MAINTAINING EQUILIBRIUM: ALTERING MATERNAL PERCEPTIONS OF MOTHERING IN THE NICU

by

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CERTIFICATE OF AUTHORSHIP/ORIGINALITY

I certify that the work in this thesis has not previously been submitted for a degree nor has it been submitted as part of requirements for a degree except as fully acknowledged within the text.

I also certify that the thesis has been written by me. Any help that I have received in my research work and the preparation of the thesis itself has been acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

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ABSTRACT

The aim of this study was to examine the developing relationship between infants and their mothers when facing serious illness in the Neonatal Intensive Care Unit. (NICU) The complexity of the NICU environment is confronting for many families and may interfere with the quality of the developing parent-infant relationship.

This research is a grounded theory analysis of mothers' perceptions of their relationships with their infants. Symbolic interactionism provided the theoretical perspective for studying how mothers interpreted their world and how this interpretation influences their behaviour in the NICU. Mothers of 12 infants diagnosed with a congenital anomaly requiring surgery were interviewed just before discharge using an unstructured interview technique.

Data were concurrently collected, coded and analysed. Comparative analysis of data with previously collected data provided theoretical leads, which were then followed by interviewing participants who were thought to be able to shed light on emerging concepts. The choice of which mothers to interview next was therefore based on theoretical purpose and relevance.

The identified core category of "***maintaining equilibrium***" described the way in which mothers dealt with their predominant problem, identified as "preserving a relationship while enduring a crisis". Mothers endured this problem within the context of, the ***"diagnosis to discharge continuum"***. What emerged from this study was the level of anxiety mothers undergo during their journey from diagnosis of their infant's anomaly to discharge of the infant from hospital. This journey equates to a series of crises which they are challenged to overcome. Three mediating factors were found to impact on mothers' perceptions of their situation during each crisis event - "***interaction with others***", "***interaction with health system "*** and "***mother and infant interaction***". The way in which mothers managed each crisis event was able to be explained through the "***maintaining equilibrium***" process. Mothers were able to regain some control of the situation

which in turn enabled them to maintain contact with their infant and sustain their developing relationship.

Armed with this knowledge the neonatal nurse can potentially alter mothers' perception of the situation, thereby lessening the distress associated with the experience and facilitating the mother-infant relationship. Recommendations for practice have been described which surround the introduction of alternative models of practice which support the efforts of mothers to develop relationships with their sick newborns. In order to implement family-centred interventions, neonatal nurses require support through educational preparation and professional development.

CHAPTER ONE: BACKGROUND TO THE STUDY

INTRODUCTION

The birth of a sick infant is a time of crisis for mothers. Mothers' initial feelings of happiness are often overshadowed by feelings of impending doom. The neonatal intensive care offers little opportunity for mothers of sick infants to comfortably connect with their sick infant. The busy neonatal intensive care unit (NICU) replaces the mothers' envisaged quiet nursery.

The importance of the development of infant-parent attachment is well recognised (Bowlby,1969; 1982). However, the experience of mothers of newborns admitted to NICU for surgery remains poorly researched. This is specifically the case in regard to the developing relationship between mothers and their newborn .

This Chapter provides an overview of the environment of the surgical NICU within which this study was undertaken. The journey faced by mothers whose infants are diagnosed with a congenital anomaly is described. Factors which stimulated me to embark on the study are then briefly discussed. Finally the structure of the thesis is outlined.

THE NEONATAL INTENSIVE CARE UNIT (NICU) ENVIRONMENT

NICU's are specialist units providing care for infants admitted to hospital because of illness or premature birth. There are nine NICUs within New South Wales (NSW), the majority of which are attached to high risk maternity units, primarily caring for infants with a medical diagnosis. Premature infants constitute the bulk of admissions to these units. Three units within the state accept infants requiring surgery. Grace Centre for Newborn Care (GCNC), where the study is located, is the largest neonatal surgical unit in the state.

GCNC resides within a children's hospital and while it is not attached to a maternity unit, it is geographically close to a high risk maternity unit in the adjacent adult hospital. Unlike most NICUs within the state, infants admitted to

the GCNC are all transported into the unit from other facilities. The majority of admissions are infants born with congenital anomalies requiring surgery within the immediate future.

The environment of the NICU is one of high activity. Paralysing and analgesic agents may be given according to the severity of the infant's condition, therefore the infant may appear unconscious and unresponsive to mothers. Emergency procedures are routine and require high staffing levels. Consultant medical teams from numerous specialist areas in the hospital review patients regularly, adding to the flow of human traffic through the NICU, which affords little privacy to mothers.

NICUs, along with other areas of healthcare, are experiencing a shortage of experienced nursing staff. This chronic staff shortage has increased the demand for NICU beds. As a consequence infants may be moved out of the NICU to special care nurseries or other wards within a week of major surgery.

Along with technological and clinical management advances, a change in clinical practice moving away from task-orientated care to the provision of developmentally sensitive family-focused care has occurred. The philosophy underlying this change is the provision of an environment which supports the psychological and developmental needs of families and their infants (McGrath, 2001). This change, which has occurred in NICUs throughout the world, is slowly occurring within Australia. One of the most important objectives of this change in clinical practice is to support caregivers in becoming more responsive to the infant's cues that signal their particular needs are not being met. Paying attention to these cues enhances the interaction between the caregiver and the infant as the infants' needs are met. This will result in caregivers being more attuned to the infant's needs, thereby enabling them to provide appropriate levels of stimulation.

THE JOURNEY MOTHERS FACE

The context within which this study is set is the journey faced by mothers whose infants are diagnosed with a congenital anomaly, either in the antenatal or postnatal period.

Commonly the preliminary diagnosis is established between 16 and 20 weeks gestation, during routine antenatal ultrasound examinations. Usually the body system affected is accurately identified; however, the extent of the anomaly may be difficult to ascertain by ultrasound. The diagnosis is explained to mothers by either the ultrasound technician or the obstetrician and mothers are usually then referred to a consultant specialist for confirmation and discussion of prognosis. As the prognosis may be difficult to estimate until birth when the extent of the anomaly is known, mothers who have received an antenatal diagnosis view the birth experience as a particularly significant event.

