discusses components of courage of chronically ill patients, and Banonis (1989) explores with three people, their lived experience of addiction. The common theme among these phenomenological presentations is the concern for describing lived experiences.

Jasper's (1994) paper has been critiqued by Walters (1995) who states that Jasper creates the misconception that there is a single phenomenological method. Nevertheless, she points out that phenomenology offers an approach for nurses which enables the needs of the client to be identified and to be of foremost importance in the provision and justification of high-quality nursing care. It focuses on the client's experience of the

care they received, which in turn can be used to plan future care. Jasper, who is referring to the English health system points out that for too long care has been dictated by the needs of the service in terms of efficiency and professional advancement. This is also the situation in New Zealand, particularly in the current economic climate where standards of care and value for money direct the focus of service initiatives.

Walters (1994) points out that Heidegger's philosophy offers nursing a theoretical framework which can be used to understand nursing practice by interpreting people's experiences with a nursing lens, and also a means to reconceptualize the technological environment into the human experience of care. Therefore phenomenology seemed particularly relevant for this study. Phenomenology involves a process of reflection which is crucial to changing and articulating more informed human care.

Benner, a nurse researcher who has developed a philosophical foundation grounded in interpretative and Heideggerian phenomenology is becoming increasingly influential in nursing (Darbyshire, 1994). Benner's work has drawn both sharp criticism (English, 1993) and strong support (Darbyshire, 1994). Darbyshire has pointed out that nurses throughout the world are moving nursing education and practice along the path cleared by Benner's work in order to value the clinical and practical knowledge which for so long has been seen as inferior to theory. Her 1984 model of skill acquisition has been presented as a framework for Project 2000 courses in education (English, 1993) and her novice to expert prototype is currently being used in many countries including New Zealand in developing the clinical career pathway for nurses. Paley (1996) examines the debate between Darbyshire and English, but his paper does not evaluate Benner's work directly.

Annells (1996) provides a caution for nurses. She states that while hermeneutic phenomenology is suitable for nursing research and offers considerable potential for informing nursing practice, there is limited critique and a dearth of cautionary advice regarding its use. For Annells it is essential that a researcher into nursing phenomena who is contemplating the application of the hermeneutic phenomenological tradition within a research project should be cognisant of not only the philosophical basis of the

tradition and the inquiry paradigm within which it resides, but also of its current use within the discipline of nursing.

Orienting to the phenomenon

This study arose from my growing awareness that nurses caring for parents of preterm babies could not comprehend the effect this experience had on the parents, and also from the realization that there had been no published research by nurses from the Australasian area to examine this. The existing nursing research, mainly from Britain and North America, examined the experience of either mothers or fathers. Very few published studies examined the effect on the couple. The focus of this study is on both parents, therefore the couple were interviewed together.

Formulating the phenomenological question

The specific research question for the study was

What did the experience of having a baby in a Neonatal Unit mean for you?

The aim of the study was to understand more about what the experience of having a baby in a NICU was like for these parents. Through this understanding health care professionals, particularly nurses, may have an increased awareness and acceptance of parental feelings and of nursing practice that meets the parents' needs.

Making explicit prior assumptions

Van Manen (1990) considers it important to "make explicit our understandings, beliefs, biases, assumptions, presuppositions, and theories" (p. 47), so that those reading the study are able to assess whether these pre-understandings have influenced the study findings. During the time of the study I was working in a NICU, therefore I had considerable contact with parents of preterm babies, and with other nurses working in this area. I had, therefore, inevitably formulated some pre-assumptions of what the experience of having a preterm baby in a NICU was like for the parents.

Before undertaking the study I believed that:

Initially the parents would be in shock at the unexpectedness of the event, and they would find it difficult to cope with seeing their small baby.

The parents would find it easier to cope with their vulnerability by becoming involved in their baby's care.

There may be some frustration and confusion for these parents because there would be many different staff caring for their baby with possible conflicting advice/information being given.

The parents would initially rely on the staff for reassurance, support and information, but would gradually learn to become discerning, and possibly critical about the care their baby was receiving.

Selecting the study participants

Five parent couples were selected based on the following criteria:

Their baby had been in a Neonatal Unit for at least three months both in level three (where the baby receives life-saving care) and level two (where the baby's condition is stable but s/he still requires care which cannot be provided at home, for example, tube feeding, monitoring of oxygen requirement).

The outcome for the baby was positive; any baby with a known long term complication or disability would be excluded.

Parents who had a multiple birth would be excluded.

Both parents had been involved in the decision-making for and care of the baby in the NICU.

The baby had been discharged for about six months before the interview took place. This time lapse was chosen by the researcher in order to avoid the settling in period at home. It was also chosen to capture the feelings of the

experience when it was not new, and the parents had had an opportunity to reflect on it. Yet, it was also necessary to capture the experience while it was still alive in their memories. It was assumed that as time went on the memories may become dulled and distant.

The participants would live within one hour's driving distance from the researcher for ease of interviewing.

Permission to begin the study was obtained from the Human Ethics Committee for Massey University. All parents in the study were volunteers. Parents were contacted by telephone, the purpose of the study was explained and they were asked if they would be willing to participate. All parents contacted expressed willingness to participate in the study. Indeed, I was telephoned by a couple asking if they could be included in the study. Another couple told me a couple who had been in the unit the same time that they were there would also like to participate. It would seem that they all had a need to 'tell their story'. No attempt was made to select a sample of participants that was homogeneous in any respect other than they were parents who had had the experience of having a preterm baby discharged from a NICU within the previous six months.

In the recruiting process I approached couples rather than one or other parent as the experiences of both parents were considered valuable. I was not seeking to understand the experience of mothers and fathers, but the parents as a unit in dialogue with myself as the researcher. They were interviewed together and asked about their experience of having a baby in a NICU. Although the data were collected as the parents' experience, there were two contributors therefore some personal experiences of individual parents were recounted during the conversation. In this way similarities and differences of fathers' and mothers' experiences if they occurred could be illustrated. The parents stories then became data which has also been used as part of the examination and illumination of the phenomenon illustrated throughout Chapters Four, Five, Six and Seven.

The decision was made to ask parents I knew if they would participate in my study. These parents, in turn, suggested others.

Introducing the participants

Interviews were conducted with five couples who had participated in the care of their preterm baby in both level three and level two of a NICU. The participants varied in age, race, prior experience of parenthood, socio-economic background, marital status and family support. The one factor they had in common was that they were all parents of an extremely low birth-weight, preterm infant. The babies at birth ranged from 23 to 28 weeks gestation, and their weight ranged from 500-750g. I had previously anticipated that six to eight couples might be required to be interviewed, but after interviewing five couples, it was considered in discussion with my supervisor, that sufficient data had been generated for this study.

Don and Edna are in their twenties. **Molly**, their first baby, was born at 23 weeks gestation. The couple have a very stable de facto relationship. As neither parent works they were able to spend time with Molly twice a day in the unit. Don and Edna's parents were frequent visitors and a source of support for the couple.

Hugh and Beth are a married couple in their thirties who have a farm about an hour away from the hospital. **Kate**, born at 26 weeks gestation, is their second child. Their first child, **Judy**, was born full-term so this was a new experience. Kate was born at calving time and therefore Hugh was only able to visit his daughter at weekends. Beth usually visited every second day and would ring the unit at least twice a day especially on the days she was not able to visit. Beth's family live overseas and Hugh and Beth did not have much direct family support. However they found the support they received from friends and neighbours very helpful.

Both Molly and Kate contracted a respiratory virus (RSV) while they were still in hospital. For Molly this made very little difference to her progress. For Kate who was almost ready for discharge when she was diagnosed as having RSV, it had a significant effect and prolonged her hospitalisation by a further 2 months, and left her with long-term damage to her lungs.

Jim and Mary are in their early twenties and had moved from another town just prior to Mary going into labour with **Sam** at 26 weeks gestation. They are now in their own home, but at the time Sam was born they were living with Jim's parents about 40 minutes drive from the hospital. Jim and Mary have a stable de facto relationship. Sam is their second baby. Their first baby was born at 23 weeks gestation and died soon after delivery. Jim's parents were a source of support for both Jim and Mary. Mary's father, although he did contact her, was not available for Mary, and Mary was disappointed that her mother who was overseas, only contacted her about 4 months after Sam's birth. Jim had shifted to gain promotion in his job, and because he was still settling into this, was not able to spend as much time with Sam as he would have liked. While Jim was at work, Mary spent all day with Sam coming early in the morning and going home with Jim after work in the evening.

David and Julie are a married couple in their mid-twenties who live an hour away from the hospital. **John**, who was born at 28 weeks gestation, is their first baby. Both David and Julie received family support especially from Julie's sister and her husband. While John was in hospital David and Julie would come every evening after work to visit him and they would also spend every weekend with him. Julie's sister would frequently come during the day. David and Julie planned that when John went home David would stay at home and care for him while Julie would continue with her job.

Mike and Joan are a married couple in their thirties. They live about an hour away from the hospital but both work in the city. Joan was not currently working and spent as much time as possible with **Bob** who is their second child. Bob was born at 26 weeks gestation. **Jane**, their first born, was delivered full-term and is now 3 years old. Mike would usually come to see Bob after work each evening. The couple gained some support from Mike's family who live in the city. Joan's family all live overseas and Joan received most of her support from friends and neighbours.

Ethical issues

As mentioned earlier, approval to commence the study was gained from the Human Ethics Committee Massey University. Every possible precaution was taken to maintain the confidentiality and anonymity of the parents in this study. In conducting this phenomenological research, the rights of participants were protected in the following ways:

Informed consent was obtained (see Appendix B) after the purpose of the research was fully explained and data collection procedures outlined. Each couple was given an Information Sheet (Appendix A) and any questions the parents had about the research were answered. All participants were given the name and contact telephone numbers of both the researcher and supervisor so that any ongoing concerns could be addressed.

Times for interview were negotiated with participants to minimise intrusion on family life. The parents were able to choose where the interview would take place. Only one interview was not held in the participants' home; this interview was held in the home of the sister of one of the participants.

The parents were advised of their right to decline participation, or to withdraw from the study at any time, and/or to withhold any information they felt unwilling to share. Participants were also informed that they would see a copy of the full interview transcripts and would be encouraged to correct anything misheard, to eliminate anything they did not want to be included, and to add anything that came to mind that they wished to be included. All participants were informed that a summary of the completed research would be made available to them.

Anonymity was assured with participants' names not used on data scripts, and by not revealing any information that would enable them to be identified. Participants were informed that those taking part in the study would be known only to the researcher. Tapes were transcribed by the researcher and copies of the transcripts were given only to those participants concerned for verification, and to the supervisor of the research.

Participants were informed that if they wished, they could have their taped recording at the completion of the study, otherwise the tape would be wiped. Every effort has been made to ensure that identifying details have been disguised in the final document. Four of those interviewed have initiated conversations with me about the study in the presence of others. It would seem that anonymity is not an issue for these parents. However, I have made the protection of anonymity for the parents a prime concern.

Collecting the Data

Each couple was contacted four times in total. Two of these contacts with each couple were for the specific purpose of data collection. When initial contact was made by telephone, the parents began talking about their experience. None of the information given at this time was included in the data, but these conversations did help set the scene to assist the parents to reflect back on their experiences. The interviews with each couple, lasting one and a half to two hours, were the main source of data. A few days after the interviews, a telephone call was made to the parents to ensure that they were not suffering any harm from reflecting on and discussing their experience. This contact was not used for data collection. Once each interview had been transcribed there was further contact with each couple to discuss their transcribed interview with them. Further data were obtained from these meetings.

One couple gave me the transcribed text to take back with me at the end of the meeting - they were certain there was nothing they wished to change or add. The other four couples wanted to keep their transcript for a few days so that they had time to discuss together anything further they wished to add. One couple returned theirs with no further changes, the other three couples eliminated some material, and added other material. The data gathered in this way consisted of written material from the couples.

Use of the phenomenological method outlined earlier, ensures that the researcher focuses mainly on the individual's participation in a situation to draw written and/or oral data from the individual. Research questions are designed to grasp lived human experiences and meanings connected to these.

I was interested in determining if the experience for the fathers might be different from that of the mothers. Each couple was interviewed together, and this proved to be a valuable way of capturing the total richness of the experience for the parents. As one parent was describing an incident, frequently the other parent would be agreeing non-verbally by nodding, and sometimes if the other parent felt very strongly s/he would interrupt and confirm that his/her feelings were similar. There were many times during each interview when one parent would remind the other about a time that was difficult, or one that held a very precious memory for both of them. One of the couples described how she had relied on her partner during the experience, and how their relationship had grown through this. As I interviewed each of the couples, the interaction between them was mutually supportive as they relayed their stories of their time in the NICU.

Throughout all five interviews, the couples demonstrated that they were aware, and very supportive when there had been a difficult time for the other partner. For example when one mother was having difficulty with breast-feeding and receiving little support from the staff, the father whole heartedly supported his partner's decision to stop breast-feeding. When a father wished he could be at the hospital sharing in the care of his baby, but needed to be at work, his partner kept him informed of what was happening. For example, she would ring him immediately the baby had been weighed, and again at the end of the day she relayed all the day's happenings for him so that he could share them with her.

Structured but open-ended interviews were used in this study as the main form of data collection, in order to obtain information in the parents' own words and to get a detailed description of situations. The manner of interviewing allowed the parents to discuss any aspect of their experience that they wished. I made a deliberate attempt not to probe, and not to ask specific questions, but rather to follow where the participants led. My comments encouraged clarification, further explanation or examples to illustrate the discussion. An open, non-judgmental approach was the aim when conducting the interviews so that descriptions which reflected what the experience was like for the parents were encouraged, rather than what the parents felt was 'expected'. Periodically, as necessary during the interview, cueing and clarifying phrases were used to refocus the

direction of the topic, to maintain the intent of the interview and to validate the message being heard. The interviews with each couple varied in length from one and a half to two hours.

All parents gave permission for the interviews to be taped so that no part of the interview would be omitted, which could happen if I relied on note-taking and/or memory. The interviews began with a very broad question: **What did the experience of having a baby in a Neonatal Unit mean for you?** Each couple were then encouraged to discuss this in their own way. The interviews did not have any pre-determined outline. At times the couples could not think of what else to say. At these times I would ask non-directive questions to help them to gather their thoughts. These broad questions are:

What difficulties were experienced?

What were the good memories?

What made the experience worthwhile and meaningful?

What helped them to 'get through' the experience?

At the conclusion of the interview and at the time when the full interview transcripts were being validated by the parents, effort was made to ensure that the parents did not have any negative feelings about what had been shared, but felt that what they had contributed was important and worthwhile. The parents did not seem to have any difficulty sharing their experience - in fact they all seemed to find it a helpful experience. After each interview had been transcribed, there was further contact with each couple to discuss what they had said and to determine if they would like to clarify, to add to, or to eliminate any of their experiences. Some of the parents did not have anything to add, some wished to eliminate a few of the more personal, intimate details they had described, and others wished to add some experiences they had remembered since the original interview. When I had questions mainly intended to clarify statements some of the parents had made, I took the opportunity of this contact to achieve this.

Analysing the Data

Each interview with the participants was taped and the reflections on the parents' experience of having a preterm infant in a NICU were recorded. The procedure involved transcribing the interviews into written form. All interviews were listened to and read a number of times to become familiar with them and to gain a feeling for the content. Significant statements relating to the phenomenon of the parents' experience were extracted. Repetitions of significant statements were identified. Several themes emerged and all texts were examined and re-examined to note commonalities and differences. These themes were read and reread and gradually it became evident that the emerging themes could be used to guide the data analysis and "as generative guides for writing the research study" (van Manen 1990 p. 168). The results were integrated into a description of the phenomenon of parents' experience of having a baby in a NICU. The language of the parents was borrowed and analyzed to construct an interpretation of their experience.

The analysis of the experiential conversations with the parents revealed the following themes:

- Struggling-within
- Living-with-uncertainty
- Relating-with-others
- Moving-from-fear

Ensuring Reliability and Validity

Final validation was considered to rest with the researcher which, according to Giorgi (1988) is appropriate, as phenomenological analysis is based on the intuition of the researcher. Intuiting is the process of actually 'looking at' the phenomenon. During intuiting, the researcher focuses all awareness and energy on the subject of interest to allow an increase in insight. Thus this process requires absolute concentration and complete absorption with the experience being studied (Oiler, 1982). To try to impose a logical-empirical philosophy of validity and reliability on a qualitative investigation

restricts the efforts of the human science researcher to describe the human experience as it is lived (Salnek, 1986). Consequently, Giorgi's (1988) position was adopted, that a researcher being true to the phenomenological method has the freedom to pursue validity and reliability through one's intuition rather than through a traditional or empirical approach. No other validation was carried out with the participants other than giving them the opportunity to validate, alter and/or clarify the full transcript of their interview. The research process necessitated reflecting on the combined stories of the parents. It would be difficult for parents to validate these combined reflections without having read the full transcripts of the other parents.

Benner (1994) suggests in phenomenological interpretation that "if the interpreter's own views have not been challenged, extended or turned around, the quality of the account is questioned, and the danger of just reading in preconceptions must be considered" (p.101). Leonard (1994) emphasises that interpretative inquiry is not simply just a description of a phenomenon but is "always concerned with some kind of breakdown in human affairs. Thus the ultimate criterion for evaluating the adequacy of an interpretative account is the degree to which it resolves the breakdown and opens up new possibilities for engaging the problem" (p. 60). I believe that this study meets that criterion, as parents' experiences formerly not described have been opened up for the possibility of increased understanding, and the possibility of nursing care being adapted to meet this need. The study fulfils Beck's (1992) criteria by the selection of parents who had participated fully in the experience being examined, and who were able to fully articulate those experiences.

As the study progressed, I believe that my prior assumptions were challenged, and this was reflected by my growing sense of admiration, respect and awe at the selflessness, caring and courage seen in these parents as they devoted themselves and their energy to the welfare of their baby.

Chapter Four begins the presentation of the findings of this study. The parents tell their stories of their struggle within themselves during the traumatic time of their preterm baby's hospitalization.