Alternatively, postnatal diagnosis occurs at birth or within the first two weeks of the newborn period, often as the result of deterioration in the infant's physical state, which is frequently an acute episode requiring emergency response. While this is also a highly significant event for mothers, they are not burdened antenatally with the knowledge that the child will be born with a condition needing immediate surgical treatment.

In both antenatal and postnatal diagnoses, the interval between birth and surgery varies according to the type and extent of the anomaly. The infant may be taken to surgery immediately at the time of birth or later after stabilisation. In some instances the infant may require more than one surgical intervention for full correction to be achieved.

Opportunities for mothers to interact with their infant between birth and surgery will also vary. While some mothers will have an opportunity to hold and feed their infants once they are stabilised, other mothers will only be afforded a fleeting glimpse of their infant before surgery. In the case of immediate surgery it is usually the male partner who accompanies the infant with staff to the surgical NICU and then to the operating theatre. Since his female partner is often physically weak from recent delivery he usually takes on the role of decision maker at that point. The mother remains in the maternity unit to recover before she makes the trip across to the NICU. She is usually alone with maternity staff during this time.

After 12 to 24 hours mothers are often in a better condition to accompany their infants to surgery along with partners and staff. Mothers are able to accompany their infants to the outer admission area of the operating theatre where they are parted from them. After surgery the infant may be returned to the NICU or to the Paediatric Intensive Care Unit (PICU) if they have undergone open heart surgery. Managing infants who have undergone open heart surgery in the PICU was the preference of the cardiac surgeons when the hospital relocated in the 1990s to its current location. Prior to relocation, there had been a dedicated cardiac intensive care unit which employed specialist cardiac nurses. After the hospital relocation to its current site, these nurses were all transferred to the PICU.

Consequently this group of newborn infants continue to be cared for in a mixed PICU for the initial post operative period while acutely unstable. They are then transferred back to the NICU unless beds are unavailable. Alternatively, when beds are unavailable in the NICU, they may be kept several days longer in the PICU and then transferred to a hospital ward. Obviously in the latter situation when infants are transferred to the PICU in preference to the NICU, mothers will be exposed to a different hospital culture.

The experience of the post operative convalescent period for mothers differs according to where their infant is admitted. If they have originally been returned from theatre to the NICU, they will convalesce in the extended care area of the unit. Staff, routines and the culture remain the same. Infants are usually transferred to home or to a unit close to their home when their condition allows. However, if they remain in PICU for an extended period and are then transferred to the ward, they are exposed to two very different staff pools, routines and cultures.

The experience for mothers will also be considerably different when the infant remains hospitalised for an extended time. An extended hospitalisation will occur if the case is complicated by the discovery of additional anomalies. Alternatively, convalescence may become complicated by the infant's inability to progress to

full enteral feeding. In both situations these infants are seen by health workers as not requiring the physical support of a high dependency unit.

The average length of hospital stay for newborn surgical patients has shortened over the past 10 years because of the increased technical expertise of healthcare teams and advances in technology. Newborns who would not previously have been offered care in the NICU are now being successfully treated. Critically ill infants, who 10 years ago would have undergone several procedures, are now undergoing a single procedure and recovering over a shorter period. A higher patient acuity has occurred as a result of these advances.

STIMULUS FOR THE STUDY

I have worked within the specialty of neonatal intensive care for many years, undertaking tertiary studies in neonatal intensive care nursing, developmental care and infant mental health. My interest in the parent-infant relationship in the acute care area began in the 1980s as a beginner neonatal nurse undergoing hospital based training. Over the years, I have marvelled at the ability of mothers to weather the demands of the NICU.

One aspect which particularly interested me was the emotional connection between mothers and their newborns. How did this develop within the context of the NICU? We acknowledge love, nurturance, and emotionally responsive care from a primary caregiver as essential for normal, healthy infant development. Attachment is a term developed by Bowlby (1969; 1982) to describe a pattern of interaction that develops over time as the infant and caregiver interact, particularly in the context of the infant's bids for attention and comfort. Bowlby described infants as being biologically predisposed to use their caregivers as a secure base while exploring the environment. When the infants feel threatened they will turn to their caregiver for protection and comfort. Over the first year of life, the caregiver's response helps develop the attachment relationship into a pattern of interaction.

Secure attachment in infancy was long ago determined a protective factor in early development (Bowlby, 1982). Attachment research has led to a deeper

understanding of the early caregiving relationship, of how it supports the infant's early development, and how characteristics of the relationship are incorporated into the infant's sense of self, influencing subsequent relationships (Sroufe, 1996). The quality of the parent-infant relationship has far-reaching ramifications for the infant, family and society in general.

As a neonatal nurse, I expected to find positive interaction between parent and infant continuing after discharge, thereby enhancing the parent-infant relationship. I had been a long-term supporter of the move to change the focus of clinical practice from tasks undertaken in the NICU to the relationships developed between caregivers and the infants in their care, I was concerned regarding the apparent lack of progress being made within Australian NICUs toward developmentally sensitive family-focused care. I was therefore keen to examine parent infant interactions within the NICU more closely in order to develop practical strategies to facilitate this change in clinical practice, thereby enhancing the parent infant relationship. This provided the stimulus for this study.

STRUCTURE OF THESIS

This thesis is presented in eight chapters. The first chapter provides an overview of the environment of the surgical NICU and the challenge faced by mothers whose infants are diagnosed with a congenital anomaly. Factors which stimulated the study and the structure of the thesis are outlined.

Chapter Two provides details of the literature review undertaken prior to the study. Themes identified within the literature include: newborn surgery; parental experiences of the NICU; the parent-infant relationship and interventions developed to facilitate parenting.

In Chapter Three a discussion surrounding the theoretical perspective of symbolic interactionism and the study procedures undertaken in the grounded theory methodology chosen for the study are included A description of the data analysis process concludes this chapter.

Chapter Four presents the study findings. The main problem for participants is identified as "preserving a relationship while enduring a crisis".

The ways in which mothers overcome this problem are explained within the basic social process of "maintaining equilibrium" in Chapter Five. Chapter Six concludes the results with an extensive discussion of the mediating factors involved in this process.
Chapter Seven compares the findings of the present study with those of other relevant theories. The thesis is concluded in Chapter Eight which outlines implications of the findings and recommendations for practice. These surround alternate models of practice and educational strategies.

CONCLUSION

The developing parent-infant relationship may be at risk within the context of the NICU. Mothers whose infants are admitted to the NICU may understandably be fearful of harming these infants and feel unsure about how to respond to the infant in meeting their needs. Mothers may feel that the usual ways of showing care to their infant are not available to them. Clinicians are preoccupied with life-sustaining measures so that developmental and attachment needs of the infants in their care are often given low priority. As a result many of these infants, while receiving state-of-the-art medical care, are at risk of being deprived of the emotional care that is also necessary for life.

My goal upon embarking on this study was to examine, in particular, the experience of mothers and their developing relationship with their infants who had been admitted to NICU requiring surgery for a congenital anomaly. The expected outcome was further insights to the developing relationship between mother and infant that would inform recommendations for neonatal nursing of strategies that would facilitate the development of the parent-infant relationship.

CHAPTER TWO: LITERATURE REVIEW

INTRODUCTION

This chapter presents an overview and evaluation of literature relevant to the area under investigation: the experience of mothers regarding their relationship with their infants requiring surgery for a congenital anomaly.

A literature search was carried out through CIAP - Cumulative Index of Nursing and Allied Health (CINAHL), Medline, PreMedline, PubMed, PsychInfo and the Cochrane database of systematic reviews. The search included the following search terms pertinent to the substantive area; newborn, infants, mothers, NICU, neonatal surgery, developmental care and mother-infant relationship. The search was limited to research published 1960 – 2005. This broad range was chosen to permit the inclusion of noteworthy research which I was aware had been undertaken in other health disciplines, such as psychology and occupational therapy in the 1960s – 70s. Themes within the literature are discussed individually under the following headings: newborn surgery; parental experiences of the NICU; the parent-infant relationship and interventions developed to facilitate parenting.

NEWBORN SURGERY

Current research on newborn surgery has focused predominantly on clarifying questions regarding clinical practice issues (Barford, Rentz & Faix, 2004; Chow, 2002; Gould, et al., 2003; Tiffany, Burke, Collins-Odoms & Oelberg, 2003; Victory, Penava, da Silva, Natale & Richardson, 2004). Studies included those researching issues such as care of umbilical catheters (Chase, 1999; Ginsberg, 1995; Green &Yohannan, 1998) and the management of sepsis (Boyd, 2001; Griffin, Moorman, 2001; Heimler, Nelin, Billman, Sasidharan, 1995; McKenney, 2001). The second major theme identified about newborn surgery was the advance in technology which has resulted in the development of new strategies to treat specific congenital anomalies (Sandberg, MaGee & Denk, 2002; Wernovsky, Shillingford & Gaynor, 2005). A substantial number of these studies dealt with

surgical techniques developed to treat congenital cardiac anomalies (Boettcher, et al., 2003; de Ferranti, et al., 2004; Hovels-Gurich, et al., 2002; Uzark, et al.,1998). However, no studies were found concerning the effect of neonatal surgery on the parent-infant relationship.

A single grounded theory study was found that discussed the long-term effects of parenting a child with congenital cardiac disease (Sparacino, et al., 1997). The aim of the study was to provide a better understanding of parents experiences of their children with congenital heart disease through adolescence and young adulthood. The study was of interest as researchers did identify several themes relevant for mothers with infants requiring surgery. These themes surrounded the dilemmas of normality, disclosure, uncertainty, illness management, social integration versus social isolation, the impact of illness and coping. While the study did not focus on the relationship between parents and their children, there was acknowledgement of the emotional distress involved for mothers of children diagnosed with congenital cardiac anomalies.

PARENTAL EXPERIENCES OF THE NICU

The stressful nature of the technical environment of the NICU has been well documented (McGrath, 2001; Miles & Holditch-Davis, 1997). The literature search revealed the most often reported aspects of the parental experiences of the NICU were stress and coping and parental participation in care. Studies reporting on stressful aspects of the neonatal intensive care experience are those which attempted to identify stressors and those which dealt with various aspects of the NICU environment (Meyer, et al., 1995; Miles, Funk & Kasper, 1992; Miles, Funk & Carlson 1993; Shields-Poe & Pinelli, 1997;Young, et al.,1997).

The birth of an infant requiring admission to NICU can be an extreme shock for parents (Chapman & Costello, 1998; Miles, et al., 1992; Nystrom & Axelsson, 2002; Shields-Poe & Pinelli, 1997). The possibility of a prolonged hospitalisation is potentially worse (Wereszczak,Miles & Holditch-Davis, 1997), as parents on discharge feel less confident about their ability to parent the NICU graduate (Griffin,Wishba & Kavanaugh, 1998; Kenner & Lott, 1990; Shields-Poe & Pinelli, 1997). Sources of parental stress identified within the literature included

pre-existing and concurrent personal and family factors, prenatal and perinatal experiences, infant illness, treatments, and appearance in the NICU, concerns about the infant's outcomes, loss of the parental role, and healthcare providers (Holditch-Davis & Miles, 2000). These factors alter parenting opportunities and impact on parental perception of their ability to care for their newborn (Goldberg, Morris, Simmons, Fowler and Levisohn, 1990; Griffin, et al.,1998; Kenner & Lott, 1990; Miles, Holditch-Davis, Burchinal & Nelson,1999).