CHAPTER FOUR

STRUGGLING-WITHIN

Jim: Sam was always in my thoughts... (p. 5). It's scary because it happened to someone so close to me. The first week or so I was mentally prepared to lose Sam, he was not supposed to be here and the chances of him surviving were still 50/50. I dared hope he was going to pull through (p. 13).

(Int 3)

The stories related by the parents in this chapter would support Kaplan and Mason's (1965) belief that the distressing experience of the birth and hospitalisation of a preterm infant causes a crisis in the lives of the parents. This chapter examines the theme of the parents' **STRUGGLE-WITHIN**. The parents' experiences before the inevitable birth of their baby and the first week s/he is in the NICU are illustrated by examples from the parents of their shock, fear, anxiety and worry. This unexpected event which the parents are powerless to prevent impacts on their lives and they feel vulnerable as they struggle with the enormity of what has happened. They are struggling-for-control in an attempt to live through the ordeal. This struggle is evident by the parents' reactions and by the raw feelings that accompanied the shock of the unexpected event. There is recognition of their helplessness to be able to change what is happening to their baby and to themselves. There were several factors that assisted the parents through this initial phase, for example the way in which they were introduced to the unit, and the openness and friendliness of the staff which helped them to feel more comfortable.

Being unprepared for the overwhelming event of giving birth to a preterm baby

Having experienced an event previously helps an individual to know what will happen and therefore to be able to cope with it more appropriately. Kadner (1989) describes resilience that is gained through mastery of prior experiences, which brings confidence and greater strength. Although all of the couples interviewed differed in their state of

preparedness for the experience of having a preterm baby none of them was prepared for what was going to happen. Two couples who had previously had a full-term birth did not talk about this previous experience of birthing as assisting them to adjust to the inevitability of this preterm birth. Despite some of the parents having time to prepare physically for their preterm birth, their emotions could not keep pace with all that was happening, and in particular with the unknown. They did not know how to prepare themselves for what might happen and this made the experience more worrying. It was a totally new experience for them made more frightening because there were often no definite answers about exactly what would happen, and when it would happen. No-one could confidently predict the outcome; only possibilities could be discussed with the parents. Two couples had prior warning that their baby would be born prematurely and they therefore had time to prepare:

Beth: I was two days in delivery suite before she was born, and [the nurse] came with the photos [of preterm babies].

(Int 2: p. 1)

Joan: I was in hospital for three weeks with placenta praevia. I knew I was going to have a Caesarean and that Bob would be premature so we were sort of prepared.

(Int 5: p. 1)

Julie and David had no previous experience, this was their first baby. They were stepping into the unknown with no control over the situation, and they had to put their trust in others. They had no warning that their baby would be born preterm. John was born very soon after Julie suddenly went into labour at 28 weeks gestation. There was no time to prepare and they talked about not knowing what was happening to them:

Julie: No one tells you about a premature baby...//..

David: Until it's there.

Julie: Or you're in full labour and the midwife says "would you like someone from [NICU] to see you"...//..you just want to get over the pain...//..The only time you find out is if you know someone who's had a preemie baby...//..we have a right to know that we may not go to full term. If we were more aware of what to expect it would have been

better.

(Int 4: p. 1)

Mary had previously delivered a live preterm baby. That experience was not reassuring as sadly her first baby died soon after delivery at 23 weeks gestation. Mary, now at 26 weeks had allowed herself to relax - she had passed the fateful 23 weeks. Suddenly she went into labour, there was no time to prepare for her baby's early birth. As Mary and her partner rushed to hospital, they were very concerned and anxious about what would happen to Mary and to their baby. They had only recently moved to this city and did not know the hospital at all. They were living with the fear that this baby might die too:

Mary: I lost a baby at 23 weeks [in another city]...I'd always felt they could have done more...You lose one baby. You want to be sure nothing happens to the next baby. You pass that 23 week stage and nothing happens...I'm mentally fine, coping with my pregnancy and at 26 weeks...it happens again. I remember thinking it will be the same all over again.

(Int 3: p. 18)

Reacting to the inevitability of the preterm birth

Some parents seemed to quickly come to accept that they did not have a choice, their baby was about to be born prematurely, and they and the medical staff were powerless to prevent this. They now had to hand over their precious baby, part of themselves, and trust that the staff would realise what their baby means to them, and that everything that was humanly possible would be done to help their baby to survive. One father spoke of the inevitability of the preterm delivery and of his faith in the ability of the doctors:

Mike: It was coming anyway and we couldn't do much, put it in their [the doctors] hands they'd do the right thing.

(Int 5: p. 1)

However, most of the parents found coming to terms with what was happening was very difficult and talked about their fear, worry, sadness, confusion and irritation as

they struggled-within. One couple illustrated their vulnerability and fear as they tried to cope with the inevitability of the preterm birth of their baby:

Don: Very frightening...wondering if [Edna would] have the baby. We didn't know what would happen and were worried.

Edna: It was frustrating. The nurse from [NICU] explained things and showed me photos [of preterm babies].

Don: ...We were told so many different things - she [the baby] wouldn't make it

Edna: would be stillborn.

Don: ...That the outcome was pretty grim if she [Edna] did go into labour which she did.

Edna: ...I got taken to the wards and [to Delivery Suite] a lot. I didn't like being shifted and got really emotional.

(Int 1: p. 1)

While Edna was still pregnant, the doctor had expressed his concern that the baby would not survive. As they reflected on this Don and Edna appeared sad that their baby did not have the opportunity to reach full-term. Up until twenty-three weeks gestation Edna's pregnancy had been progressing well. At this stage they had to face the unknown. All of the parents had this feeling of sadness and loss in various degrees.

Don's reference to being told different things provides evidence supported by other parents that confusion in the worrying time before the delivery can be exacerbated by staff giving conflicting advice and information. Don said the experience was "very frightening". Other parents expressed this when they did not know what was going on and they were fearful that their baby would not be born alive, or would not survive.

There were elements of irritation in the manner in which the parents spoke with me as they explained their experience. My interviews with the parents were taking place six months after their babies had been discharged from hospital, yet Edna expressed her irritation as she described in clipped, sharp words, and with an increase in body movement, the frustration of being moved from Delivery Suite to the ward and back, several times before she had her baby.

Reassurance was essential and needed by all the parents although most were not able to be as definite as Joan:

Joan: We spoke to the consultants about the chances of survival for a baby born at [25 weeks] gestation, and what percentage would have disabilities. I wanted reassurance.

(Int 5: p. 1)

Being left with empty arms, wondering and worrying about what will happen to their baby

Frequently, the preterm baby is transferred to the NICU as soon as possible after delivery especially if s/he is very small or sick because urgent life-saving medical treatment is needed. None of the parents in this study had the opportunity to hold their baby initially because all of the babies were very small and in need of respiratory assistance. There was also little time for them to see their baby before s/he was taken to the NICU. The mothers still required further care and were unable to be with their baby. They were left with empty arms, wondering where their baby was, and what was happening to him/her. All of the fathers were able to go to the NICU with their baby but they found themselves often separated from him/her by a wall of staff. They felt powerless and could only watch and wait while strangers took control planning the life-saving treatment for their baby.

When it is known that a couple will experience the preterm birth of their baby, where possible they are given the opportunity to be shown around the unit to see a baby close to their baby's current gestation, the equipment their baby will be likely to require, and to be introduced to some of the staff. This helps the parents to be aware of the environment where their baby will be cared for over the next weeks or months and to possibly not feel so overwhelmed. Being shown around the unit before Kate was born gave Hugh and Beth comfort, and was helpful for them in gaining a sense of security in their new environment:

Hugh: My first impression before Beth had Kate, was all the incubators, alarms, wires and all the staff (p. 1).

Beth: ..//..and equipment.

Hugh: Absolutely surprised me..//..skill involved, it must be daunting..//..(p. 2). Everyone was friendly. The nurse who took us around was really helpful. All the staff had a smile for us, put you at ease as best they could (p. 1).

(Int 2)

Being introduced to their baby by strangers in a totally foreign environment

Merenstein and Gardner (1993) examine the intense and sometimes chaotic appearance of a high-risk nursery and discuss what makes it a frightening experience that increases parental feelings of helplessness and anxiety. The sophistication of highly technical care and heroic measures to attain survival may be met with both awe and uncertainty. Daley (1984) points out that seeing a member of the family amidst all this technology can cause emotional crisis.

Gottwald and Thurman (1990) have identified several features of the NICU which include the constant stimulation provided by lighting and the sounds of technological equipment, the continuous and often unpredictable interventions provided by caregivers, the acute and rapidly changing nature of the infant's medical status, as well as the intimidating presence of the apparatus needed to maintain infant stability. All of these factors were significant in increasing the fear of the parents in this research and their feelings of helplessness and anxiety as they saw their baby for the first time and as they tried to adapt to the unfamiliar environment. Julie illustrates this:

Julie: It's very frightening especially for first time parents when you go into the unit..//..We didn't know what to expect ..//..knew nothing of premature babies. We were very scared at the start.

(Int 4: p. 1)

One couple describe how frightened they felt in the early stage of their baby's hospitalization when they were dependent on the staff to help them to learn about their baby's environment. They had received no orientation to the unit as the early birth of

their baby was unexpected:

Don: It was pretty grim.

Edna: I got scared because [the ward nurses] were so negative. They'd say "We know what goes on in the unit, and she won't make it." In the end I thought "You don't work there so you don't know".

(Int 1: p. 5)

For the parents, once their baby was born, the machinery and tubes s/he was attached to had conflicting significance. They realized that it was necessary to monitor the baby to keep him/her safe yet for some parents the equipment and the procedures being carried out made their baby seem even more removed from them. They acted as a barrier, they felt kept-at-bay, at a distance from their baby. Some found this intimidating and very frightening:

Don: Seeing Molly there with things in her arms and legs, really shook me.

(Int 1: p. 2)

Jim: You seem so far removed at times...because your baby is removed from you in a foreign environment.

(Int 3: p. 14)

Some of the parents found that the technology and equipment was too overwhelming. They felt in a daze unable to take in everything that was happening to them and to their baby. Two of the fathers interviewed were able to cope initially by focusing not on the equipment but on their baby:

David: He seemed very sick...I don't remember a lot, I was concentrating on John.

(Int 1: p. 2)

Mike: All my attention was focused on Bob. I knew the machines were there but I wasn't concerned about that, just about Bob.

(Int 5: p. 3)

For other parents the initial uncertainty was alleviated when they were able to see their baby and the environment in which s/he was being cared for. Although they found the technology and equipment daunting, they also found it reassuring and a comfort:

Mary: Here they are more equipped [than the hospital where Mary lost her first baby]...The help is here...When I saw the unit I thought this is the best place for my baby. I found that gave me more hope. You see all the monitors beeping away.

(Int 3: p. 18)

All of the parents interviewed found the size of their baby was as much of a shock for them as the environment of the unit. Many did not expect to see other babies in the nursery who were just as small, or even smaller than their baby:

Hugh: My first impression...all these little babies I can't get over how small they are and how they actually survive.

Beth: Nothing prepared us for how small she was.

(Int 2: p. 1)

Mary: The shock to see him...you're too scared to touch [the babies] they're so small...It's hard to think a block of butter, a teeny bit more, that's my baby.

(Int 3: p. 5)

As well as the size of their baby, some also found their baby's general appearance was a shock:

Beth: It takes a while to realise that its actually your baby and they're not the prettiest of sights when you first see them...after a while you don't think about it. Other people see them and you look at the reaction on their faces especially earlier on and its shock and that would have been the same with us.

(Int 2: p. 2)

Yet other parents described how when they saw their baby they were relieved because they had imagined that the baby would appear worse:

Edna: They showed me photos of [another preterm baby] she didn't look like those photos...didn't look like a baby she just looked like a miniature adult.

(Int 1: p. 2)

Living hour by hour with intense emotions, their baby's life in jeopardy

Following the delivery of their baby the first reaction the parents in my study experienced was shock, feeling numb and dazed. They could see what was happening, they knew it was happening, but there was a feeling of unreality. Too much was happening too fast. The parents could only watch stunned and disbelieving.

Jim: When the doctors brought him out of the theatre I couldn't believe it. I said, "He's too far gone to do anything, isn't he?"... (p. 19). It was tough. I wanted to believe he was going to be all right. I also wanted to prepare myself for anything but I wasn't anyway. I was a mess (p. 14).

(Int 3)

The parents continued to experience feeling the 'protective' shock for some time after the preterm birth. Jim explains how it was for him initially when he was unable to comprehend and to take in everything that was being said to him. He and his partner had to cope with the crisis of their baby being born preterm, superimposed on other stressful demands:

Jim: The first couple of days I was more shell shocked than anything, unable to settle, under a lot of stress starting a new job, and only moving here a week or so before this happened...Changed our plans. There was confusion.

(Int 3: p. 1)

As their minds became less frozen, the recognition and realization of the implications of their baby's preterm birth gradually began to dawn on the parents. However, the shock that they were experiencing helped buffer them and gave them a shield to cope

with the immediate happenings. Two of the parents described how for them, not being aware allayed the anxiety at the time:

Jim: There were lots of stresses...you didn't think were there at the time I always felt that we were dealing with it very well.

(Int 3: p. 1-2)

Beth: I didn't realise [the baby] was on an Ohio [specially heated open bed used to nurse unstable or critically ill babies] until afterwards. When I first saw her she was in the incubator...It would have frightened me if I saw her on the Ohio.

(Int 2: p. 11)

Feeling distanced and detached from what was happening to them, feeling that the situation was not real, was the experience of two of the fathers:

Don: It was quite hard to take sometimes...pretty intense...It was unreal.

(Int 1: p. 5)

Jim: It all seems rather unreal now. You block a lot of it out...the most incredible feeling I've ever had seeing my little boy lying there...it's like walking in a dream, a daze...(p 19). It's completely unreal...like your looking down on it (p 14).

(Int 3)

As the shock and numbness lessened, the parents' texts illustrate how they became aware of the enormity of what had happened to them. They were in a situation that was like another world, another culture with customs and rituals they did not understand. At this stage they felt like an outsider, yet their baby was in the midst of all the activity. They felt unable to do anything, and for all the parents interviewed this helplessness was the worst feeling. It seemed to increase the growing fear and anxiety they were experiencing as the numbness and shock surrounding the birth and admission of their infant gradually diminished. They were now feeling very vulnerable. The parents were always waiting for 'bad news'. At this very early stage their shock was preventing them from getting 'too close' to their baby. This distancing themselves helped buffer them so that if they did hear 'bad news' then perhaps it would be more manageable:

Jim: I found it very hard to get close to Sam...the first couple of weeks I didn't let myself get close. It was too scary. I worry...I didn't let myself get close for a while.

(Int 3: p. 14)

Don and Edna were trying to come to terms with the birth of their daughter at 23 weeks gestation. It seemed to them that the nurses wanted them to 'face up' to what was happening with their baby. Don and Edna did not feel that the nurses understood their anxiety and fear. This 'forcing' of their emotions made them want to leave the hospital and go home where there was an atmosphere of calmness, and they felt 'safe' because each understood and accepted how the other was feeling:

Don: [The ward nurses] were so negative. One nurse... actually felt the need to make [Edna] cry. Edna left after two days. We had to go home and cope on our own.

(Int 1: p. 5)

Continually resurfacing anxiety about the unknown

During their baby's first week of life, the parents were faced with the unknown, they were fearful for their baby. They knew they could not help their baby to get better, they could only watch and wait. They longed for reassurance, but often the best they could hope for was honesty. The fear and uncertainty continued for the parents:

Don: It was a day to day thing... (p. 3). The first week was the longest it went so slowly waiting for something to happen (p. 5).

(Int 1)

Julie: I hated when you had time to think...my thoughts weren't good thoughts. If your baby's not doing well you think something is going to happen.

(Int 4: p. 4)

Jim: Sam was always in my thoughts... (p. 5). It's scary because it happened to someone so close to me. The first week or so I was mentally prepared to lose Sam, he was not supposed to be here and the chances

of him surviving were still 50/50. I dared hope he was going to pull through (p. 13).

(Int 3)

Feeling worried or concerned is an experience repeated in the parents' texts. They had an underlying concern that their baby would die. Especially initially, the parents in my research were never able to relax and feel that everything was now going to be all right. They seemed to carry an underlying anxiety with them all the time about the progress or lack of progress their baby made. This anxiety never left them and created their greatest struggle-within. One father talked about his worry:

Don: You'd have a good day and she'd [the baby] have a set-back, and have two bad days...//..It was quite hard to take sometimes...//..pretty intense.

(Int 1: p. 3)

Continually feeling helpless increased the parents' frustration and caused increased anxiety. The parents experienced reassurance and gratitude for the care being given. At the same time however, there was a reinforcement of their feelings of uselessness, and inadequacy. Kate's parents described their feeling of helplessness, of being an observer:

Beth: They said I could stay but...//..there's nothing more you could do...//..

Hugh: You were more helpless weren't you?

Beth: Exactly...//..They couldn't do any more than they were doing...//..She was 100% ventilated...//..She just had to hang in there...//..Nothing you can do only sit and watch her.

(Int 2: p. 6)

Receiving information in the early stages to help relieve the fear and anxiety

Being given information as required was important for all the interviewed parents as it gave them a framework for understanding events around them and helped them to feel included in their infant's care. In the initial stage, information was vital and it often had

to be repeated as the parents were usually unable to take in everything that was being said to them. All the fathers interviewed spoke of early discussions with the consultant about the outcome for their baby. Two of the fathers relate their experiences:

Don: The doctor said what it would be like...very hard for her [the baby] to make it, she could have complications and she'd definitely be in the unit for three or four months (p. 2)...good to lay it straight out at the beginning. The doctor didn't give us any false hopes (p. 3).

(Int 1)

Hugh: The doctors weren't hiding anything from us; we knew exactly her chances 50:50.