However, the highest source of stress was the infant's medical problems, followed by worry about whether the infant would be normal, when the infant could come home, and whether they would always be sick. The delay in taking on parenting responsibilities results in extended emotional and psychological stress that may lead to the postponement of mothers becoming emotionally attached to their infants at the time of discharge, and may contribute to greater parenting risk (Affleck & Tennen, 1991, Huber, Holditch-Davis & Brandon, 1993).

The majority of studies focusing on parental stress in the NICU have only reported on maternal distress. Fathers have been under-represented in previous research samples. Presumably, this lack of representation is due to the increased accessibility of mothers compared to fathers (Franck & Spencer, 2003). The lack of research regarding father stress is disturbing when attempting to support families since the father is in an especially vulnerable position. Fathers may be unprepared to take on a primary caregiver role, they may feel intimidated by female staff and, although expected to assume a focal role, may require comfort themselves.

Both parents experience high levels of emotional distress considerably above normal values; however, the stress and anxiety experienced by mothers appears to be greater than that of fathers (Doering, Dracup & Moser, 1999; Shields-Poe & Pinelli, 1997). Increased levels of maternal emotional distress in comparison to paternal emotional distress may be related to longer time spent by mothers in the NICU, and biological or social role differences between mothers and fathers. In addition, studies investigating parental coping showed that there are similarities and differences in the types of coping strategies used by mothers and fathers (Hughes, McCollum, Sheftel & Sanchez, 1994).

A study undertaken by Miles, et al. (1999) indicates that, along with distress, mothers may, however, experience growth as a result of their medically fragile infant's illness. Personal growth may be the outcome of struggling with a serious life event such as illness. Maternal characteristics of personal sense of mastery, maternal education, satisfaction with family, and maternal illness-related distress, hospital environmental stress and worry about the child's health influenced maternal distress. These findings support a model of stress that suggests that personal, family and situational factors influence outcome in a stressful situation (Lazarus & Folkman, 1984; Schaefer, 1991).

Mothers of infants admitted to the NICU may already be experiencing challenges and are then faced with a medically fragile infant at risk of adverse outcomes. Parental perception of their infant's illness has been reported as the most powerful variable associated with stress. (Docherty, Miles & Holditch-Davis, 2002; Miles & Holditch-Davis, 1997). Variables statistically significantly correlated with stress were reported as trait anxiety, desire for the pregnancy, and where and when parents first saw the baby (Shields-Poe & Pinelli,1997). However, maternal psycho-emotional state prenatally was reported as being related to post delivery distress, a factor which had not previously been identified.

Several studies have been undertaken to examine the coping strategies of parents whose children were admitted to paediatric intensive care (Miles & Carter, 1985; Meyer, Snelling & Myren-Manbeck, 1998). Seideman, Watson, Corff, Odle, Haase and Bowerman (1997) conducted a study to identify parental perceptions of their stress and coping experiences. The authors compared 20 parents of children in the PICU with 31 parents of infants in the NICU. Parents in both units experienced the most stress from alteration in their parenting role and in their infants' behaviour and appearance. Parents of children in the NICU found emotion-focused coping more effective than parents of children in the PICU. Acknowledging that parent behaviour may be reflective of the emotional distress they are experiencing makes their behaviour more predictable. This knowledge could positively influence the way in which staff interact with parents.

Very little is known about the ways in which parents cope with the stressful environment of the NICU. A single study was found examining the coping strategies of parents of infants admitted to the NICU (Hughes, et al.,1994). Although this study is over 10 years old and may not reflect current parental coping strategies, it was noteworthy in that it identified over one hundred different coping strategies used by parents in the NICU. The most commonly reported strategies were positive communication-social support, escape-avoidance, relying on religious faith, crying, taking care of oneself, focusing on the infant, generic emotion-focused strategies, and generic problem solving.

Parental participation in care in the NICU varies enormously. Often mothers complain about a lack of information and of being given conflicting advice which affects their ability to participate. Coyne (1995) undertook a literature review of parental participation of care and reported that parents are often unsure of staff's expectations and may perceive the role differently to healthcare workers. Interestingly, Coyne (1995) reported that parents became more assertive with increased experience. Coyne's (1995) review revealed that some nurses felt threatened by parents who wished to undertake tasks seen to be within the realm of nursing but were happy for parents to attend to the traditional mothering duties. The decision regarding the level of parent participation seemingly as being up to the discretion of the individual nurse supported the findings of Miles, Funk and Carlson (1993).

Singer, Salvator, Guo, Collin and Lilian (1999) reported a longitudinal study comparing maternal psychological distress and parenting stress between mothers of high risk and low risk very low birth weight infants with a term control group. This longitudinal study researched a prospectively recruited sample of 329 infants followed up to three years of age. A number of validated tools were used for assessment. The major outcomes of the study illustrated that the different parenting patterns displayed by parents depended on their infant's medical risk, age and developmental outcome. Initially no difference in high and low risk groups was found. Both groups displayed high levels of psychological stress. At the initial assessment at eight and then at twelve months they were the same as other groups. However, by two years mothers of high risk babies displayed more

distress. The implication of this study is that psychosocial supports should be provided for high risk groups for extended periods.

Parental involvement and visiting patterns are relevant to the provision of family-centred care. The results of the study by Franck and Spencer (2003) support the theory that mothers may be faced with competing needs of infant and other siblings and husbands. It is well recognized that most mothers visit more often than fathers (Franck & Spencer, 2003). However, little has been done in terms of reviewing fathers' participation in the care of the NICU infants.

THE PARENT INFANT RELATIONSHIP

Many variables impact on the parenting behaviour of families of newborns admitted to the NICU (Browne & Talmi, 2005; Strathearn, Gray, O'Callaghan & Wood, 2001). Traditionally, the work of the NICU has been focused simply on the infant's physical wellbeing with little attention given to the infant's developmental and emotional wellbeing. Infants are separated from the expected intimate parent and family environment when admitted to an intensive care unit. Previous work suggests that such separation may interfere with the quality of the developing parent-infant relationship and the subsequent quality of the attachment relationship (Bialoskurski, Cox & Hayes, 1999; Tilokskulchai, Phatthanasiriwethin, Vichitsukon & Serisathien, 2002).