(Int 2: p. 1)

All the mothers interviewed received information later than the fathers. For these mothers this was unavoidable because of complications during or following the delivery of their baby. When these mothers received information several hours after the birth of their baby, it was more specific - what complications could occur from that point on:

Julie: The second day the doctor told us the valve between the heart and lung might not close and they might have to operate. They did lay things down.

(Int 4: p. 5)

Beth: All the things that could happen like the heart muscle or the valve, the ostomy if she had to have it...they did make us aware they can occur.

(Int 2: p. 1)

Sometimes, despite the best intentions of the staff, parents may not get the information they need to allay anxiety due to fear of the unknown. One mother described how she missed out on the information in the early stages altogether. This mother, in order to get reassurance, went to see her baby although she was supposed to be resting:

Edna: They kept saying the doctor would come to my room and he didn't...They reckoned I couldn't go [to the NICU] because of my blood pressure but I got hold of my drip anyway and went down.

(Int 1: p. 4)

Although the parents need to be kept informed, initially they may find it very difficult to take in what is being said to them about their baby because they are in shock:

Julie: There was too much to start with...//..we were looking at this little lifeless creature on the Ohio and he was so bruised. Everything was happening.

(Int 4: p. 9)

Beth: To start with you've got the initial shock of seeing her. It took me a while to think she's small and alive.

(Int 2: p. 2)

The shock and numbness continued for some time and the parents had difficulty in concentrating on what was being said to them. Some of the fathers particularly, had a need for an explanation of the function of the equipment used for their baby. This seemed to give them something definite on which to focus. The parents described how sometimes they needed the information repeated:

Julie: People would tell us things even if we'd been told before, and we found that repetition really helpful.

(Int 4: p. 4)

Mary: Some nurses even 'though they knew you'd probably been told would tell you again...//..We found that really good.

(Int 3: p. 9)

Beth: Everything we asked was explained. It's mind-boggling what they explain. You forget and may need to ask again.

(Int 2: p. 1)

The interviewed parents differed in their level of comprehension, preferences and readiness for information. Sometimes information-giving occurred with little opportunity for questions or clarification. All of the parents had a need to be informed, but there were some who did not wish for too many details and accepted small amounts of information at a time without question, possibly as a means of dealing with an otherwise overwhelming situation. For some it was too much too soon:

David: Everytime they went to do something to him they told us.

Julie: You get so bombarded in a short space of time...the first few days with the shock...I thought as long as I can see John breathing I don't really care. There's a lot of information to face at first.

(Int 4: p. 3-4)

For other parents the information given was at the right time and the right amount:

Beth: When they said things it was not too early or too late. The first day they told us what could happen.

(Int 2: p. 2)

Joan: I don't think too much information is given. You need to hear it. If you have something written you can pick it up later.

(Int 5: p. 2)

For the parents in this study prompt, direct, timely explanations from the beginning presented in a calm manner were shown to be important and reassuring. Explanation of the process of what was or what would happen helped the parents to organise at a time when they were extremely vulnerable and feeling out of control, and aided in avoiding unnecessary anxiety. Overcoming, or keeping negative feelings under control meant that the parents' total focus could be on what could be done to help their baby and how they could participate in caring for their baby.

The parents were **living-with-uncertainty**. How this experience affected the parents, and ways that they relied on the NICU staff to help them to live with their uncertainty is the focus of Chapter Five.

CHAPTER FIVE

LIVING-WITH-UNCERTAINTY

Jim: Every bit of stress and worry that I'd felt we'd dealt with over the past ten days suddenly rekindled, and there was no followup. I just carried that through. Now I was too scared to ask questions because the answers I got seemed to be negative.

(Int 3: p. 11)

It was evident from the parents' stories that they were able to cope with the initial shock. However they had to live with the uncertainty, with their anxiety and with their feeling of helplessness. Having a baby prematurely is coping with the unknown, with uncertainty, with living day by day and hour by hour until such time as the baby's physical condition is stable and s/he is progressing well. In this chapter the parents illustrated the theme of **LIVING-WITH-UNCERTAINTY**. They gave examples of incidents in their baby's progress which could cause them to have heightened anxiety. The parents found many strategies which helped them. Knowing what may happen was helpful in coping with this uncertainty. Being kept informed by timely information about what is or what might be happening was seen by the parents as being the most important way of helping them to cope with the situation. Although the parents wanted to be kept up to date with their baby's progress, they were also frightened about what they might be told. Telephone calls, or anticipation of a telephone call was an example of this.

Their baby would progress and they would begin to feel safe and to relax a little. Focusing on recognisable signs that their baby was progressing gave hope, reassurance and encouragement. Despite this, there was also the realisation that their baby was very immature and that no-one could give a guarantee of a good outcome. They would be almost scared to have too much hope. They always carried a concern. For the parents this meant that there was an underlying, ongoing anxiety, a dread of what may happen and the ultimate fear of losing their baby which caused them to feel very vulnerable during the time their baby was in the NICU.

Living with a sense of loss and heightened anxiety and fear

The babies of the interviewed parents were in the NICU for many weeks. When their baby was well and progressing, the parents found that they were not aware of the underlying anxiety and fear which they described as quickly coming to the surface and becoming obvious if there were any changes in treatment or if their baby's condition altered. Throughout the period their babies were in the NICU parents illustrated how they travelled an up and down pathway, sometimes feeling that their baby was improving and other times receiving information that their baby's progress was less than satisfactory. This pathway was one paved with anxiety. The uncertainty created by the prematurity of their baby, the use of technology which was not understood by the parents, and the many times individual progress would be thwarted by complications created this anxiety. For some parents the anxiety and fear was more marked, appropriately so as their babies had more complications. For other parents the cause of increased anxiety was not being able to be with their baby as much as they would have liked. Sometimes questions that the parents asked the staff could not be answered because no-one knew the answer. This inability to understand 'why' added to the parents' anxiety. When their baby deteriorated markedly, and the reasons for this deterioration were limited, the worry experienced by Kate's parents' was unable to be alleviated:

Beth: She [Kate] got the virus [RSV]. I'm not blaming anyone...I wish I knew...why she got it so much worse than any other baby there...They say there's no specific reason, and she went back on the ventilator...

Hugh: That was about the first time I realised that we might lose her. The other times she progressed so much.

(Int 2: p. 6)

Another reason for the parents' anxiety and fear was when their baby required surgery. Sometimes it is known in advance, perhaps a day or two beforehand that surgery is necessary, in other instances there is no time for any preparation for the parents. During her time in hospital, Molly had three operations. When she went for her first

two, her parents had only a few hours to prepare. They knew she would need a third operation and had several weeks to prepare for this. For Molly's mother, this third operation was the most worrying:

Edna: The last time I got quite stressed because we thought anything can go wrong in theatre. Everytime, the anaesthetic is a risk.

(Int 1: p. 9)

Underlying the parents' worry and anxiety, was always the fear of their baby dying. All of the parents interviewed experienced times when their baby was very sick and times when s/he had been doing well and then deteriorated. From the parents' comments it was apparent that they had thought about their baby dying while s/he was in the unit as they were aware of the limited chance of survival for their baby. However, they discussed how they were unable to talk or ask questions about this at the time because of the answers they might receive. The more complications their baby had, the less likely they were to verbalise their fears as this would increase their awareness of the need to face up to the reality of this possibility. Two of the parents expressed their concern and their fear:

Jim: Every bit of stress and worry that I'd felt we'd dealt with over the past ten days suddenly rekindled, and there was no followup. I just carried that through. Now I was too scared to ask questions because the answers I got seemed to be negative.

(Int 3: p. 11)

Julie: If your baby's not doing well you always think something is going to happen.

(Int 4: p. 4)

The anxiety and fear continued, often despite reassurance. The parents needed to see and believe that their baby would get better and survive. For one father, recognising that he was being told his baby was now stable and that there was no need for worry, did not help to allay his anxiety and concern:

Jim: The hospital is saying your baby is fine, stop worrying, but we don't stop worrying because someone told you to, so we're still under a high level of stress.

(Int 3: p. 4)

There were definite milestones to indicate the baby's progress, and the parents in this research were aware of these. Moving from the intensive care required in level three to the less intensive level two was one such milestone. When their baby was moved to level two some parents were very excited and saw this as a major sign of their baby's progress. Other parents expressed concern because they saw level three as being more 'secure' with more staff and all the equipment they had now become familiar with, and to rely on, as part of gauging their baby's physical stability. Bob's parents were anxious and worried when he was moved from level three to level two. They talked about what made this a difficult adjustment:

Mike: New surroundings...doctors don't come as often...//..

Joan: Quieter in terms of back-up staff...monitors and the pulse oximeter weren't the same, and they had to share them [among the babies] at that early time.

(Int 5: p. 9)

All of the parents recognized that worrying about their baby was unavoidable and inevitable, however two parents pointed out that worrying did not help:

Beth: Can't worry about what might happen...//..If they told me something wasn't right, then I would worry, but not until I know. I'll take it as it comes.

(Int 2: p. 4)

Mike: I thought if something bad happens I'll deal with it, not get worked up before it happens. If he does come out with a disability nothing is going to change - he is still our son.

(Int 5: p. 13)

As they gained more confidence and became more familiar with the unit and their baby's care, the parents felt very protective of their baby and expressed anxiety about what might be happening with their baby when they were not there. Joan gave the following example:

Joan: Someone was telling a knock knock joke, and used the side of an incubator to do the knocking. Even though it wasn't Bob's incubator you think they might do that when I'm not here.

(Int 5: p. 6)

It was difficult for parents to say anything when they were feeling irritated by what happened in case it was interpreted by the staff as criticism. They still relied on the staff to care for their baby, and did not want to say anything which might jeopardize the quality of care their baby received. Their fear was that the staff's irritation might be taken out on their baby, and they would rather put up with the situation than risk any harm to their baby:

Edna: I didn't say anything, only between ourselves. We didn't want to upset anyone.

Don: Just keep the peace.

(Int 1: p. 11)

Seeking strategies to live-with-uncertainty

The parents survived their initial shock. They continued to feel anxious and vulnerable and their feelings vacillated as they became more hopeful that their baby would do well. They would have periods when they would feel positive and very hopeful, but the slightest hint of deterioration in their baby's progress would cause the parents to feel concerned and anxious again. The parents sought different ways of coping. All of the parents visited regularly as being with their baby helped reassure them and gave comfort:

Don: Going and seeing her [Molly] helped us get through. Chatting to the nurses, getting an idea on her progress.

(Int 1: p. 5)

All the interviewed parents visited as often as they could. Two of the mothers were with their baby most of the day every day. Because of work commitments some of the fathers came mainly at weekends, but they visited during the week if at all possible. Other parents came regularly once or twice a day. The parents telephoned the unit if they were unable to visit or if they required information. For some of the parents it was harder not to be with their baby than to be there, and yet they also found it difficult to be there. To cope with this paradox, parents tended to come and go, a number spending short periods of time with their baby, the visits timed to coincide with when their baby's care would be due. Beth described how she needed to see her baby, but did not find it easy being there as it seemed to increase her feelings of helplessness. It reminded her of her baby's and her own vulnerability. Beth lived an hours drive from the hospital. She visited Kate every second day:

Beth: I couldn't have stayed [with Kate] like some mothers... You don't forget about her but you get on with life. For me there's a limit of sitting and looking into an incubator... hard to talk to a baby in an incubator, takes a while to realise it's your baby... We held her hand, but it's scary because she looked so fragile and small.

(Int 2: p. 2)

The parents felt powerless when they could only watch and rely on the staff to keep their baby safe. Gradually they learned how they could help their baby and this gave them a feeling of comfort. Knowing what to do when her baby stopped breathing reduced the feeling of helplessness for one mother:

Julie: When John first stopped breathing the nurse said "Hit your baby!". I said "You hit him!" she stimulated him. After that it was good, I knew what to do... I can do something to help my baby.

(Int 4: p. 9)

Most of the parents continued to meet their usual responsibilities, for example they continued to run their farm, go to work and care for their other children. These activities helped the parents to structure their day, and gave them a focus. Keeping busy, and keeping to a daily routine helped one father to cope with the unexpectedness, and the overwhelming nature of the event:

Jim: We were thrown in so quickly and had little time to ourselves to get used to a normal life here [they had just moved from another city]...It was all so new to us... (p. 2). I didn't have time to dwell on it because I was so busy ...go and see Sam, go to work...the same routine (p. 1).

(Int 3)

Each parent and each couple found their own ways to cope with the ongoing uncertainty. One mother took a more philosophical approach as she described how she coped:

Beth: People say "how do you cope". You could cry everyday but it wouldn't do any good. You cannot change what has happened. ...can't do anymore than what's being done. She's in the best place. We have to take it as it comes...got to accept.

(Int 2: p. 7)

Recognising that distressing, painful reality can sustain hope

Affleck, Tennen and Rowe's (1988) research shows that people in threatening circumstances tend to make "downward comparisons" with less fortunate others, and derive comfort from doing so. If the parents could see babies who were sicker or smaller than their baby, they tended to feel that because their baby was not so 'bad' then, perhaps they did not need to be so anxious, and therefore they could relax a bit. Comparing their baby with other babies in the unit gave the parents in my research comfort and helped them to cope by sustaining their hope. One couple illustrate this:

Jim: The majority of [preterm babies] do very well, and when its yours that's doing well...

Mary: Deep down you're overjoyed.

Jim: Feel lucky, your baby is doing something another baby isn't.

Mary: ...You're all at a level then one baby goes ahead, and if it's your baby it's yippee! When the rest catch up that's good. Another baby goes ahead and you think how come that baby's doing better than my

baby...more concern for your own baby, and you start waiting, and the waiting seems forever... (p. 6). You were always curious about other babies to see if your child is doing as well... (p. 5).

(Int 3)

The parents would compare their baby with photos in the unit's foyer of babies born at the same gestation as their baby. These babies had done well and had been discharged home from the unit. The parents gained much comfort from seeing these photos:

Mary: We looked at the babies photos on the wall and thought...My baby's up to this weight, you look for a baby who was born at that weight.

Jim: You look at the ones who were worse off, the ones who made it, and the ones who don't. The 600 or 700 gram baby who made it always made you feel really good.

(Int 3: p. 20)

One baby, Peter, was very sick while six of the parents interviewed were still visiting their babies in the unit. He died after being in the unit several months. The death of Peter had an effect on other parents. Mary reflected on how this affected her and Peter's parents:

Mary: What helped me a lot...watching Peter, you think I am really lucky...my son's doing well. You notice it when someone's baby isn't...You distance yourself from it as well...Peter didn't make it... (p. 19). Even though it was hard for me it was harder for them [Peter's parents] to deal with (p. 20).

(Int 3:)

Although the parents talked about how they did not discuss with medical or nursing staff the fact that their baby could have died, they were nevertheless very aware that this was a possibility. Thinking about a baby dying increased the parents' feelings of anxiety and fear, but also drew them closer to their own baby. In the discussions with

the parents, the dominant feeling was how lucky they were to have their own baby, and as they saw how much more progress their baby was making each day, they dared hope that s/he would do well. Through the experience of knowing Peter and his parents, Julie and David came to appreciate having their own baby more:

Julie: We were there when Peter was very sick and when he died...It's like losing our own...I appreciated John more after that. At the start I distanced myself from John.

(Int 4: p. 16)

Joan and Mike had also come to know Peter and his parents. They remembered the effect that Peter's illness and death had on them:

Joan: Babies dying was difficult. I didn't know that he'd [Peter] died...All his stuff had gone and it was a shock...[Peter's father] and I had talked about Peter and that there wasn't anything that could be done. [Peter's father] used to say he looks so perfect on the outside, it's hard to realize what's on the inside.

Mike: I found it hard talking to Peter's parents about him...Nothing you could say would help. Just to be there was really hard.

(Int 5: p. 11)

Joan described how Peter's death also affected another mother in the unit:

Joan: [The mother of another baby] said no-one told her about Peter dying...everybody knows, and sees when a baby disappears. We were quite confident that Bob was going to be OK, but [this other mother] thought if it could happen to Peter, it could happen to [her baby], it needed someone to...acknowledge that a baby has died and that others might be feeling scared about their own baby.

(Int 5: p. 11)

Seeking ways to feel secure, safe and confident in their baby's environment

The parents in this study developed several mechanisms at different times in their attempt to gain a feeling of control over the situation, for example some concentrated on other activities or other babies in the nursery, some asked many questions and became very interested in technical aspects of their infant's treatment, some of the parents, uneasy with entrusting their child to strangers, felt a need to remain at their infant's side, **maintaining a vigil**. Some requested to read the infant's chart or material on their infant's particular condition, others became angry and upset about their infant's care or about nursery policies. Julie gave examples of what upset her. Even six months after going home this mother's annoyance was still evident:

Julie: The policy of who is allowed to visit your baby needs to be looked at. After 8 weeks one nurse asked [my sister] to leave - that was wrong and we sorted that out. Some doctors treated parents as nobodies - very free with morphine without our consent...//..make you feel so mad...//..They should have contacted us. They should call parents by name...//..We have our own identities. I am John's Mom, not those nurses' Mom.

(Int 4: p. 12)

The environment in which the baby was cared for influenced several factors which affected the feeling of ease the parents had, how 'at home' they felt for example, the quality of communication between parents and staff, and how secure the parents felt the unit was for their baby. All the parents in this study believed that open communication between staff and parents was very important. However, one mother talked about how the environment of the unit was not conducive to ensuring confidentiality:

Joan: Ward rounds are not private enough. Everyone knows what is happening to everyone else's baby.

(Int 5: p. 8)

The parents discussed how having trust and confidence in everything that was happening with their baby was important for them. They needed to know that s/he was safe.

Feeling that her baby was secure helped to comfort one parent. Beth relates how she felt when her baby was moved from a situation Beth felt comfortable and familiar with, to one which caused her to feel unsure and anxious:

Beth: I didn't want Kate to come out of the incubator...how vulnerable she looked [in the cot]. In the incubator she looked safe. I was used to seeing her there...if I'd had my way she'd probably have stayed in the incubator a lot longer because she looked so good in there.

(Int 2: p. 4)

The parents began to relax and to become more comfortable in their environment. Nevertheless, the worry about their baby continued to be with them all the time - in the unit and at home as Edna points out:

Edna: I used to have nightmares about the ventilator. I would hear it in the bedroom and think the cat would climb up and try and sit on her [the baby]. I'd hear the machines.

(Int 1: p. 5)

Being kept up to date with information about their baby and thereby alleviating the fear and dread

To avoid unnecessary anxiety and worry, the parents needed to be kept up to date with their baby's progress and treatment plans. Receiving appropriate, timely information was one of the most important ways the parents in this study gained help in living with the uncertainty. Avoiding false or misleading information or any lack of information and conflicting advice helped the parents to live hour-by-hour and day-by-day with the situation. Several of the parents commented positively about how this need was met:

Jim: The staff at the unit were excellent information wise.

(Int 3: p. 1)

Julie: Any questions we had we were told. The nurse said if I didn't understand anything to let her know...If she didn't know she would find out for us.

(Int 4: p. 8)

Beth: You just had to ask or they'd say what they were doing (p. 1).

Hugh: I think everything that could have happened was actually said to us (p. 3).

(Int 2)

Mike: They were very clear about what would happen.

(Int 5: p. 1)

Although the parents recognized that the staff did their best to help keep them informed, Joan pointed out that only the parents know what information they require:

Joan: There's information that you're given that the staff think is important for you. They would never know what is important to a parent.

(Int 5: p. 2)

Although most parents found that the information they were given met their needs, sometimes when parents had been visiting the unit for many weeks it was assumed that they realized what was happening with their baby. Jim and Mary discuss how they needed ongoing reassurance and explanation:

Jim: Information was always readily accessible, but often you had to ask for it...Some nurses take the time to make sure that you know, and some don't (p. 9).

Mary: In level two they [the nurses] should realize that parents who have had their babies in level three for a while are wanting to feel more part of it...Only one or two [nurses] said this is what is happening (p. 4).

(Int 3)

Communication was critical, and regular meetings between the family and staff were one way to give consistent medical information and emotional support. This was a concern of the parents interviewed. They felt that there was a need for ongoing regular meetings with the medical staff, especially for the parents with the long term babies:

Jim: One improvement...a channel to the doctor...as much as you respect the nurses and their knowledge you would want to hear it from the doctor.

Mary: ...parents should be able to sit in [medical discussions about their baby]. You're curious about what they'll say about your baby.

(Int 3: p. 9)

Parents of babies who have been in the unit for some time may lose track of the progress their baby has made, Joan points out one way of helping parents to keep in touch:

Joan: If parents attended [planned medical discussions] every 4-6 weeks to talk about what's been happening with their baby during that time.

(Int 5: p. 8)

Each parent and each couple discovered their own ways to find out what was happening with their baby. Sometimes it was planned by staff when information would be given to parents, othertimes the information the parents gained was because they asked for it, or it was received by chance because parents were chatting with staff. Several suggestions were given by one mother to help ensure that parents were informed about the progress of their baby, and what would be expected to happen to their baby during this progress:

Joan: The parent information folder has no booklet on the usual progress with prem babies...really useful for parents of long term babies...so you're prepared...The fact that apnoeas and bradies are normal for prem babies. When Bob first had an apnoea I thought "He's going to have brain damage"...I felt totally terrified...I often wanted specific information, not general information which was freely offered.

(Int 5: p. 2)

Receiving anxiety-relieving timely information

Consideration needs to be given by the staff as to how much information the parents want, what kind of information they need, what is the best way, and the best time to give the information. From the parents stories, it seemed that sometimes it was difficult for the parents to ask questions, often they did not know the questions to ask or they

were sometimes too scared to ask. Parents appreciated when staff took the initiative to discuss possibilities in their baby's progress with them. One mother discussed what she found most helpful:

Beth: A nurse showed us another baby born at 25 weeks and he had an ostomy...//..She said it...//..could be rectified...//..you think if Kate has to have it...//..it can be fine. It's better to know than suddenly be told she's going to have to have an ostomy.

(Int 2: p. 4)

When the parents knew they could question what was happening with their baby and feel they had been listened to, that their concerns were being taken seriously, this helped to relieve their worry:

Joan: Sometimes Bob'd need a touch of oxygen...//..He'd been left on 40% oxygen for the whole shift and there's no way he'd have needed that. I mentioned it to the nurse, and she followed it straight up...//..rang me at home.

(Int 5: p. 5)

For some parents, the information was not given at the time they needed it. Sometimes information was given, and what the parents found difficult about this was that no-one followed with an up-date later on about the progress the baby had made, and the likely outcome once the unstable period for the baby had passed. Jim and Mary were left wondering and were frightened to ask in case they were unable to cope with the responses:

Jim: The medical care Sam got...//..always put me at ease, but something unknown was hanging over your head all the time. When we got out of the danger period we weren't told...//..Two or three months after they said there was a 50:50 chance, no-one had followed up to say your boy is going to be all right...//..When we could muster the courage to ask, obviously he'd been in a satisfactory condition for some time. We could probably have relieved some of the stress a bit earlier. We carried it

around for a long time, we were worried.

(Int 3: p. 1)

The parents in this study desired information about diagnosis and causes of the baby's treatment and expected outcome. They talked about their wish to ask many questions reflecting their concerns about their infant's survival; this was especially true after the baby had received medical attention, and decisions were being made about treatment. However, sometimes they felt unable to ask the questions to which they desperately needed answers, and the difficulty increased when the staff did not realize that this need existed and therefore the necessary information was not given:

Jim: All the doctor said was...problem intubating Sam...He [the baby] went backwards really quickly. It was never satisfactorily explained to us what the problem was and what actually happened...

Mary: Why didn't they tell us afterwards?

Jim: ...The one thing we carry was that Sam was very close to dying...later the nurse said that he went without oxygen and they didn't know what damage had been done.

(Int 3: p. 10)

These parents' anxiety was not relieved until after Sam's discharge from hospital:

Mary: It took until the follow-up appointment [after discharge] for the doctor to say that everything was fine.

Jim: When the doctor did Sam's brain scan...There wasn't enough emphasis on allaying our fears...It was a real worry to us...(p. 11).

When the doctors are having a problem they're doing their darndest but the follow-up isn't there...that shook my confidence...If I hadn't asked the right question [at the follow-up appointment] we would never have found out...we had a right to know what happens to our baby (p. 10).

(Int 3)

Some of the parents became better informed after the event, and often wished that they'd had more information to help make informed decisions at the time. One couple felt that they were not given enough information from the time of admission to hospital. As she talked about her experience, Julie still sounded unsure if John's early delivery could have been prevented:

Julie: Nobody actually said if you hold on to him a bit longer he will have a better chance of survival...When it's your first, you don't know anything...After you think back and we were told nothing...John might have had a better chance if I'd got past some more weeks if I could but I probably couldn't.

(Int 4: p. 3)

No information was deliberately kept hidden from the parents who were involved in the major decisions made for their baby, and whose opinions were valued. One mother described her experience when she thought information was being held back from her:

Joan: [By chance] I saw a letter about Bob's heel prick results [Guthrie test]...the test had come back positive for cystic fibrosis...[A relative] has cystic fibrosis. I went to [the consultant] and he explained it. That was the only information we felt was not given to us, but there was a reason.

(Int 5: p. 2)

The parents appreciated that the staff made a conscious effort to keep them up to date with everything that was happening to their baby. They also commented that sometimes due to frequent staff changes, or if the staff were very busy, then sometimes parents might not be given current information about their baby. One mother pointed out how parents could miss out on information:

Joan: When it's busy the nurses may not have time to tell you things and then the next shift of nurses might think you've been told.

(Int 5: p. 2)

Living with the fear of receiving 'bad news' about their baby

While all the parents wanted to hear everything about their baby, sometimes they would be anxious about this in case the news was not good. All the parents found telephone calls, or the anticipation of a telephone call to be a cause of fear. They described in very emotively descriptive language, the effect that this had on them:

Don: I'd get paranoid the 'phone was going to ring...[the unit] give us bad news, waiting for something to happen.

Edna: The only time the unit did ring it was something stupid - just about gave me a heart attack.../..

Don: Gets you all jumpy getting 'phone calls from there, you think it's an emergency.

(Int 1: p. 6)

Beth: One of the worst things is when the 'phone rings.../..I do want to know but when they ring and say it's the unit, your heart stops.

(Int 2: p. 4-5)

Mary: We'd jump through the roof everytime the 'phone rang.../..You automatically thought the worst.

Jim: Especially a couple of times we had 'phone calls in the middle of the night [not from the unit].

(Int 3: p. 13)

Julie: It was scary when I first went home and the 'phone used to go, and you'd think that could be the hospital.

(Int 4: p. 4)

Frequently when parents were unable to visit their baby they would look forward to 'contact' by telephone. Bob's parents described how telephoning the unit to see how their baby was could be reassuring:

Joan: I used to ring every night to see how he was.../..It's neat when staff say he's very good, then.../..describe what the baby's doing - little things that as a parent you want to know.

(Int 5: p. 6).

Sometimes, however, calling the unit could cause fear:

Joan: I rang and was told he'd [the baby] started to have periods of stopping breathing...//..It was a shock to hear because I wasn't expecting anything. To the nurse it was no big deal but to me it was, he hadn't been having them for ages...//..if you're not there, it's really hard, you can't see what's happening.

(Int 5: p. 10)

A telephone call asking one couple to come in immediately caused severe shock and panic. All the fear and dread they had felt in the past was in their hearts and minds when they answered the telephone and realised that it was the unit. They expected the worst:

Jim: I believed we'd lost Sam. The impression I got from the message was be prepared.

Mary: ...//..Any 'phone call saying can we come in, and you're going to think the worst.

(Int 3: p. 13-14)

Although the parents lived in dread of the telephone ringing expecting it would be bad news from the unit, sometimes the seriousness of the situation was not understood from a telephone call. One couple's baby had been through many life-threatening situations. Their baby was now almost ready to go home. These parents described a call they had from the unit in the middle of the night. It was almost as if they were being protected from the awful realisation of the truth:

Beth: [The doctor] phoned and said she'd been intubated. I thought they meant suctioned out...//..I rang in the morning and they said " She's still ventilated"...//..then we realized intubated means ventilated...//..The doctor...//..probably thought they took it well.

Hugh: ...//..Maybe it was better that way.

(Int 2: p. 9)

For the parents interviewed, telephone calls, or the anticipation of a telephone call was important, but frightening, causing an ongoing underlying anxiety, fear and uncertainty which the parents continued to feel all the time their baby was in the unit right up until discharge from hospital.

The comments of the parents in this study showed that they never fully resolved the complexity of feelings of loss and grief over their baby's preterm birth. Although the parents gradually proceeded through the stages associated with the grief process, and succeeded in coping adequately and realistically with their baby's prematurity, acceptance and "restitution" did not seem to occur until their baby was well enough to be discharged. All the time the baby remained in the unit the parents, although appearing to be coping well with all that was happening, continued to have an underlying dread of something going wrong.

Having a preterm baby admitted to a NICU may be complicated by a series of events which cause a continuing crisis state for the parents who need social support throughout the NICU hospitalization to assist in their parental adjustment. If parents are to effectively care for their baby, they need help which often comes from family, friends and professionals. McHaffie (1990) found that there may be many reasons which cause parents to need and/or seek counselling, support or a chance to chat. Relating with supportive others helped the parents to cope at a time in their lives when they felt very isolated and vulnerable. **Relating-to-others** is the theme developed in Chapter Six.

CHAPTER SIX

RELATING-TO-OTHERS

Julie: Even when John wasn't having the best of days we got through this ordeal by being positive, and having the support of each other and our family.

(Int 4: p. 12)

The theme of this chapter is **RELATING-TO-OTHERS**. The focus is on **parents relating to each other, to others and to their baby**. This chapter describes how the parents developed **dependent-relationships-with-others**, and how existing close relationships were strengthened as they drew closer for mutual support. As couples lived with the uncertainty and fear constantly, they relied on one another for understanding. Protecting others, for example their parents, tended to bring the couple closer together as they shared with one another everything that was happening.

There were changes in the parents' **relationships-with-each-other** and their **relationships-with-others**. There were new relationships which assumed an importance sometimes surpassing existing relationships. The parents had complete dependence on strangers - the medical team - for the survival of their baby. Other strangers who were parents with babies in the unit became very important, as they shared the anxieties and joys associated with the progress of the babies. The parents were now also developing a new relationship - that of **becoming-a-parent** for their new baby. This new relationship is discussed in the next chapter.

Friends and workmates of the parents also helped them to bear some of the burden. Openness in their relationships with other parents of preterm babies was more likely because they shared similar experiences. Openness was also more likely with friends than with staff members. There was a reliance on the staff for help and therefore a reticence to criticise or complain. The staff were mentioned the least by the parents interviewed as providers of support for these couples.

Competency and consistency of care were seen by the parents interviewed as being essential for their baby's safety, and they experienced a loss of confidence in the staff if these were not provided. When difficulties were experienced by the parents, especially regarding their baby's care, sometimes they felt they had access to someone who was able to make a change. When the parents did not feel comfortable about asking for help, for example asking for a different nurse because they did not trust the nurse assigned to care for their baby, they would stay with their baby themselves until the next shift.

Developing inner strength as individuals and as a couple

The parents in my research enjoyed a mutually supportive relationship based on open communication. The feelings each couple expressed about their experience in the NICU were similar. As one partner described his/her feelings the other partner would frequently indicate agreement by nodding or by verbal confirmation that s/he experienced the same or similar feelings and understood how their partner had been feeling. Three parents describe the support they received from their partner:

Joan: I think about things and worry and Mike tends to be more balanced. We seem to balance each other.

(Int 5: p. 13)

Jim: We were support for each other.

Mary: ...That was the most intense time Jim and I have shared together. I learned so much about Jim - the way he copes...reacts to me when I'm stressed (p. 17)... discuss what was happening with each other (p. 16).

(Int 3)

The crisis of having a preterm birth can provide an opportunity for deterioration, or for strengthening of the couple's relationship. The parents in my study found that their relationship became stronger. Jim and Mary discuss how they felt that their relationship developed as a result of Sam's preterm birth:

Mary: My relationship with Jim had its straining points... didn't have time together... living with Jim's mum and dad... Now we're in our own home we do things together... The stress has brought us closer together.

Jim: Much stronger relationship.

(Int 3: p. 17)

Adversity can be a catalyst in helping people to develop an inner strength. All of the parents in my research talked of how the preterm birth of their baby had a positive effect on them. They were very honest about how difficult their time was in the NICU, but from all the worry, the waiting, the helplessness, they found something within themselves that helped them to pull together in their fight for their baby's survival. Two of the mothers describe how the experience helped them and their partners in their personal growth:

Julie: Made David and I much stronger people... You get strong standing up to people... want the best for your baby.

(Int 4: p. 11)

Mary: Through it we've come out stronger... better people.

(Int 3: p. 17)

Walking a tightrope, giving support to and gaining support from family members

Most of the parents in this study found their parents and parents-in-law helpful. Jim and Mary describe the support they received from Jim's parents:

Jim: We were lucky that we had the support of my parents we were staying with at the time which was really great.

(Int 3: p. 17)

The parents can feel isolated, very alone coping with the unknown in a strange environment. Being able to share and discuss all worries and concerns with others close to them was valuable and important for the interviewed parents. Don describes the support he and Edna received from his parents:

Don: Edna's and my parents would...be dying to get up once a week to see how Molly was going, and we'd get 'phone calls...It was good to share it with them because they're part of it.

(Int 1: p. 7)

Most of the parents interviewed for this study expressed that support from a spouse, partner, or friends was significant in influencing satisfaction with their parenting role and was a major influence in helping them to adapt positively. One mother described her experience:

Julie: Even when John wasn't having the best of days we got through this ordeal by being positive, and having the support of each other and our family.

(Int 4: p. 12)

Some of the interviewed parents found that their parents were not able to be supportive because they were also struggling to accept what had happened with their new grandchild. They too, were coping with something unknown, and were suffering 'doubly', as their son or daughter and their grandchild were needing their help and support. Julie indicated that she could not really expect support from David's or her parents who were all very anxious about the early arrival of their baby:

Julie: Not share our worries with our parents...they'd panic too much. My [sister and brother-in-law] were good.

(Int 4: p. 5)

Joan's parents were also very anxious and frightened by the preterm birth of their grandson. Joan found the time when her parents visited very difficult. As well as living with all the ups and downs Bob was experiencing she found she was also supporting her parents:

Joan: Mum was really worried...never had anything to do with prem babies...She thought he wouldn't be a proper looking baby and would probably die...she was terrified, didn't want to hold him...I felt torn with spending time with her outside the unit and spending time with

Bob...//...we were supporting my parents more than they were supporting us.

(Int 5: p. 12)

Newman and McSweeney (1990) point out that the inclusion of other children in the events surrounding the birth of a sick newborn is important. From a sibling's point of view, the anticipated birth of a new baby is a stressful time of noticeable physical and psychological changes within the family. Two of the couples interviewed had a preschooler. These children were included in the excitement and joy of having a new baby in the family. They usually came with both their parents, would visit the baby and then would spent time outside the nursery with one of their parents while the other parent visited their baby. Beth described the effect having a new sister had on her 3 year old daughter Judy:

Beth: Judy knows I go to the hospital. She held Kate's hand once through the incubator, and kept on telling everyone...//...It was hard for her when people came to visit, because all they talked about was Kate.

(Int 2: p. 12)

Being helped through the difficulties by sharing the concern with significant others

For Joan whose family lives overseas, friends were her main source of support especially one friend who had also been through a similar experience. She had given birth to preterm twins earlier in the year:

Joan: My main support was [a work friend]...//...I knew she knew exactly what was happening.

(Int 5: p. 12)

Beth's family also live overseas and were therefore not able to be with Beth and Hugh. The couple did not mention Hugh's family. They found that their friends were very helpful. Beth described their support and interest:

Beth: Friends. The 'phone never stopped ringing. How's Kate?