Numerous studies confirm that mothers whose infants have been admitted to NICU do experience greater levels of psychological distress which consequently places the parent-infant relationship at greater risk (Franck & Spencer, 2003; Papousek & von Hofacker, 1998; Strathearn, et al., 2001). It was understood that the parent-infant relationship was not simply a one-way street with the parent feeding into the infant but rather that the infant had the capacity to respond to and elicit stimuli. These studies were undertaken by researchers such as Pretchl (1974), Brazelton (1973) and Als (1979, 1983). As a result the research focus changed from studies of individual infant behaviours to examination of the patterns of early social behavior and their development in the context of the earliest social relationship – the mother–infant dyadic interaction (Shaffer, 2000). Studies of reciprocity and detailed analysis of the structure of parent–infant

interactions and the link between the quality of early parent–infant interactions and later developmental outcomes were undertaken (Crnic & Greenberg, 1983; Goldberg & DiVitto, 1995)

The work carried out in the 1960s and 1970s surrounding the hospitalized child advanced the understanding of 'attachment theory' and emphasized the protective function of the caregiver providing a 'secure base' and the foundation of infant's emotional ties to parents (Ainsworth, Blehar, Waters & Wall, 1978; Bowlby, 1969). Growing understanding of the importance of early contact stimulated rapid acceptance of the bonding theory and led to changes in the delivery of newborn care in maternity hospitals. Particular emphasis was placed on keeping newborns with their mothers. Hence mothers of healthy newborns were encouraged to participate in their care within the maternity units. However, this philosophy was not extended to sick infants nursed in the NICU at that time. Practice change acknowledging the importance of the parent-infant relationship has been slow to develop in the NICU.

Secure attachment is associated with the expectation that the caregiver will be effective in restoring psycho-emotional homeostasis (Sroufe, 1996). Negative patterns of interaction result from either the mother or the baby being unavailable to the other within the relationship. Families under acute stress are often dysfunctional and are therefore at higher risk of being emotionally unavailable to their baby. Distressed mothers are more likely to have impaired interactions with their infants. Robinson, Eyeberg and Ross (1980) suggest that abnormal baby behaviour and conduct problems in toddlers is a manifestation of parent-infant interactions.

Singer, Fulton, Davillier, Koshy, Salvator and Baley (2003) evaluated the relationships of high risk babies and maternal psychological distress symptoms to maternal-infant behaviours during feeding using a standardized feeding tool. A literature review of maternal infant interaction was included. The review considered both maternal and infant factors which impacted on the developing relationship. Singer, et al. (2003) supported the theory of multiple contributory risk factors to infant developmental outcome. The paper highlights, as have other

studies (Bakeman, Adamson, Brown & Eldridge, 1989; Singer, et al.,1999), the importance of ongoing maternal support external to the hospital setting for mothers of high risk infants beyond the immediate postpartum period.

There has been a great deal of work on attachment research and theory, including the long-term attachment outcome in the premature infant population (Bialoskurski, Cox & Hayes, 1999; Salisbury, Law & Lester, 2003). In the acutely ill population reviewed by Bialoskurski, et al. (1999), the process of attachment formation was found not to be automatic but rather an individualized process. Bialoskurski, et al. (1999) concluded that attachment may be dependent on the health status of the infant and the mother, environmental circumstances and on the quality of nursing care.

Tilokskulchai, et al. (2002) undertook a descriptive study to explore attachment behaviours demonstrated by the mothers of premature infants. However, the mean gestational age of this population of infants was 34.5 weeks and would therefore not be representative of the most acutely ill population of the NICU. Maternal attachment behaviours were confined to verbal and non-verbal behaviours and rarely involved eye-to-eye contact. Tilokskulcha, et al. (2002) illustrated the vulnerability of mothers in special care and NICUs (feeling that they required permission to connect with their babies restricted opportunities for contact). The authors provided a good literature review and discussion of attachment behaviour.

The quality of the maternal-infant relationship has been conceptualized as an important mediating variable between prenatal events that result in biological risk and the later developmental outcome of the baby (Bakeman, et al., 1989). Despite this given importance, the only studies found focusing on the developing parent-infant relationship in the NICU were concerned with intervention programs such as the NIDCAP program (Als, 1986; Ladden & Damato, 1992; Liaw, 2003).

INTERVENTIONS DEVELOPED TO FACILITATE PARENTING.

Traditional care in NICU has centred on the physical wellbeing of infants leaving the mothers' psychological needs unmet. Admission to the NICU is particularly stressful for parents, leading to chaos in most aspects of their lives and a need for psychosocial

support. Healthcare professionals have attempted to prevent these negative effects by encouraging parents to visit frequently, breastfeed, and interact with their infants (Meyer, et al., 1994; Tarabulsy, Tessier, Gagnon, & Piche, 1996). However, the experience of admission to a NICU continues to exert a negative effect on the acquisition of parenting skills and may potentially alter the attachment process. NICU practice guidelines often include family presence and participation: but this philosophy is not evident in routine clinical practice (McGrath, 2001).

Mothers need interventions that reduce stress and help them achieve their identity as mothers. They experience a great deal of stress related to seeing their sick child undergoing treatment, the overall sights and sound of the hospital environment and the alteration of the expected maternal role (Miles, et al., 1999). Mothers may continue to need help through reflective debriefing regarding their recall of these stressful experiences post discharge. Over the last 20 years there has been a move amongst neonatal health professionals to provide NICU based parent support programs to address the comprehensive needs of NICU families. Provision of a parent support program has been identified as a key principle of family-centred newborn intensive care (Gale & Franck, 1998; Harrison, 1993).