(Int 2: p. 7)

When John's condition became stable Julie, his mother, went back to work and his father was to care for him at home. Julie found her colleagues at work very helpful in assisting her to settle back into work and achieve a normal daily routine. They allowed her to talk about John:

Julie: They were very good at work...//..The more I talked about it, it was good therapy. I had the support of the people in the whole office.

(Int 4: pp. 4-5)

Jim also received support from his work colleagues and from his customers. Jim was not able to be with Sam as much as he would have liked and he gained much pleasure in telling people about his baby:

Jim: The best thing about having a prem baby is telling people. I've never talked to so many people in my life. You see their baby and you say I've got a little boy now.

(Int 3: p. 16)

Understanding and support from other parents suffering through the same ordeal

All the parents found they were living with the support of like others. They recognised that the other parents in the unit were a group who understood exactly what it was like having a preterm baby in a NICU:

Edna: Parents talk among themselves...//..about how they feel like how they feel about staff.

Don: ...//..You got to know a few of the other parents and it was great. Just relate - hear what they have to say about the hospital, the staff. Pretty similar.

(Int 1: pp. 13-14)

Exhaustive explanations were not necessary with the other parents in the unit. There was a mutual understanding, and an empathy for parents whose baby was not having a 'good' day.

Julie: It was good speaking with other parents understanding what they were going through. We had just been through it or going through it at the same time.

(Int 4: p. 11)

Beth: Its good to talk to other mothers...and see babies who are further down the track than you.

(Int 2: p. 11)

The parents in this research realised that other parents whose baby had been in the unit for some weeks, could be a valuable source of information and support. These parents often shared their experiences with 'newer' parents. They were able to give these parents information about treatments, and also help them to gain confidence in themselves:

Edna: We shared with [another mother] about the ostomy, she told us the surgeon was good that [her baby] did well and what to expect after the operation. You take it better from her than from a doctor because she'd been through it. It was her child, she knew the feelings.

(Int 1: pp. 13-14)

Joan: You build up relationships with other mums building confidence if someone was feeling anxious. It would boost you to ask questions so it was getting some peer support.

(Int 5: pp. 5-6)

Jim: Some parents you bond with and some you don't... discuss everything - progress, daily struggles, problems.

Mary: Right through it is very supportive - you can share with other families...The mothers' room is where you can have good conversations - no doctors or nurses or partners...you find out how they [the mothers] are feeling.

(Int 3: pp. 6-7)

Although support and help was available from other parents with preterm babies, two of the parents interviewed found it was important to be very sensitive to these parents

when making comparisons with their babies. The parents felt very proud when their baby was doing well, and when they could see that their baby was doing better than another baby. This excitement was shared between the parents, their family and sometimes the staff caring for their baby. However, the parents realised that the others whose baby may not be doing as well could also see what was happening:

Jim: Huge competitive environment between parents.

Mary: If something good happens to your baby...I felt bad telling [another mother]...guilty. I couldn't say...he's doing really well...her baby may not be...you start distancing yourself from other parents. At the beginning...a bond...waiting for the same thing.

Jim: It's like you're there to support parents having problems, but don't talk about your baby who's doing well.

(Int 3: pp. 6-7)

One method of particular value to help parents share and express their feelings has been the use of parent or parent-staff support groups. These can be useful sources of comfort and feedback. Otherwise, as Thorne (1985) points out, parents may feel it is inappropriate to criticise one aspect of care while being so grateful for the clinical care their baby is receiving. Utilizing the experience of like others, parents who have had a preterm baby in the NICU and have successfully lived through this ordeal can be extremely valuable in providing support to parents by sharing common feelings, reactions and experiences. The only parent in the study who talked about the parents' support group spoke of how helpful it was for her but said that it was poorly attended.

Desperately seeking help and guidance from the staff

Ideally nurses and other health professionals could be an integral part of the parents' support network, however the parents interviewed did not discuss this as part of their experience. Relating with significant strangers who were the staff members, was described and parents had different experiences about the availability and approachability of the doctors and nurses:

Jim: The doctors seem...aloof...if you really want to see them you can...there's a bit of a barrier there at times.

(Int 3: p. 9)

Beth: The doctors are always nice, always there, they'd...say what she was doing, couldn't wish for better care.

Hugh: The nurses were really professional...probably got as much information from nurses as doctors. They were good (pp. 2-3).

Beth: When I first met one of the nurses, I was quite upset with her...later [on a visit to the hospital after discharge] I went to find her specifically to show her Kate because I know she really hung in there for Kate (p. 10).

(Int 2)

Edna: The nurses were good to talk to...We had favourites.

Don: ...Some you got on with straight away.

Edna: ...One nurse was really good. She'd talk about her family - breaking off what you're thinking about.

(Int 1: p. 8)

Julie: There are some good nurses and some stink ones...treating us as if we don't know what we're doing and that they know, but most were good support for parents and very helpful, it just takes a few to make it horrible...(p. 1). Some try to comfort you, others were a bit standoffish (p. 7).

(Int 4)

It was evident from the parents stories that some staff felt that they knew what it was like for the parents. Some of the parents gave examples of how this was not so. One mother pointed out that the staff could never really appreciate how the parents felt:

Julie: Some staff think that they know what you're going through, but unless they've had a premature baby they don't know the emotion you have. They have an idea from seeing different parents, and how they cope, but they don't truly understand.

(Int 4: p. 7)

The parents were putting the life of their baby in the hands of strangers. Joan knew some of the doctors who worked in the unit. Even although she did not know any of the other staff there, Joan gained support and encouragement from the knowledge that she could receive help and information from these doctors if she needed it.

Joan: I was lucky because I knew the doctors beforehand...I didn't know the nursing staff...having access to them [doctors] was good.

(Int 5: p. 1)

The parents needed to feel that the staff respected them and their views. Knowing that the staff cared about them and their baby gave the parents comfort. One mother described ways that the staff demonstrated that they were interested, that they cared:

Joan: Remembering parents...babies' and siblings first names... (p. 1). The overall experience at the unit was good. The staff are dedicated people...not just dealing with the baby, dealing with the family...a really strong emphasis other places it's more just the patient (p. 13).

(Int 5)

Longing to have trust in those caring for their baby

It would seem that many of the parents who were interviewed were very concerned about the care their baby received at times and that this was either not recognised by the staff, or if recognised, sometimes there was no obvious attempt at alleviating the concern. The parents felt helpless and were unable to provide their baby with what s/he required for life. They had to place their baby in the staff's hands. Trust was an important factor in helping the parents to feel confident in the staff. Sadly, many of the parents interviewed did not trust the nurses who were caring for their baby. They were so anxious about the safety of their baby that they would stay until the next shift:

Joan: I wasn't able to relax and feel he was being well looked after...hadn't met the nurses looking after him and have the trust...your baby is so precious to you, can't choose who is going to look after your baby, you know everyone is doing their best, they don't have the same love for your child ...I had to share him with people I

don't know...//..Being able to trust other people looking after your child, that's the hardest.

(Int 5: p. 3)

The competency or experience of the staff gave the parents confidence. They quickly came to recognize staff who were competent and staff who were not, staff they felt happy about leaving their baby with and staff they did not want to care for their baby. Jim describes how secure he felt about the care Sam received in level 3 and his reluctance seeing his baby leave this environment that he had come to trust, and be cared for in one where he knew there were less staff and less monitoring of the babies:

Jim: My reliance on the knowledge of the nursing staff ...//..the monitors and alarms...//..big shock [going to level two]...//..we didn't really want him to leave [level three]...//..he's your baby. You want 100% best for him...//..While Sam was in level three I was very comfortable. We felt secure and safe because we had complete confidence in everyone there. It was a great feeling, and once we got to level two, the care wasn't so one-to-one.

(Int 3)

The parents also came to appreciate that if the nurse caring for their baby was familiar with care of preterm babies, and particularly with their baby's needs, then they could have increased confidence that the care their baby received would be safer. Several of the parents graphically describe how worried they felt when they realised that the nurse caring for their baby did not have the necessary skills. They did not feel the care their baby received was safe:

Mary: What scared me about level two...//..agency nurses there. Some things I disliked...//..agency nurse hit the incubator as part of telling a joke...//..not my baby's incubator but you feel what's going to happen when I'm not here, is she going to be just as careless with my baby...//..(p. 3). With the agency nurses I didn't really feel comfortable.

Jim: They didn't give great levels of confidence (p. 4).

(Int 3)

Don: Worried about the agency ladies. We had problems because they didn't know the baby well (p. 8).

Edna: A nurse from [another hospital] was looking after Molly when she was still quite little. I didn't want that lady looking after her. It was a worry that she wasn't one of the regular staff, and she didn't know Molly (p. 11). Molly used to go up and down a lot [oxygen requirement] they'd panic [the agency nurses]...so scared something was going to happen...didn't know her...Everytime we'd come I'd see if it was an agency (p. 12).

Don: Relief when there were regular staff because they knew the babies. You get paranoid that they'd [the agency nurse] do something drastic (p.14).

(Int 1)

Joan: The nurse...hadn't worked in the unit before... way she dealt with [Bob desaturating] was different from the unit nurses...The worst thing that happened...an agency nurse didn't know the machinery...[Bob] had an enormous brady...went on to have an apnoea. She kept checking the machine and not checking Bob. I watched him change colour...I felt totally freaked out.

(Int 5: p. 4)

Sadly, the parents gave many examples of their inability to trust the nurses who were caring for their baby. They felt they could not leave their baby with these nurses. Six of the parents describe their experience:

Joan: I felt anxious, and didn't want to leave until the end of the shift and so I stayed.

(Int 5: p. 4)

Jim: We felt protective of him if there were not regular staff on...we would just stay around.

Mary: That way we could look after Sam.

Jim: If we didn't feel confident we'd go home and worry. The confidence they [the nurses] inspired in you was very important from a parent's

point of view.

(Int 3: p. 4)

Edna: We stayed on especially when agency were on, we were frightened they'd do something...One lady told [a unit nurse] "I don't want to do this, I don't know what to do if something happens". She was really scared, and that worried me...Molly was in isolation [Molly had RSV]...you can't see anyone else...

Don: We stayed 'til the next shift to see the lady through.

(Int 1: pp. 11-12)

Julie: My sister and her husband stayed...and watched John until the nurse finished her shift...felt they had to watch our baby...didn't trust the nurse - what she might or might not do...to make sure our baby was OK...I put forward that under no circumstances was that nurse to touch our child.

(Int 4: p. 10)

The experience of the parents interviewed is similar to that summarized by Thorne and Robinson (1988) who describe family relationships with health care professionals as an evolving three-stage process. The first stage is naive trusting, which refers to family members trusting that all health care professionals will act in the sick member's best interests; family members wait passively for this to happen while they familiarize themselves with the professional care setting (see Mike's example p. 46 Chapter 4). The second phase is the disenchantment phase, which is characterized by dissatisfaction with care, frustration, and fear. Families learn that they are expected to leave the care of their ill member in the hands of the professionals. Families face a dilemma, knowing that if they remain passive, the sick member might suffer a negative experience, and if they actively seek involvement, they may alienate the health care professionals, thus placing the sick member in greater jeopardy (see Edna and Don's example p. 63 Chapter 5). The third phase is guarded alliance, in which involved families state their own perspective and expectations more clearly, and promote negotiation of mutually satisfying care. However, Thorne and Robinson found that families still experience the frustration of waiting and anger from recognizing that their own expertise is devalued.

Disappointingly this was also the experience of some of the parents interviewed in this study as described by Edna:

Edna: When Molly went to level two, the [agency] nurse didn't hand her over properly...they turned it [oxygen] up to 90%...I was trying to tell the nurses that she doesn't go that high, but they were rude to me - like I didn't know anything...They weren't listening to me.

(Int 1: p. 8)

When there was consistency of nursing care it was less worrying and frustrating for the parents. There was an opportunity to build a relationship based on trust if the same nurses were caring for their baby for several days at a time. However this was not always the experience for the parents interviewed. Inconsistency of care due to different nurses caring for their baby each day left them lacking in confidence and feeling unsure about the care their baby received:

Joan: Some I would feel happier with looking after Bob than others because of the consistency...When a new nurse is looking after your baby you watch how they do things, get to know them, and get them to know you (p. 3). I didn't want agency nurses. They weren't consistent. I didn't get to know and trust them...Some obviously don't want to be there...pick up when someone is nervous about your baby (p. 4).

(Int 5)

Julie and David's frustration was obvious, they found lack of continuity and inconsistency in nursing care very difficult. Losing confidence with parenting skills was a risk:

Julie: Different nurses was a nuisance.

David: ...You'd be told one thing. You'd do it that way, and another nurse tells you to do it another way (p. 8).

Julie: Sometimes you felt you were really hopeless...I got shown how to do a nappy and another nurse says "Well for a start I'd do that nappy differently" (p. 9)

(Int 4)

As well as distressing the parents about the quality of care their baby received, an inconsistent approach by staff also meant that one mother could never be certain if she would be ‘allowed’ to carry out kangaroo care [skin to skin contact between baby and parent]:

Joan: The unit promotes kangaroo care, but there is not a consistent approach...I'd been told that Bob couldn't have kangaroo cuddles...another nurse took the time for me to do it...you know you will get kangaroo care when a particular staff member is on rather than when Bob is ready for it...that definitely wasn't consistent.

(Int 5: p. 7)

All the parents interviewed found it exhausting and frustrating having to get to know new nursing staff, and trusting they could safely leave their baby in these nurses' care. Joan described how for her, consistency of care helped to improve the quality of care her baby received:

Joan: When Bob went to [level one]...the staff from there had been working in [level two] so, I'd got to know them. Other people found that hard...having to get to know new staff... (p. 9). I think that's where the quality tends to go down if you don't have consistency (p. 5).

(Int 5)

Documentation of the nursing care planned for each baby was one way of trying to ensure that there was a consistent approach by nursing staff. This meant that any special needs the baby had or any particular factors for the baby could be outlined so that the baby could be cared for with greater consistency. Joan found that working out her baby's plan of care with the nursing staff made consistency of care more likely:

Joan: When I went to level two...people assumed I knew what I was doing...The nurse and I did the nursing care plan together and it clarified things...because it was in the nursing care plan the nursing staff knew as well.

(Int 5: p. 8)

Seeking social support was important for all the parents who were interviewed. Parents sought this support in the form of information, material assistance, emotional support, and the sharing of similar ideas and feelings. The social support they gained helped them towards an enhancement of parental coping abilities, increased self-esteem, reduced parental anxiety, and an increased feeling of control and mastery of the situation. The support that the parents in this study received came from each other, from family members, friends, workmates, from other parents in the unit and from the staff.

Relating-with-supportive-others helped the parents to cope at a time in their lives when they felt very isolated and vulnerable. Other ways the parents came to feel at home in their environment are outlined in Chapter Seven.

CHAPTER SEVEN

MOVING-FROM-FEAR

Mary: My fondest memory was the environment especially in level three that the nurses give you...calming feeling for the parents. The nurses are...open with you...watching to make sure everything's fine, and they keep their cool when some machine goes beep. They make you calm.

Jim: ...like a family being there...hard there though.

(Int 3: p. 19)

The NICU is a foreign environment for most parents and with the added stress of having their very tiny preterm infant there, it was a frightening environment. In this chapter, the theme **MOVING-FROM-FEAR** is portrayed by the parents stories of how they learned to adjust to the unfamiliar environment of the NICU. Slowly the parents came to feel more 'at home' in the unit as they became aware of what was happening to their baby and more used to the equipment that was necessary for his/her survival.

Focusing on recognisable signs that the baby was progressing gave hope, reassurance and encouragement. Despite the hope, there was a realisation that their baby was very immature, that no-one could give a guarantee of a good outcome. For the parents this meant that the dread of what might happen, and the ultimate fear of losing the baby was present throughout the time their baby was in the NICU.

Allowing themselves to become involved with all that was happening with their baby in the unit helped them to grow to feel more comfortable there as they came to know their baby. This feeling of ease helped the parents to develop the new relationship of being a parent for their new baby. Gradually the parents gained confidence in caring for their baby as s/he became stable and eventually able to be taken home to the parents' own environment.

Preparing for the transition from NICU to home began once the baby's condition had stabilised. The parents took on the parental role as they felt more at ease and able to do so, beginning by carrying out their baby's mouth and eye cares and changing his/her nappy. The parents discussed how their confidence increased as little by little they felt more natural touching their baby, doing things for him/her and recognising signs from their baby that indicated when s/he felt comfortable or uncomfortable. By discharge all of the parents in this study found that they had built up a relationship with their baby and confidence in caring for him/her. They could not wait to take their baby home.

Feeling more 'at home' in the NICU

At first, none of the parents felt at ease in the NICU. It was foreign to them and they had to allow others to be in control. Gradually as they came to understand what was happening with their baby, they began to feel more comfortable in the environment. Several of the parents describe how they began to move-from-fear.

Don: We got to know the unit as a whole...just about every nurse...didn't feel foreign there at all, we settled in quite well.

(Int 1: p. 12)

Beth: Takes you a while to get used to the heat...we both felt at home.

(Int 2: p. 19)

Mary: My fondest memory was the environment especially in level three that the nurses give you...calming feeling for the parents. The nurses are...open with you...watching to make sure everything's fine, and they keep their cool when some machine goes beep. They make you calm.

Jim: ...like a family being there...hard there though.

(Int 3: p. 19)

Beginning to see light at the end of the tunnel

The parents quickly began to learn about and recognize non observable and observable signs of improvement in their baby. They looked for and asked about progress, focusing initially on decreases in ventilation rates and pressures and decreases in oxygen

requirement, to later more observable signs for the parents such as increasing feeds. Gradually the parents could allow themselves to relax a little. They felt encouraged when they saw improvement, and dared begin to have hope:

Jim: The fact that Sam made nice steady progress the whole way through apart from one incident made it a lot easier for us because we could see him improving everyday.

(Int 3: p. 1)

Don: When she first went on a prong [nasal pharyngeal airway] that was a good thing.

(Int 1: p. 6)

Beth: When she had an arm or a leg without anything in it, reducing the amount of lines and things going into her...when she came off the ventilator and then she was on CPAP [continuous positive airway pressure] you could see she was progressing forward.

(Int 2: p. 3)

Nance (1982) stated that an expression of hope is a pervasive feeling experienced by parents of preterm children and quotes one of her study parents as commenting, "You never give up hope." For the parents in my study there was ongoing fear and anxiety. They were never completely reassured that their baby would go home. Nevertheless, as the parents spoke, it was evident that they always had an underlying hope. They needed to hope but at times, for them, hoping increased their feelings of vulnerability. If they didn't have hope then their feeling of sadness and grief increased. If they did dare to hope then each time the baby's medical condition became unstable, their feelings of devastation and despair because of the possible loss of their baby became more acute. This never giving up hope was apparent in Julie's situation where she and her partner tried not to get their hopes up too high:

Julie: We didn't get our hopes up too high because John had a tendency of [not improving] we used to think, if he lasts today, that's a bonus, if he lasts another day, that's another bonus.

(Int 4: p. 5)

Hope was expressed in a number of ways. The parents would become excited and be eager to share with their partners, other parents and those caring for the baby, when their baby began to do 'normal' things. They would treasure these moments:

Mary: You see your baby open his eyes, the actual act of opening their eyes is really important.

(Int 3: p. 19)

There were many steps of progress the baby made which gave the parents hope even although they expressed a realisation that the progress may not be permanent, that their baby may still take some backward steps before being well on the road towards requiring less care. Being moved from the high dependency area, level three to level two, demonstrated great improvement:

Beth: When she went to level two it was a really positive step...real excitement and you swell at the breast because you know you're progressing then...If there was any reason to take her back [to level three] I would have been upset but she could come forward again.

(Int 2: p. 5)

The parents wanted to see their babies progress. They would watch and wait, looking for any little sign that their baby was better than s/he had been the previous day. To be able to feel and express realistic hope of improvement helped:

Beth: You hope that she won't go back on CPAP...She did...then pulled back again and things were OK.

(Int 2: p. 3)

As the parents were living through this experience, most felt that they would never forget anything that happened, that all the events would stay with them forever. However, so much eventuated over a short time with their baby and during part of that time they felt in a daze, unable to concentrate on all that was occurring. Frequently their initial experience became dulled, not forgotten, but sometimes less reachable as the parents had to cope with new difficulties each day. Keeping a diary and taking photos and videos gave the parents a record of their baby's progress, and also of their

own ups and downs as they came to terms with all that was happening:

Beth: The diary is good...You forget...We took photos and a video. I can picture what the ventilator looks like now but they're for Kate, and also for Judy [Kate's sister].

(Int 2: p. 12)

All of the parents focused on their baby's weight. They would eagerly wait for the baby to be weighed, and compare the weight with the previous one. Frequently, if their partner were not there, the other parent would telephone him/her to discuss the baby's weight. Weight gain gave the parents a great thrill because it was a positive sign that the baby was doing well:

Jim: The weight is the single most important sign...every weight gain was so good...when he got to the 1000g mark that was such a rush.

(Int 3: p. 5)

Edna: The days [the baby] got weighed were important

Don: And when she reached the big 1kg

Edna: and got to her birth weight.

Don: That was exciting and then she passed it.

(Int 1: p. 6)

David: Every time John gained weight...great feeling because we knew he was nearly ready to come home with us.

(Int 4: p. 4)

The parents also appreciated when the staff took time to make events special. They wanted to enjoy their time with their baby, to make it a positive experience for themselves and their baby. One mother found that the little things were important:

Joan: They each got their little stocking at Christmas...A nurse drew holly on the disposable nappies...People telling you how cute your baby is...Bath time was good.

(Int 5: p. 8)

Treasuring the time spent learning to relate to their new baby

Spending time with their baby, getting to know his/her little ways, likes and dislikes, helped the parents to grow closer to their baby. Mary talked about how important this was for her:

Mary: I had my bonding my way which was very important and Jim had the opportunity to bond with Sam...//..being with Sam was great I would never have missed it for the world...//..something I really enjoyed doing...//..(p. 16). You want to do that little more...//..to make sure he knows I love him (p. 20).

(Int 3)

Although one mother described how she found it difficult to be with her baby (see p. 64 Chapter 5 Beth's statement), all of the parents interviewed spent as much time with their baby as they were able to and wanted to and did carry out their baby's care when they could. They were with their baby, and held him/her as often as possible. The parents described ways they found helped them in coming to know their baby:

Mary: You want to be there...//..If he had a good day it was easier for me to go home, but there were days when...//..I didn't want to leave him, didn't want to miss out on anything.

(Int 3: p. 4)

Joan: I'd go and see Bob. I'd stay if he wasn't doing so well, or if I didn't get a chance to have a good cuddle...//..(p. 4). One of the good things was being shown how to do his 'cares'.

Mike: Working with him, doing his 'cares', touching him was good (p. 6).

(Int 5)

Julie: Bath times were always great holding John and feeling him close.

(Int 4: p. 5)

The parents needed to be 'allowed' to touch their baby as they felt comfortable to do so. They talked about how they wanted everything possible to be done to make this an enjoyable, positive, memorable experience. Initially, however, there was often trepidation about touching or holding their baby:

Hugh: Felt like she'd break even by touching her - she was so small...//..

Beth: Probably the best thing was when I held her the first time, a bit frightening when they handed her to me.

(Int 2: p. 1)

For one mother, caring for her baby became the most important time of her day and she almost felt jealous of the nurses who were able to be with her baby all the time:

Jim: You got quite possessive over doing his 'cares'.

Mary: Yes I did...//..kind of resent it because nurses are the ones who can do more for him.

(Int 3: p. 2)

Every new experience was treasured. The parents held this experience in their memory and it felt special to be privileged to share these memories with them:

Julie: Our first hold of John at midnight 4 days after he was born, kangaroo care, feeling skin against skin. The first hold without the tubes and ventilator...//..seeing his whole face with no tapes on it.

(Int 4: p. 5)

Joan: His first cuddle even though he was all wrapped up ...//..was amazing and that was within the first week.

(Int 5: p. 6)

Jim: To me every new thing was such a big event. The first time he opened his eyes and seemed to look.

(Int 3: p. 5)

In this research, each couple was involved in the care of their baby as a couple. Most of the fathers because of work commitments tended to be in the unit less often and therefore were not able to participate in their baby's care as often as their partner could.

This was not so for Julie and David who had decided that Julie would go back to work and that David would look after John when he came home from the hospital. Julie realized that this was necessary for their family, but she found the idea of not being her son's primary care giver difficult. Distancing herself from her baby helped her to cope with this:

Julie: I knew I wasn't staying at home with him, and if I got too close I mightn't want to go back to work.

(Int 4: p. 6)

Desperately searching for help from others in their desire to breast-feed

The mothers interviewed wanted to be able to breast-feed their baby, however the physical condition of their infant, the neonatal intensive care environment, the limited physical contact the mothers were able to have with their baby and the need to maintain milk flow for several weeks by mechanical expression contributed to difficulty in achieving breast-feeding. The mothers in this research who were successful in continuing to be able to maintain a good milk supply and who wished to breast-feed eventually, had expectations of the staff which included assistance with breast-feeding when required, and positive encouragement and interest in helping the mother maintain a good milk supply. One of the mothers discussed her experience of breast-feeding. It would seem that she did not receive timely information from staff:

Joan: I think people assumed I knew what I was doing. I was asked if I needed help. It wasn't so much that I needed help, I'd never discussed the strategy for establishing breast-feeding...I read a breast-feeding book and realized I should be giving him the breast every second feed instead of every feed so as not to tire him.

(Int 5: p. 8)

One couple describe the effect that feeling 'pushed' to breast-feed by staff had on them and on their relationship. They talked about how unsupported they felt when they made the decision to bottle-feed their baby. The experience for this couple became very distressing; it would seem that this distress could have been avoided or at least

minimised if it had been recognised:

Mary: Pushing me to breast-feed and I was already stressed out and didn't need them telling me I must breast-feed.

Jim: ...you didn't count for very much because you were bottle-feeding. I'd like to say to those nurses to get a 14 week premature baby and try and keep your milk going everyday to breast-feed.

Mary: I got stressed...The nurses didn't pick it up, it was more the other mothers [who identified Mary's stress].

Jim: It's almost like a regime [for the nurses]. You must breast-feed, breast-feeding is good. I agree but [the nurses] are only thinking about the physiological aspects. There seemed to be very little empathy for the mother.

(Int 3: p. 8)

Eventually, after several weeks of aiming to breast-feed their baby, the couple decided to bottle-feed:

Jim: A week or two before Sam came home you were a mess all over breast-feeding. Your milk was going off, your stress was...getting worse until you made a conscious decision [to bottle-feed]. The instant you made the decision...we were much happier. It wasn't worth the stress on the relationship, and it wasn't good for Sam either.

(Int 3: p. 8)

Joan discussed needing the support of like others rather than relying on the staff who did not always know what was needed or how to provide this support. Her friend, who had successfully breast-fed her preterm twins, gave Joan the support she needed when she was having difficulty with continuing to breast-feed:

Joan: Everytime I started thinking about bottle-feeding, [my friend] would say the right thing, and keep me going.

(Int 5: p. 12)

The mothers who decided to bottle-feed rather than breast-feed did not include staff when they talked of those who gave them encouragement and support in their decision making. Mary talked about living with the support of like others, of how other mothers were supportive of her decision to breast or bottle-feed:

Mary: I got stressed out expressing...but you'd talk it out with other mothers. They were the ones saying that... there's nothing wrong with bottle-feeding.

(Int 3: p. 7)

Staff valuing or ignoring the parents' knowledge about their baby

As the parents began to feel more at ease in the NICU, they were aware that they could contribute to their baby's security and comfort by passing on their special knowledge of their baby. Two of the mothers described how, when possible, they would try to be there to ensure that the staff caring for their baby knew all they could about the baby:

Joan: I would try to be there and put in my bit about Bob's particular things...I knew from seeing a lot of him.

(Int 5: p 4)

Mary: You try and help them [the nurses] if you know something [about the baby].

(Int 3: p 19)

Another mother felt angry and frustrated when she tried to tell the nurses about her baby's needs and became aware that the nurse was not listening to her:

Edna: I was trying to tell the nurses...but they were rude to me -like I didn't know anything...they weren't listening to me.

(Int 1: p. 8)

Struggling to develop confidence as parents

All of the parents - both mothers and fathers were as involved as possible in their baby's care. As parents gained a sense of security in their environment they felt more

confident and comfortable caring for their baby. They began to realize and accept that they had an important part to contribute to their baby's care. This acceptance took some time and the parents' texts describe how this did depend on the attitude of the staff, the stability of their baby's condition, and the confidence the parents had in themselves. Julie talked about feeling scared at the beginning, and how she eventually felt at ease and in control:

Julie: Very scared at the start...you know nothing. The nurse says do this, you do it...by the end, we knew what was right, and knew more than them about our baby - what he likes and doesn't like.

(Int 4: p 1)

Knowing that they felt confident in taking care of their baby was important for the parents as Jim and Mary explain:

Jim: For thirteen weeks you've been with your baby, and inevitably you're picking up knowledge.

Mary: ...you pick up little things that for a new mother, it's excellent.

(Int 3: p. 15)

Sometimes parents would find that different nurses would do things differently:

Edna: Sometimes I'd touch her hand, and some nurses would say "Oh don't do that," and others would say "it's good to do that." I'd feel like I was being shoved around.

(Int 1: p. 11)

Miles (1989) pointed out that parental role alterations that occur as parents hand over their infant's care to NICU staff are extremely stressful. The parents interviewed were reluctant to relinquish any care that they felt confident in carrying out. They talked about how they resented this and how they were left with the feeling of being pushed out. Sometimes the parents felt that the nurse would take over their baby's care. Although the parents were learning to feel very 'at home' in relating to their baby and caring for him/her, they were aware that they were still in the NICU, not in their own

environment. Two of the mothers describe how at times they felt pushed out, confused and/or annoyed:

Joan: I got really upset...agency nurse came, flicking the thermometer, looking all efficient (p. 6). I felt angry when Bob's 'cares' were done by the nursing staff when I was there...pushed out, not recognised as someone who has capabilities to look after their own child...it's like they know how to look after your baby better than you (p. 9).

(Int 5)

Edna: Depended who was looking after Molly, some [nurses] watched you more closely. Some didn't know we were capable of doing things. They tried to do everything...felt like I was being pushed out, like she was theirs... (p. 10). Sometimes I'd get irritated...

(Int 1)

Although the parents felt apprehensive about caring for their baby, they wanted to do as much as they could for him/her. They looked to the staff for support, encouragement and help, and appreciated when staff took the time to show them how to care for their baby rather than doing it for them. They also liked it and felt more at ease when staff asked for their advice and help about their baby's particular needs as Joan explains:

Joan: I was still...getting confidence with trying to get him comfortable. [A nurse] would say "I'll help you"...he would fall asleep just like that. I'd think I'm hopeless, why can't I do that with my baby. It was good when people would spend time and encourage you to do it rather than doing it for you...when they'd ask you, "What do you think is a good position for him to be in? "

(Int 5: p. 9-10)

The parents were frequently left with the feeling they were missing out because they could not be with their baby all the time. One mother described how she felt:

Joan: I remember ringing one night...The nurse was giving Bob a cuddle...I felt upset that I wasn't there doing it for him.

(Int 5: p. 10)

Preparing to leave the unit environment

Gardner and Merenstein (1993) and Samrall (1987) note that as the time for discharge from the NICU nears, preparation of the family is important. Discharge from the NICU is a time of mixed emotions for most parents. Salitross (1986) described how some parents find it difficult to believe their baby is judged 'well', and that they are now competent to look after him or her, which may cause ambivalent feelings about taking the baby home. All of the parents in this study were encouraged to develop their caring role by being involved in the care throughout their baby's stay in hospital. None of these parents described any feelings of panic on discharge from the unit. They were all looking forward to going home and were experiencing the realization that they would be caring for their baby on their own. One parent described what she found was the most frightening part of having her baby home:

Julie: The breathing was the scary part about taking John home. The apnoea mattress is good. I think it was more security for David and I than for John.

(Int 4: p. 6)

Despite the many ups and downs that Kate went through, her parents were very relaxed about taking her home. However, they did admit that perhaps they might have had some apprehension:

Beth: When we were driving home from the hospital [with Kate] I said to Hugh "this is the most natural thing in the world, been to hospital, had a baby, and coming home" - not like months later we're coming home...that night we never slept much...more highly strung up than you think.

(Int 2: p. 8)

Joan was realistic about her needs before taking her baby home. Although this was not her first experience of breast-feeding, she recognised the need for more time to ensure that her breast-feeding was better established before taking her baby home:

Joan: We needed time to learn mothercraft especially for feeding. I was

going to full breast-feeding from tube-feeding... (p 10). We were ready to go home (p. 11).

(Int 5)

Other parents just could not wait until their baby was home with them. They had had many weeks of caring for their baby in the unit and they felt ready to take him/her home:

Jim: From the time we went to level two we couldn't wait to get home... (p. 3).

Mary: Being with him in the unit prepared me. I was not scared having him home...you learn how to look after your baby especially because they were prem, it gave you more confidence... (p. 15). I'm not tired and stressed... and more mentally prepared for looking after a baby (p. 18).

(Int 3)

Edna: I could have handled going home earlier... The nurses left me alone because I knew what I was doing.

(Int 1: p. 10)

When a preterm baby is born it takes many weeks for the parents to adapt to this crisis. The parents stories have illustrated that this adapting to the crisis involves a process which each couple works through at their own speed depending on their personality, time to prepare, previous experience, the circumstances surrounding their baby's progress and the parents' support system.

In the previous four chapters, the parents have openly and honestly related their experience of having a preterm baby in a NICU. Reflecting on what implications this experience has for neonatal nursing practice, education and research, is the focus of Chapter Eight.

CHAPTER EIGHT

DISCUSSION

Introduction:

Phenomenology was the research method used for this study which examined parents' experiences of having a preterm baby in a NICU. Kretlow (1990) states that phenomenology offers one way of viewing the human experience of illness. Its descriptive nature provides a portrait of what being ill is like for the individual and his/her family, revealing implications for improving the quality of care that nurses provide. Family-centred care with the parents of the preterm baby being central to this process was the focus of this research. During the interviews for this study, the parents related incidents that they felt they would always treasure and also what for them were distressful episodes during the time their baby was in the NICU. Frequently, painful memories were uncovered that reflected the quality of care their baby had received.

Those who were caring for these parents' babies did not have the opportunity to participate in this study, therefore my reflection on neonatal nursing practice which results from the study is not a critique of the nursing and how this could be altered. Rather it is a reflection on developing neonatal nursing practice to help nurses to recognize when parents are struggling with all that is happening with them and with their baby, and to develop ways that nurses could assist these parents. Areas where further neonatal nursing education and research would be useful are also examined. The parents' loving, caring, concern for their baby was constant. This study weaves the parents' stories into a portrayal of the pathway their experience took them in their *loving vigil with their baby*. My research shows that parents, with a tiny sick infant face an existence that is reliant on hospital staff for their baby's every need, in an environment that is foreign to them. Common themes and issues experienced by the parents as they lived through a time of a loving vigil with their baby are illuminated.

The four data chapters follow the process through which the parents' experiences took them, and the headings of these chapters have been used to set out results of my study. This is followed by an examination of the strengths and limitations of the study and then, utilising the parents' data, ways of developing neonatal nursing practice have been set out and examples given where further research in the area of neonatal nursing could be useful.

Fostering positive experiences for the parents as they *struggle-within*

The theme struggling-within illustrates what the experience was like for the parents from the time of the mother's admission to hospital until the beginning of the baby's second week of life. All of the parents in my study were very open as they graphically described how they felt throughout the experience of their baby's hospitalisation in the NICU. Although they found their time in the unit was difficult, from the parents stories this first week was the most difficult.