Parent support groups have traditionally been established within the NICU environment. Group support meetings were used for the provision of information and emotional support. Positive outcomes from such programs have been reported (Bracht, Ardal, Bot & Cheng, 1998; Minde, et al., 1980; Shosenberg ,1980). However, there has been a move from health professionals toward one-to-one parent support programs. As all mothers may not be comfortable in a group setting, a program which matches veteran parents with new NICU parents may be more appropriate (Jarrett, 1996; Lindsay, et al., 1993). Individual NICUs continue to use a combination of support programs; however, parent peer programs have been found to be effective in providing new NICU parents with the emotional, informational, and maternal role support they require throughout their infants' hospitalization and after discharge home (Jarrett, 1996; Lindsay, et al., 1993; Preyde, Ardal & Bracht, 2003).

Studies undertaken to evaluate NICU parent support programs remain limited (Bracht, et al., 1998; Jensen, 1999; Cherniss & Cherniss,1987; Preyde, et al., 2003). Findings suggest that one-to-one parent support, in a nurse-managed program, may influence maternal and maternal-infant interaction outcomes. This is an area of research which requires extension as data would provide information on the benefits and limitations of individual programs.

Infants admitted to the NICU are accepted to be at greater risk of social, cognitive, linguistic and behavioural disturbances and are also at risk for auditory, visual and neurodevelopmental deficits (McCormick, 1993; Young, et al.,1997). McCormick (1993) reported that children who did not have apparent neurological or cognitive deficits, as infants in the NICU, also experienced a relatively high incidence of problems in information processing and attention-related deficits at preschool and school ages. The consensus in the literature (Als, 1995; Als, et al., 1996; Harrison, 1993; Kleberg, Westrup & Stjernqvist, 2000) is that the stressful nature of the intensive care environment contributes to these problems. The resultant stress placed upon infants has become a focus for staff and families alike.

There has been much written regarding the various programs which have been developed specifically to enable staff to work with parents in an effort to improve the parent-infant relationship. The underlying concept of these programs is the provision of developmentally supportive care that is family-centred. The programs emphasize parent-professional collaboration in an effort to support family members in developing positive relationships with their infant which will in turn facilitate secure attachment. The Assessment of Preterm Baby Behaviour scale (APIB) and the Newborn Individualized Developmental Care Assessment Program (Als 1979: Als,1982: Als, 1983: Als & Gilkerson,1995 & Als, et al.,1996) are examples of relationship-based, developmentally supportive programs for parents of newborns

Fowles (2005) reviewed the Neonatal Behavioural Assessment Scale (NBAS) program, which provides training in the assessment of the infant in interaction with the environment and the examiner and is not simply a physiological

assessment of the baby alone. The NBAS can be used as an intervention for the purpose of sensitizing parents to their baby's uniqueness and to promote positive parent-infant relationships. Women who witnessed the NBAS demonstration viewed their infants as more predictable. Similarly Als and co-authors (1995; 1996) have written numerous papers on the Assessment of Preterm Baby Behaviour scale (APIB) and the Newborn Individualized Developmental Care Assessment Program. The NIDCAP program, while similar to the NBAS focuses on the sick and premature newborn rather than the healthy term baby. Despite the recognised need for these programs, there is a lack of research investigating the effect of these programs on mother-infant relationships (Kleberg, et al., 2000).

Existing research on intervention programs has primarily concentrated on neurodevelopmental outcomes and parent and staff satisfaction measures (Iversen, Shimmel, Ciacera & Prabhakar, 2003; Pelchat, Lefebvre, Proulx & Reidy, 2004). Poor neurobehavioural outcomes have contributed to the move toward developmentally sensitive, family-centred care. This move toward more developmentally sensitive care has been supported by research on infant brain development (Als, et al.,2004: Shore, 2002) and research on the destructive effects of stress and trauma on developing neurological pathways (Graham, Heim, Goodman, Miller & Nemeroff, 1999).

CONCLUSION

Admission to the NICU has been shown to be particularly stressful for parents, leading to the disruption of their lives and a need for ongoing emotional and psychosocial support. Parental stressors in the NICU include poor staff communication and environmental factors; maternal factors of inadequate parent participation or illness; baby factors of illness, poor prognosis or lack of ongoing family support networks. These factors are not confined to the postnatal period; they may include factors affecting mothers during pregnancy. The majority of studies reviewing the provision of support during pregnancy for women delivering high-risk babies were concerned with threatened premature delivery rather than congenital anomaly.

There is a paucity of research surrounding the development of infant-parent attachment behaviours in the NICU environment. Numerous studies confirm that mothers whose infants have been admitted to NICU experience greater levels of psychological distress which consequently places the parent- baby relationship at greater risk. It is therefore surprising that so few studies examine what parents find supportive or how they cope under these difficult circumstances.

Support programs have been developed and implemented within the NICU area. The most successful programs implemented to this point are parent support programs involving partnership with parents of NICU graduates with new NICU parents. In the last 15 years, Australia has lagged behind the world in the implementation of developmentally supportive, family-centred care programs into NICUs. There is generally little understanding of what really constitutes developmentally supportive care (Fenwick, Barclay & Schmied, 1999; Fenwick, 2001; McGrath & Conliffe-Torres, 1996,). Similarly, there is a lack of research examining the effect of these programs on the parent-infant relationship

The quality of the parent-infant relationship has been identified as having ramifications for the ongoing physical, neurological and social-emotional development of the infant. Research confirms that mothers experience a degree of emotional and psychological stress that may lead to the postponement of emotional attachment to their infants at the time of discharge, and may contribute to greater parenting risk.

Despite recognition of the importance of the development of infant attachment, there has been little research into the developing parent-infant relationship in the NICU environment. The increased availability of mothers as research participants, as opposed to fathers, has resulted in relationship studies predominately focusing on maternal rather than paternal or parental experiences in the NICU. Despite the increased availability of mothers as research participants, little research has been undertaken on the experience of mothers of newborns admitted to the NICU for surgery. It is useful to note that existing studies concerning the experience of mothers whose newborns were admitted to the NICU were primarily carried out within the context of the birth of a premature infant, little work has been done in

relation to the experience of mothers whose newborns have undergone surgery (Bakewell-Sachs & Gennaro, 2004; Hurst, 2001;Van Riper, 2001). This need led me to undertake the current investigation of mothers' perceptions of their relationships with their infants who require surgery for a congenital anomaly.