The parents in my study were adjusting to the preterm delivery of their tiny fragile baby and to the strangeness of the environment. They varied in the psychological and physical time they had to prepare for the preterm birth of their baby. Prior to this experience, none of the interviewed parents had ever had a baby requiring hospitalisation in a NICU. Two of the couples had previously had a baby born full-term, and sadly another couple's baby had died immediately after delivery at 23 weeks gestation. However, these experiences were not helpful as they faced this early delivery of their baby. All of the parents were unprepared for the overwhelming event of giving birth to a preterm baby.

The parents' stories illustrated that nursing interventions at this emotionally vulnerable stage were extremely important because as well as helping the parents through the unexpected early labour and delivery of their baby, they also laid the foundations for subsequent interactions between parents and the staff. This finding is supported by Merenstein and Gardner (1993) who found that early comments and influential statements during this critical time can have lasting impressions in the minds of parents.

Although some of the parents had the opportunity to be shown around the unit before their baby was born, all the parents felt unsure about what was happening in this unfamiliar environment. They knew that their baby was going to be in the NICU for some months, being looked after by strangers who used strange equipment to help sustain their baby's life. Merenstein and Gardner (1993) point out that as the parents attempt to adapt to the unfamiliar environment, their fear can become heightened. They must learn a new language, establish trust in the staff, and accept their role in this setting (Siegel, 1982).

My research supports that of Miles et al. (1992) who found that parents may be so overwhelmed by the event that at first they may block any observable emotional responses. Initially, the parents felt numb, felt frozen, their emotions were raw and they would sit with their baby feeling scared and powerless to help. Gradually, as the numb feeling left them, they became more aware of their surroundings. Part of the parents' lived experience at this stage included a focus on the technology involved. The parents were in an environment that was totally foreign to them, surrounded by equipment and technology they did not understand and yet they knew this was vital for their baby's survival. They were constantly meeting staff who were essential to their baby's survival and to their feeling of safety and security for their baby. The parents differed in the length of time it took them to overcome this shock and to be able to begin asking questions and opening up to others. There was ongoing fear and anxiety.

All of the parents in my study wanted to see their baby as soon as they could. They were with him/her as often as possible and s/he was constantly in their thoughts when they were not able to visit. Seeing and holding their baby when s/he was first born was not the experience for most couples in this study. One mother waited in vain for medical information about her baby. When she could no longer bear to wait, she held onto her intravenous infusion and went to see her baby despite the fact she was prescribed bed rest because she had elevated blood pressure. Samrall (1987) points out that early contact with the baby, even if very brief, minimizes the parents' sense of loss and anxiety and fosters attachment.

All the parents in my research treasured the time they spent with their baby. In this early stage they waited with anticipation until the baby was stable enough for them to touch and to hold. If unable to visit they would telephone the unit for news of their baby. The parents described their initial reactions to the unit and the value of explanations to help them to feel more at ease about their baby's care and about the equipment being used. Samrall (1987) states that encouraging parents to visit frequently, to telephone to check on their baby, and to ask questions conveys to the parents the staff's desire to include them in the infant's care, and allows families to feel less impotent.

Valuing the parents' ability to *live-with-uncertainty*

The babies were in the unit for several months. During this time the parents were living with a sense of loss, heightened anxiety and fear. They were never completely reassured that their baby would be well enough to go home. They would watch their baby's progress and become anxious if there were no obvious signs of improvement.

The literature reviewed would suggest that feeling guilty is very common for these parents. My own clinical experience with parents of preterm babies would support this. However, none of the parents I interviewed spoke of feeling guilty. I recognize that phenomenology has not been previously used as a research method to elicit the feelings of parents of preterm babies, nevertheless, if guilt had been a concern, I believe it would have come out in the parents' stories. They did describe sadness about the preterm delivery, but for them the situation was seen as being inevitable and they were powerless to have altered the events. As each couple in my research told their stories, there was no noticeable difference between the mothers' and the fathers' feelings. McHaffie (1992) points out that, handled advantageously, a stressful event can lead to personal growth, while less effective coping may evoke new conflicts and a reduced state of mental health.

The parents I interviewed for this study developed strategies to help them to survive their ordeal. This finding supports Anderson (1981) and Barbarin and Chesler (1984)

who have reported a striving to maintain a sense of competency and mastery over having a preterm baby. Breznitz (1983) indicated that parents frequently attempt to promote normalisation processes, for example they continue to meet normal responsibilities and to show adaptive strength. The parents in my study found that visiting their baby, being listened to, being involved in their baby's care, knowing what to do to help their baby, seeing improvement in their baby, having hope, seeing their baby do normal things, keeping a diary about the day to day happenings with their baby and keeping busy with a daily routine helped them to survive what was happening with them and their baby each day.

Progress and deterioration of other babies became obvious to the parents and they compared their baby's progress with the other babies in the nursery. In the unit's foyer were photographs of babies who had been in the unit. Parents also compared their baby with these photographs of babies of the same gestation as their baby. Affleck and Tennen (1991) found that mothers evaluated their infants selectively on dimensions that made their own baby's condition seem relatively less serious. They found that those who were searching for information from which they could draw a comparison were usually comforted by what they learned. No difference was found between the mothers and the fathers in my research; all gained comfort and a sense of pride when they felt their baby was doing well.

The theme that emerged as the most talked about by the parents as a way of helping them to live with the uncertainty, was 'being kept informed'. Mishel (1983) described how clients want and need information because it is their right, it helps them deal with uncertainty and the anxiety associated with uncertainty and that it is imperative for developing future plans and making decisions. Nurses see the parents more than other health professionals do, and have a greater opportunity for assessing the parents' information needs to ensure immediate information and feedback is given. The parents in this study described how it was easier to get information from nurses as they were available, than it was from other members of staff on the other hand because often different nurses cared for the baby each day, informed, individualized information about their preterm baby was sometimes difficult to obtain. In my study the ability of the

nurse to assess the parents' need for information was shown to be central to evolving an individualized plan of family-centred nursing care.

The interviewed parents found that honest, clearly given explanations presented in a calm manner were reassuring. Informative reassurance is a purposeful, conscious and deliberate attempt to restore confidence (French, 1979; Teasdale, 1989) and reduce uncertainty (Boyd and Munhall, 1990). In this study the parents found that being given up to date information about their baby helped to reduce their sense of uncertainty and gave them a framework for understanding events around them at a time when they were extremely vulnerable and unsure.

The parents in my research study differed in their level of comprehension, preferences, and readiness for information. Although they needed information about their baby in order to get through each day, the parents were often reluctant to approach nurses because they were overwhelmed, and in some situations frightened of the replies they would receive. Very vivid examples were given by the parents of how avoiding, or not talking to them about their baby only added to their anxiety. The perception of nurses and parents about the kind of information that parents need can differ. One parent in my study pointed out that no-one would know what was important for the parent to know. Some did not want too many details and accepted small amounts of information at a time, without question, possibly as a means of coping with an otherwise overwhelming situation; others appreciated having the information repeated. Some felt able to ask questions reflecting their concerns about their infant's survival; this was especially evident after their baby had received medical attention, and when decisions were being made about treatment. This finding supports Perlman (1987) whose work indicates that parents particularly desire information about diagnosis and treatment, expected outcomes and causes of the infant's condition while in the NICU. The study also supports Bok's (1978) finding that staff shape parents' access to information about their baby, their understanding, and their interpretation of the information, and parents' ability to participate effectively in the decision-making regarding their baby's treatment.

All of the parents spoke emotively about their anxiety every time the telephone rang, or in anticipation of the telephone ringing in case it was the unit with bad news about their baby. The parents had no reprieve from their uncertainty and fear and their stories illustrate that they wanted prompt, direct, timely information and support.

The parents in this study saw the doctor as the authority figure in their baby's care, and they valued medical information and support. One father discussed how doctors gave critical information but that follow-up later, with more information, was sadly lacking. This parent gave a graphic example of the importance of following up all queries and explanations and described how he and his partner had lived in dread for several weeks. They became afraid to ask questions because of the answers they might receive. All the participants indicated that they would have appreciated regular meetings, especially with medical staff. Cave et al. (1985) and Holloway (1988) support the suggestion of group meetings between health professionals and families as a way to meet families' information needs.

Encouraging the parents to seek and gain support by *relating-to-others*

Reappraising a threatening experience as beneficial or gainful is a way in which people bring meaning to misfortune. The parents in my study recognised that the support of others was a major influence in their ability to adapt positively by giving them more time with their infant and thereby assisting in affecting the quality of their relationship with their baby. The interviewed parents claimed that this event brought them closer to their partner and other family members, taught them valued lessons about the priorities of life, enhanced their ability to empathize with others in need, engendered other positive personality changes, and caused them to see their baby as more precious because of his or her closeness to death. The parents' stories support Edwards and Allan (1988) who state that the opportunity for growth which may be evidenced by a stronger relationship between parents, siblings and extended family members is the positive outcome of the premature birth experience. When the baby survives, the parents may have a renewed sense of their own strength and ability to live with adversity and an increased confidence in their ability to parent.

Samrall (1987) discusses how the myth that sharing a crisis brings partners closer together ignores the fact that each parent caught up in his or her own pain may not be able to give emotionally to the other and the marital situation can rapidly deteriorate with resulting communication difficulties. This was not the situation for the parents in my research who all enjoyed a mutually supportive relationship based on open communication. Two studies support the findings of my study. According to Lieberman (1982) the marital relationship has a strong and consistent effect on the mothers' wellbeing, and Adams (1963) found that the father of the preterm baby was the primary source of support for the mother.

All the parents interviewed spoke warmly of the support they received from family and friends. My study supports Crnic, Rogozin, Greenberg, Robinson and Basham's (1983) study which demonstrated that mothers of preterm infants with more social support and less stress reported greater general satisfaction with life and increased pleasure and satisfaction in their role as parents.

Disappointingly, nurses were not seen by these parents as a major source of support. They saw a need for nurses to be aware of the importance of encouraging them and explaining how they could be involved in their baby's care. The parents were shown how to care for their baby, but frequently their confidence in their ability to do this was undermined when nurses carried out the baby's care when the parents were present. Some parents described how they felt pushed out, and at times, hopeless when the nurse was not willing to include them. Others felt that although they had been doing their baby's 'cares', they should not go ahead without asking the nurse first. The parents found this very frustrating and 'downputting'. They would have preferred to have been 'trusted' to carry out their baby's 'cares' once they had gained confidence in doing so.

The interviewed parents quickly recognized if the nurse caring for their baby had the necessary skills. If they did not trust the nurse they described how they would stay with their baby until the next shift. Some parents in my study felt so concerned about the competence of the nurse caring for their baby that they spoke to the person in charge to ensure that a nurse who had the necessary skills would be caring for their baby. This

research demonstrates the effect on the parents when their baby was cared for by a nurse in whom the parents did not have confidence. Benner and Wrubel (1982) found that the skill of the nurse gave confidence. Jolley and Brykezyinsko (1992) state that in order to be capable of demonstrating care and caring attitudes as a professional nurse, the nurse must first be a competent practitioner of nursing.

In this study the parents gradually understood what the equipment attached to their babies meant and came to rely on it. They would become anxious and quickly point out if a reading seemed to be different, or if a machine were programmed differently. They also quickly picked up when a nurse caring for their baby was not familiar with the equipment attached to their baby. Technical competence is extremely important, but this must be grounded in relevant nursing theory and always accompanied by critical analysis and continuous reflection on the efficacy of practice (Barber, 1991).

Helping the parents to *move-from-fear* and develop confidence in themselves and in others caring for their baby

Although the parents found various ways to feel secure in the environment especially gaining confidence in caring for their baby, nevertheless they never felt completely at home. Their anxiety and fear often resurfaced later in the baby's hospitalisation when they felt that the nurse did not listen to their comments about their baby's needs and possible changes in condition. By this stage the parents had come to know all the little things about their baby and it seemed to them that sometimes nurses did not value this knowledge. At times parents were given conflicting messages, sometimes being told it is good to touch their baby, other times that touching upsets and unsettles him/her. They found this 'interference' with the way they wanted to relate to their baby frustrating. Miller and Holditch-Davis (1992) found that assumptions cannot be made about how infants will respond to parents based on how they respond to nurses. Instead, these researchers point out that nurses need to evaluate infant responses to parents independently of their responses to nurses.

All the parents in my study enjoyed learning to relate to their new baby when nurses made it a positive experience. What is illustrated by the parents' comments is that nurses can affect the pleasure of the time that parents spend with their baby by the way they encourage or discourage the parents' interactions with their preterm infants. Sometimes, as Als, Lawhon, Brown, Gibes, Duffy, McAnulty and Blickman (1986) point out, nurses may restrict parental contact with their baby through concern about protecting preterm infants from overstimulation.

Caplan (1960) Kennell (1978) and Merenstein and Gardner (1993) point out that all childbirth produces anxiety and the preterm birth much more so as the parents are unable to cope alone and unresolved anxiety may lead to a poor mother-child relationship with many mothers of preterm babies feeling alien to their infants. They may not feel that the infant is really their baby making it easier to have feelings of rejection towards the baby. Pederson et al. (1987) describe how parents may be reluctant to form close attachments to a sick infant because of fear that the infant may die and also because they were unable to control their baby's care. This attempting to be a stranger to the baby was similar to the experiences of the parents interviewed. Not all of the parents in this study found it easy to get close to their baby. Some were too scared to get close initially because they were frightened, or because it was hard to realise that this was indeed their baby. All of the parents appreciated being able to be with their baby whenever they wanted and touching and/or holding their baby. They found it very confusing when some members of staff would 'allow them' to touch their baby and other staff members would encourage them to just look at their baby.

The parents gave many examples of the difficulty they had not being able to be with their baby all the time, and having nurses take over their parental role. Brown (1967), Greenberg et al. (1973), Seashore et al. (1973), Jeffcoate et al. (1979) and McHaffie (1990) found that maternal confidence was impeded by postpartum experiences such as separation, lack of contact and the birth of a preterm infant. Although in my clinical experience I have heard many parents comment that their preterm baby looks different from the baby they expected, only one of the interviewed parents discussed their baby's appearance.

Two mothers and one father interviewed for this study, described the lack of help given to breast-feeding mothers. The negative attitude of the nursing staff towards bottle-feeding mothers was emotively described by one couple. In this study, several of the mothers interviewed found that they had formed a bond with other mothers in the unit through sharing their experiences and gained support from one another for their decision to breast or bottle-feed. It was disappointing to hear one couple describe how they felt judged by staff when they made the decision to bottle-feed. Another mother described how she picked up a leaflet by chance and discovered that she had been trying to breast-feed her baby too frequently and he was getting tired with the result that he was unable to suck effectively. This study showed that parents felt confused with conflicting advice about breast-feeding, they felt judged if they decided to stop breast-feeding. It seemed to them that some staff members were not skilled in helping them with breast-feeding and they were left to 'fend' for themselves.

All the parents dreamed of the day when they would be leaving the unit and taking their baby home. Preparation for discharge was important to help the parents to feel confident. Although not all the parents were happy with the way in which parentcraft was encouraged, nonetheless, all of them felt they had been given the opportunity to gain confidence in caring for their baby. For one couple the date for discharge was very uncertain and changed at times because of this uncertainty. Marshall, Kasman and Cape (1982) state that preparation for discharge must be done with a consistent, well planned and documented approach. The findings of these researchers support the expectations of the parents in my study who were working towards a successful discharge.

This thesis demonstrated the value for parents of understanding and support from nurses and other health professionals and for more attention to the parents' feelings and opinions. The study brought to light an assurance that nursing practice would be enhanced through an increased awareness of the parents' ordeal if neonatal nurses let themselves open the door to the parents' experiences, even if they cannot enter through that door. The stories of the parents in my study would support McHaffie (1990) who interviewed mothers in a NICU with low weight babies and found that they needed someone who could be quiet and still, who would listen attentively without interfering,

who would be comfortable simply to be with the parents rather than preoccupied with activities. McHaffie (1990) argues that this is part of the nurses' role, and the findings from my study strongly support McHaffie's argument.

STRENGTHS AND LIMITATIONS OF THE STUDY

This study examines the experiences of five couples who had a preterm baby requiring hospitalisation in one NICU in New Zealand. The study findings are particular to those couples, and cannot necessarily be generalized to couples with preterm babies in another NICU. Although the sample is small, it is nevertheless appropriate for a phenomenological study. A qualitative method was chosen as the most appropriate way to conduct this particular study because the parents' experiences could be clearly captured with this method. A quantitative approach could also have been used to examine the parents' experiences but would have yielded a different kind of result in that the parents' actual stories would not be expressed.

The parents were all aware that I had nursing experience in a NICU. This had more advantages than disadvantages. It did not seem to detract from their openness, or willingness to discuss their experience, instead, my understanding of experiences similar to theirs, seemed to assist them in relating their stories. During the interview phase these parents were no longer reliant on the services of the unit except for outpatient appointments, and therefore trusted anything they said would not affect their baby's care.

Validation of the data was ensured by the parents reading the transcripts of their interview, and being asked to alter or add to their stories as they chose. Some parents did alter what they had said, some deleted passages of script which related experiences which were very intimate and personal, and others added further examples to illustrate their experiences. In keeping with my contract with the parents regarding confidentiality and anonymity, no parent had access to another's transcript and all records were given pseudonyms. This also meant that my reflections on the combined data would not be seen by the parents until completion of the study when a summation of the findings will be given to them.

The data recorded only what the parents said. Parents were not prompted except by the broad questions set out in Chapter Three p. 41. In keeping with the chosen research methodology, the parents were asked to recall past experiences and therefore there was potential for retrospective distortion. However, as the parents recalled their experiences they were real for them. Some of the parents appeared to relive the experiences as they related them.

Time and resource constraints meant that the first five couples who agreed to participate were accepted for the study. No consideration was given to the parents' age, race, socio-economic status, marital status or to the effect that these factors may have had on the parents' experience.