CHAPTER THREE:METHOD

INTRODUCTION

This chapter initially discusses the merits of the theoretical perspective of symbolic interactionism. In order to gain a better understanding of the impact of the complex nature of the NICU environment on the mother's relationship with her infant, it is essential that her perception of her individual experience be considered.

The rationale for the choice of a grounded theory methodology is then provided. The methodological differences in grounded theory attributed to both Glaser and Strauss are outlined. This is followed by a detailed description of the study procedures and data analysis undertaken.

SYMBOLIC INTERACTIONISM

The basic premise of the theoretical perspective of symbolic interactionism is that behaviour is related to the meanings people attribute to situations and to other individuals. Meanings are central to the analysis rather than behaviours. Therefore the context of the environment in which individuals find themselves should be considered in relation to how it may influence the individual's perception of that context. Symbolic interactionism acknowledges the meaning a mother attributes to her relationship with her infant as unique to her, which will influence her perception of the relationship and, in turn, her behaviour within that relationship. Therefore symbolic interactionism will facilitate an understanding of the meanings that mothers attach to their present life situation. A better understanding of the mother's perception of her relationship with her infant within the context of the NICU will provide a sounder base for implementing strategies to support the provision of quality neonatal care that is family-oriented.

The foundational work of symbolic interactionism is attributed to a number of scholars from the areas of philosophy, sociology and psychology. Symbolic interactionism was most strongly influenced by the pragmatist philosophers, including Dewey, Cooley, and Mead (Manis & Meltzer, 1972). The pragmatic approach holds that the truth-value of an idea is to be found in its practical application in everyday life. This theory rejects the idea of universal truths, rather

it holds that people are proactive in everyday life, making choices about the objects of their existence.

The many contributors to the theory interpreted its constructs in different ways. John Dewey developed the concept that the thinking process included the definitions of objects that occupied a person's world (Manis & Meltzer, 1972). He argued that individuals create lines of action after reviewing the various alternatives available to achieve their goals. Thomas Cooley (Manis & Meltzer, 1972), renowned for his concept of "the looking glass self", demonstrated that humans grow through interaction with others. By examining possible actions that one might take, by working out definitions of the situation, the person defined oneself in the process. This process was observed in the study, whereby when interacting with one another, both the mother's and the infant's perception of themselves and each other was influenced by their mutual responses. As Cooley (Manis & Meltzer, 1972) posits, the perception each person holds of their ongoing relationship and of themselves as individuals is influenced by the situation.

Despite the considerable contributions to symbolic interactionism made by earlier scholars, George Herbert Mead is known as the father of symbolic interactionism. Mead's work was regarded highly by philosophers in his own lifetime and by the students he taught at the University of Chicago (Manis & Meltzer, 1972). He exerted a wide influence on philosophical thinking of the time, despite the fact that he published infrequently. Mead's work was heavily influenced by the work of John Dewey, a close friend and fellow philosopher. It was with John Dewey that Mead took up a position at the University of Chicago in 1894. He continued to teach at the university for most of the following 40 years.

Philosophically George Mead was a pragmatist; scientifically he was a social psychologist (Morris, 1962). Mead belonged to an era in which there was no antagonism between the activities of science and philosophy. This philosophical approach grew out of a belief that knowledge was tied to the immediate experiences of everyday life, such as the knowledge of being a parent gained through the process of parenting, and referring to others who shared this

experience. In the years that followed, this integration of knowledge and experience became the hallmark of philosophy at the University of Chicago.

Mead had through his lifetime called his approach "social behaviourism". In this approach he refined the concepts of the "mind" and the "self" (Benzies & Allen, 2001). Mead described the "mind" as being the result of social exchange. In regard to the "self" Mead recognized that a human being can be an object of his/her own action. Therefore the "self" emerges as the result of social interaction, as in the way that parent and infant come to recognize who they are in relation to the other, through reflection on the dynamic relationship and interactions occurring between them over time

The interaction of an individual's self-conception and the perceived view that others have of them is central to social behaviourism. For example, a mother throughout her pregnancy is developing a perception of her future relationship with her infant. In addition to this perception, she is developing perceptions of herself as a mother and the foetus as her infant. These perceptions influence her behaviour during her interactions with the infant, which in turn influence the newborn's perception of her and the infant's behavioural responses toward her during the interaction. The developing relationship between the mother and infant is built initially on these brief interactions. The mother's perception of herself as a mother is influenced by these interactions with her infant. She will alter her behaviour to elicit a positive response from her infant. If the infant responds positively toward her she is more likely to develop a positive image of herself as mother. The infant's perception of being worthy of being cared for will be influenced by the mother's behavioural responses during these interactions. If the infant's needs are not met in a timely and caring manner the likelihood of the infant developing a sense of self worth is improbable.

Mead's thesis is that we become competent in the utilization of social symbols through a process of continual reflection of ourselves as others perceive us. The theory of the "self" is extended by differentiating it into a spontaneous "I" and the

socially determined "me". Mead described the "self" as a process of interaction between the "I" and the "me". He saw the possession of the self, the ability to interact with oneself, as crucial to the formation of social skills.

At the time of his death Mead had published very little. Several of his students had kept class notes and Herbert Blumer (1969) was one of these. While the symbolic interaction perspective is associated with Mead, it was the sociologist Herbert Blumer who took Mead's ideas and developed them into a more systematic sociological approach. Blumer coined the term "symbolic interactionism" in 1937, keeping this sociological perspective alive through the early 1950s at Chicago, and then in California where he was a professor at the University of California in Berkeley.

Although Blumer only presented some of Mead's ideas, his development of these ideas form the basis of the current symbolic interaction approach. Ervin Gofman (1969), also a well-known sociologist, continued to popularize symbolic interactionism through the recognition that people seem to follow scripts and play games in interaction (Manis & Meltzer, 1972). His ideas about the presentation of self and their interactive rituals formed the basis for symbolic interactionism research that continues to this day. For many years the oral tradition was used to pass down the teachings and advances in symbolic interactionism theory development. Mead's teachings represent a prime example and as a consequence, major concepts were inaccurately defined.

While most scholars agreed on Blumer's (1969) basic tenets of symbolic interactionism , there were areas of disagreement. This is apparent in Manford Kuhn's approach (Manis & Meltzer, 1972). Kuhn emphasized that each person has a core self, that is, every human has a stable set of meanings and attitudes towards themselves through socialization. This is evident in the different parenting rituals that occur within different cultures at any one time, and over time. The core self shapes and constrains the way we define situations. Humans seek and have continuity and predictability, which are socially and culturally

defined. For example, parenting in the medically defined NICU environment is quite different to those skills learned and practised in the home environment

As a consequence of these different explanations of symbolic interactionism theory two different schools of symbolic interaction developed. The first developed at the University of Chicago. This school reflected the basic assumptions of symbolic interactionism that were conceptualized by Mead and elaborated by Blumer. The second school was developed by the University of Iowa overseen by Manford Kuhn. This school was influenced by logical positivism and therefore presented a more structured approach to symbolic interactionism.

The perspective used in this grounded theory study on the developing relationship between the infant and parent in the NICU environment is that of the University of Chicago. Symbolic interactionism focuses on understanding the world of the parent and the infant in the constrained world of the NICU. The theoretical perspective of symbolic interactionism rests on three premises: Blumer (1969) described these basic assumptions which underlie symbolic interactionism as follows:

- First premise:

  People act on the basis of the meanings that things have for them. They do not react to things but attach meaning to the things and act on the basis of that meaning. Meanings are central rather than behaviours.

Mead (Morris,1962) applied the term "thing" to everything that the human being may note in his world. He categorized things into three sets which I have related below to the world of the NICU:

1. Physical objects - such as monitoring equipment in the NICU
2. Social objects - other categories of human beings such as members of the clinical team, for example, doctors, nurses, physiotherapists

3. Abstract objects – guiding ideals, such as the policies and procedures, theatre schedules and bedstate that impact on delivery of care to infants admitted to the NICU

Although there is general agreement with this first premise (Blumer,1969; Manis & Meltzer, 1972), that people act on the basis of the meanings that things have for them in reality this premise was ignored in the social science and psychological sciences of the day (Blumer, 1969). Human behaviour was regarded as the product of factors that play upon human beings. This interpretation of human behaviour resulted in the meanings of things either being ignored or being included as one factor used to account for human behaviour. Hence the second premise discusses the origin of meaning.

- Second premise:

  The two traditional ways of accounting for the origin of meanings were as follows:

  - To regard meaning as being intrinsic to the thing that has it (Morris,1962). No process is involved in the formation of meaning. This is the traditional position of "realism". An example would be an isolette being regarded by all as an isolette, or an intravenous infusion being just that.

  - The second view regards the meaning of things as the expression of the psychological elements involved in the perception of the thing (Morris,1962), for example the parents' feelings and understanding of medical and surgical interventions on their infant

On the other hand, symbolic interactionism sees meaning arising from the process of interaction between people, such as the interaction between parent and infant, or parent and healthcare professionals in the NICU. Blumer (1969) explains that the meaning of the situation for an individual grows out of the ways in which other individuals act toward them with regard to the "thing". So, for example, in the context of the NICU the way in which staff behave toward the mother in

relation to the physical status of her infant. In this sense, meanings are the social products formed by the interaction of individuals.

The meaning of objects for a person arise fundamentally out of the way they are defined to themselves by others with whom they interact (Blumer, 1969). We learn from others, such as nurses, that an intravenous infusion is a device which provides necessary fluids and electrolytes to the infant. Consequently, our individual worlds consist of objects for which we have mutually agreed meanings. In order to understand the action of an individual it is, therefore, necessary to identify their world of objects. This leads to the third premise which examines the interaction process.

- Third premise

  Meanings are assigned and modified through an interpretative process which changes due to redefinition, relocation and realignments (Morris, 1962). The use of meaning by a person in his action involves an interpretative process.

Blumer (1969) outlined two distinct steps in this process of interpretation. The first step requires the person to indicate the object towards which he/she is acting. This is an internalised social process, wherein the individual engages in a communicative process with himself. The individual is capable of being an object of his/her own action. Mead (Morris, 1962) saw the human being as an organism having a "self", that is being an object to oneself. He described the individual's ability to perceive, communicate, and act toward oneself in the same way as being able to perceive, communicate, and act toward other objects. Within the context of the NICU, mothers initially perceive themselves as playing a minor role in their infants' care. They perceive others as being the experts. These perceptions influence their interactions with their infant and with others such as clinical staff and other parents.

Blumer's second step in the process of interpretation involves dealing with meanings. The individual engages in a process of selecting, checking, suspending, regrouping and transforming the meanings in the light of the situation in which they are placed and the direction of the action taken. Therefore,

meanings are used as instruments and revised for the guidance and formation of action. The possession of a self provides a mechanism of self-interaction with which to meet the world, to form and guide behaviour (Morris,1962). Meanings play an important role in action through the process of self-interaction. In this study, as the NICU experience changed for mothers, such as their infant being transferred to a less acute area, mothers were faced with readjusting their perception of the situation. The meanings they had previously attached to objects were altered – the infant's physical status, NICU routines, verbal and non verbal communication. Meanings on which they had previously based their behaviours needed to be revised and trialed in order to guide future behaviour. In this way, realty is never absolute because meaning for the individual changes depending on the context.

Symbolic interactionism recognizes social interaction to be of vital importance in its own right. Blumer (1969, p. 8) describes social interaction as "a process that forms human conduct rather than being a means for the expression of human