IMPLICATIONS FOR DEVELOPING NEONATAL NURSING PRACTICE

The New Zealand health system is putting resources into services only when there is a clearly defined need. My literature search did not reveal any New Zealand studies which examine parents' experiences in a NICU. The help required by the parents' of preterm babies to cope with their experience is not known and therefore no financial provision has been planned to ensure that adequate money and appropriately skilled personnel have been made available to aid these parents. From the findings of my research it can be demonstrated that recognition of the emotional needs of parents is worthy of further consideration and that this has significance for future development and improvement of neonatal nursing practice.

Several factors emerged as being important for the parents interviewed for this study. I have chosen to examine four areas that are relevant to current and future neonatal nursing practice:

Developing understanding and skill to assist parents to grow through the difficulties and the joy of having a preterm baby.

Giving the parents timely, appropriate information.

Providing consistent, competent nursing care.

Encouraging the parents as they bond with their baby.

Developing understanding and skill to assist parents to grow through the difficulties and the joy of having a preterm baby

My research demonstrates that to assist parents through the difficult experience of having a preterm infant, it is helpful to be able to identify the psychological tasks and to recognise the emotional reactions they experience. The direction provided by the nurse, and his/her understanding of the potential for the parents' growth during this period is critical.

The stories of the parents I interviewed showed that neonatal nurses need knowledge and understanding to be able to recognise and assess the parents' possible emotional reactions, their problem solving abilities and patterns of adjustment, so that these can be incorporated into the plan of care. These stories support Zahr's (1991) comment that nurses often base their support, interventions and teaching on observations rather than on the parents' feelings. Other areas illustrated by the parents' texts where neonatal nurses need further skills are in exploring their own ability to handle the parents' emotional responses, and conveying an attitude of acceptance and support towards the parents and extended family members. The neonatal nurses' appreciation of the uniqueness of each parent's approach to their preterm baby is essential. This understanding may enable the neonatal nurse to work more insightfully with parents, assisting them towards effectively adapting to the events following their baby's preterm birth. My study supports the findings of Miles et al. (1992) who point out that this should include both mothers and fathers with particular attention placed on the stress related to their altered parental role. Allowing parents to discuss their feelings may help them to live with the unpredictability.

Merenstein and Gardner (1993) state that in assessing families' reactions, it is critical to look at how they cope over a period of time. My study supports their finding that initially there may be a tremendous amount of upset, disruption, and upheaval within the parents and their family that eventually can lead to an improved functioning and a sense of growth and mastery. The key is how the individuals or families reorganize, how they return to a state of equilibrium, the coping strategies they are able to devise, and whether these coping strategies are adaptive or maladaptive.

The admission of a baby to the NICU has both immediate and long-term effects on the entire family. Careful observation, assessment and supportive care by the health care providers can improve family strengths and adaptive abilities. Family-centred nursing is the aim in the unit where the interviewed parents' babies were cared for. However, often there was no focused intervention for many of the parents/families. Crises were recognised and help given. There was no one person to help the parents with the emotional effects of having a preterm baby. Frequently this was left to the nurse who was caring for the baby for the particular duty. This nurse may or may not have had the opportunity to develop a helpful relationship with the parents. The barriers to family-centred care that the parents in this study experienced which have also been reported by Geary (1979), Siegel (1982) and Yoder and Jones (1982) include lack of time, lack of a systematic approach to the family as a unit of care and lack of knowledge and skills of how to deal with families in crisis.

Working with these families requires specific knowledge, skill and strength. Health professionals need to be willing not only to explain the facts, but also to listen and to recognise the 'pain' that families of preterm babies experience. The texts of the interviewed parents in this study support Fraley's (1986) statement that the observation and assessment of the reactions and behaviours of the parents of preterm babies is essential in assisting these parents to deal with the multifaceted complex problems and stress associated with their baby. Currently there is little guidance for neonatal nurses in New Zealand to effectively assess how parents are managing to live through the experience of having a preterm baby in a NICU. The care that is planned for the parents is often fragmented because several care-givers are involved and it is often based on the nurses' intuition, common sense or his/her own life experiences.

Giving the parents timely, appropriate information

Parents tend to see nurses more frequently than they see other health professionals. They have an opportunity to get to know nurses and to trust them to answer their questions. Neonatal nurses need to have clear communication skills and an awareness that the parents may have many unanswered questions. Although informative

reassurance is given with the intention of comforting the parents, sometimes they may continue to be bewildered. It is important for nurses to consider how much information is necessary, what kind of information is wanted and the best way to communicate this information. The nurse caring for the baby can comfortably tell the parents the known facts and what nursing care is being provided without giving any diagnosis, prognosis or medical forecast for the future course of the infant. As some of the interviewed parents pointed out, information is often provided within a short period of time, especially when the baby is first admitted, and there may be little opportunity for questions or clarification. This research shows that neonatal nurses need to spend time with parents to ensure they are meeting the parents' information needs and not projecting their own perceptions of those needs onto the parents, endlessly repeating what is already known, overwhelming the parents with unwanted details, or providing too much information too fast for assimilation.

It is also important to ensure that information is given to the parents as it is needed. As demonstrated by this thesis assessing readiness to receive information and ensuring that adequate follow-up is given with information are two areas which require increased understanding and skill. One way to assist this happening is by aiming for consistency of care for the baby. The nurses caring for the baby are then more likely to know what information has been given and to build on this appropriately because of the rapport they have had the opportunity to build up with the parents.

Providing consistent, competent nursing care

Difficulties for the parents were often increased when there was no consistency with patient care. To have continuity of care in practice as an essential pre-requisite component of effective nursing care would seem to be self-evident. However this is not always the practice in New Zealand neonatal units because of the ready acceptance by nursing management of the need for agency and casual nurses to 'make up the numbers'. This system is used because administrators consider it better allocation of resources to use nurses where there is a need. Rostering of nurses for a NICU is difficult because of the inability to predict requirements accurately. The high turnover

of nursing staff and the large numbers of part-time staff with their own family commitments means that, in practice, providing consistency of care for the babies and their families in a NICU is very difficult. Nevertheless, perhaps it is time to look at cost effectiveness in terms of quality of care - the cost to the baby and to the baby's family receiving care from different nurses every day.

In the NICU where the interviewed parents' babies were nursed, an extremely high turnover rate for nursing staff was accepted as the norm and this contributed to the parents' experience of being exposed to many different nurses during their baby's stay in the NICU. With high turnover of staff, usually less is known about the baby and the family by the nurses caring for the baby. There is also less time for the nurse to reflect on the nursing practice involved because his/her time and energy is being spent becoming familiar with the nursing care needed for that day. Evaluating the nursing value of regular unit staff compared with agency and casual staff has not been carried out and is long overdue, as demonstrated by the comments of the parents in this study.

Thorne (1985) pointed out that an inconsistent approach from staff does not encourage confidence and reported that mothers who carried out a procedure successfully one day were prevented from doing the same tasks by a different staff member the next day. The parents in my study gave many examples which support Thorne's finding. Continuity in the assignment of nurses to particular babies is one way to help overcome this. Neidig, Megel and Koehler (1992) state that by combining expert management, clinical knowledge and skills, nursing case management can ensure the delivery of the patients' care with efficiency and effectiveness and could be one way to ensure continuity of care and provide work satisfaction for nurses working in a NICU. All of the parents in my research study gave examples of how they valued consistency of nursing care. This thesis shows that neonatal nursing intervention needs to be planned where possible with the parents, and this is best carried out when the nurse knows the parents and understands how they are coping.

As well as the importance for the parents of consistency of care a significant outcome of my research was that the parents quickly came to recognise if the nurse had the necessary knowledge and skill to care for their baby competently. Helping the families to become confident in their role as parents is vital. Clinical knowledge constraints include work overload, staff shortages, a preponderance of inexperienced staff nurses and high staff turnover. High staff turnover and utilisation of agency nurses who vary in their neonatal nursing experience, gives rise to inconsistency in the amount and quality of care given to the babies and their parents. Consistency of care helps to promote competency of care, with increased knowledge about the baby's needs and how best to meet these and a development of trust between the parents and the nurse. Building up a relationship with the nurse can increase the support the parents receive and help parents to have more individualised, personalised family-centred care with increased likelihood of any difficulties they experience being recognized earlier. This also raises a question about measures of quality from the parents' viewpoint.

Staff shortages and a high proportion of inexperienced nurses due to the high staff turnover seems to be an ongoing difficulty in NICUs. Unfortunately the reasons for this have never been documented in the literature, but informal discussions with nurses reveal that incompatibility with family life and rotating shifts, maternity leave, overseas travel and wanting a change from the unit either because of its intensity or to get further nursing experience were common reasons for nurses leaving the NICU. In the unit where the babies in this study were nursed there were serious concerns about staff recruitment and this included searching overseas to Britain to interest experienced neonatal nurses to come to New Zealand to work. Disappointingly, the same effort and expense was not devoted to seeking ways to retain experienced neonatal nurses. Hospitals also face increased expenditure in time and money for orientation of staff. Further research examining methods for rostering of nursing staff in NICUs, methods for recruiting staff likely to remain working in NICUs, as well as ways of retaining existing neonatal staff would prove more helpful in working towards consistency of staff to provide nursing care and also assist in more prudent spending of financial resources.

Clinical knowledge development offers a means of job enrichment and retention of the experienced nurse (Benner & Wrubel, 1982). Currently in New Zealand, there is an effort towards developing the role of the neonatal nurse through an advanced course offered in Auckland and Hamilton for those nurses wishing to gain skills in managing the treatment of babies in NICUs. Successful completion of this course gives the nurse the title of Neonatal Nurse Practitioner, and qualifies him/her to carry out the work that would usually be delegated to Registrars in a NICU. The emphasis of this course is on the medical management of the sick neonate. Some nursing papers which are not specifically related to neonatal nursing have been included in the course and are taught at the Polytechnic. The emotional effect of the experience for the parents is not examined in this course or in Neonatal Intensive Care Courses currently being offered. It is either expected or assumed that nurses already have the skills to assist the parents of preterm infants through their emotional trauma. This study demonstrates the need to include in courses currently planned for neonatal nurses ways to assist parents cope with the emotional upheaval.

Encouraging the parents as they bond with their baby

Parents need to trust the nurse, to know s/he has the necessary skills to care for their baby and also to help them to learn and to feel confident caring for their baby. Neonatal nurses need to take the initiative to suggest various ways in which parents can enhance their self-esteem and confidence as they care for their baby. Both the mothers and the fathers in this study wanted to participate in their baby's care, and valued the caring activities as opportunities to meet and bond with their baby. Holding and caring for their baby were included in their most precious memories. This experience is supported by Minde, Shosenberg and Thompson (1983) and Nurcombe, Howell, Rauh, Teti, Ruoff and Brennan (1984) who found that providing education and support about infant care increased the mothers' confidence and may facilitate her caring for the preterm infant and her adaptation to the maternal role.

Darling and Darling (1982) and Miles and Carter (1983) state that parents' readiness to participate in their baby's care also requires consideration. Assessment of parents'

readiness to participate in their baby's care is a skill which usually relies on nurses' intuition and common sense. From my clinical experience and from the parents' stories this assessment requires more than common sense or intuition. Nurses need knowledge and skill to balance the stability of the baby's physical condition with helping the parents to get to know their baby, to gain a sense of security in their environment and to feel confident about carrying out their baby's 'cares'. Frequently in the clinical area I have heard neonatal nurses express uncertainty about determining how much 'handling' a small preterm baby can cope with. Some nurses, in a conscious effort to avoid compromising a small baby's physical stability, will actively discourage parents from touching their baby. From the parents' stories it is evident that parents picked up the uncertainty that the nurses were feeling. These parents wanted contact with their baby; they needed this to help them to live through their ordeal. They felt they needed to establish this contact as soon as their baby was born if his/her condition allowed.

Sometimes nurses need to recognise that they do not necessarily have the skills that the mothers may require. For example, others may have greater skills in assisting mothers to breast-feed their baby. A network of mother-to-mother support organized by and for mothers with backup from health professionals might prove helpful to avoid a negative experience for the mothers. It is interesting to note that groups such as the La Leche League, midwives and lactation consultants were not mentioned by the parents. If a support group were to be set up it is possible that the availability of mothers who have specific experience with preterm infants would be more acceptable and helpful than the current method of the mothers relying on the skill the nurse caring for their baby may have.

FURTHER NEONATAL NURSING RESEARCH

The initial feelings of the parents were affected by the way they adapted to what was happening to their baby, their ability to assimilate information, and how they were able to relate to their baby. Further research is needed to understand the variables that determine the nature of the earliest interaction between preterm infants and their parents and ways that parents could be helped to adapt to their situation. Also of value would

be examining not only how the parents interact with their infant during NICU visits, but also how they interact with each other and with staff members.

Development of their role as parents was very important for both the mothers and the fathers interviewed. Examination of the factors which assist them to feel confident in their role as parents would be helpful. How differences in the physical and psychosocial aspects of a variety of NICU settings affect the way parents adapt might be explored in further research.

My research examined how parents who were healthy young couples coped with their experience which had a positive outcome. Many parents of preterm infants are solo parents, and a significant number of older parents have a preterm baby. Some have the added stress of their baby suffering from a long term physical or mental disability. Studies examining the effect of a preterm birth on these groups of parents would be very useful in assisting nurses to help the parents to cope.

My study focused on the parents' ordeal while their baby was in hospital nevertheless, I recognise that the difficulties do not stop once the baby is discharged. Further nursing research is needed to examine how the stress responses surrounding the infant's hospitalisation affects parents after discharge. Although many studies have been focused on parenting the preterm infant after discharge, there has been little evaluation of how parental stress during hospitalisation may affect later parenting of the child (Miles et al., 1992).

The practising nurse is most likely to demonstrate clinical caring competence when s/he knows what to do because of adequate nursing knowledge relevant to the area of work, and provision of the necessary appropriate skills to assess, plan and deliver care and to function independently. Further research is essential to look at what is expert neonatal nursing care and how neonatal nurses can provide effective family-centred care.

CONCLUSION:

When normal circumstances change and their infant is born critically ill because of prematurity, parents are thrust into a crisis and are in need of special support and care. Miles (1989) states that during this crisis, parents must cope with intense and confusing emotions stemming from an unexpected delivery, concern about a sick infant, admission of the infant to a NICU, appearance of the preterm infant, grief from the loss of an ideal pregnancy and birth experience, and the need to communicate with many unknown health care providers.

These intense stresses, Perchudoff (1990) points out may lead to such difficulties as the inability to establish a satisfying relationship with the infant, a lack of desire to interact with the infant, and a perception of the infant as 'different' or 'abnormal'. Hawkins-Walsh (1980) determines that these problems can be prevented or minimized by reducing parental anxiety caused by the stressors of the NICU. The parents are likely to experience difficulty relating to their infant unless this anxiety is diminished.

Throughout this crisis, parents must call on all their existing defence and coping mechanisms (Shellabarger & Thompson, 1993). They must also develop new skills to help them face their shattered dream of a perfect, healthy infant and to help them adapt to the reality of the present situation. In many cases, the only people available to help the parents are members of the NICU staff. The parents require factual information concerning their infant, and they need caring support and understanding to help them cope with the fear and uncertainty of the situation.

Benner and Wrubel (1988) state that the flexibility and diversity of expert practice depends on making the interventions unique through care and involvement. Several areas in this study emerged as being valued by the parents. these include recognition by staff of the tortuous pathway the parents walk as they scale the heights and plummet the depths during the time their baby is in the NICU and awareness of the ways that will help parents for example, encouraging them to develop a bond with their baby, providing competent, consistent nursing care and ensuring that parents receive timely, appropriate information.

Further study into these areas as well as the knowledge and recognition of parental problems in coping with their baby's early birth will help reduce long term suffering and promote family health. Nurses learn the unimaginable courage and resilience of the human spirit from patients and their families. In the final analysis there can be no magical reassurances or bravado, only the acknowledgement that the suffering is real, that it cannot be completely erased.

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APPENDIX A: Information for prospective participantsSTUDY - PARENTS' EXPERIENCE OF HAVING A PRETERM BABY IN A NEONATAL UNIT

My name is Maureen Murphy and I am a registered nurse currently studying for the degree of Master of Arts at Massey University. As part of this degree I am undertaking a study of *Parents' experiences of having a preterm baby in a neonatal unit*. I am seeking your agreement to participate in this study which will be supervised by Valerie Fleming, Department of Nursing and Midwifery, Massey University.

If you agree to participate you would be asked to take part in one or two interviews in which you would be asked to describe your experience of having had a preterm baby in a neonatal unit. These interviews would take from one to two hours and would be held in a place and at a time which was suited to you.

You will not be asked to evaluate hospital personnel but to talk about what was important to you. Should you agree, I will audio-tape the interview and you will receive a copy of the transcript. Any material which you do not want in the final report will be deleted, and the tape will be returned to you when the study is complete.

You have the right to refuse to answer any particular question and to withdraw from the study at any time. You have the right to ask any further questions about the study that occur to you during your participation. All information you give will be completely confidential. All information will be collected anonymously and it will not be possible to identify you in the study or in any reports or publications that are prepared from the study. If you agree to participate you will be asked to sign a consent form. When the study is complete you have the right to be given access to a summary of the findings from the study.

Should you be interested in participating or should you require further information I may be contacted at [telephone number given] or my supervisor may be contacted at [telephone number given]. I look forward to hearing from you.

APPENDIX B: Consent to participate in research**PARENTS' EXPERIENCE OF HAVING A PRETERM BABY
IN A NEONATAL UNIT**

I/we have read the information sheet for this study and have had the details of this research explained to me/us. My/our questions have been answered to my/our satisfaction and I/we understand that I/we may ask further questions at any time.

I/we understand that I/we have the right to withdraw at any time and to decline to answer any particular question in this study. I/we agree to provide information to the researcher on the understanding that it is completely confidential. The information that I/we give will be included in the thesis and in selected publications in which I/we will not be identifiable.

I/we agree/ do not agree to the interviews being taped.

I/we understand that I we may view the transcript and delete any information I/we do not want included in the final report.

I/we hereby give consent to participate in the project: **parents' experiences of having a preterm baby in a neonatal unit.**

Name:

Signed:

Date:

Name:

Signed:

Date:

Researcher:

Date: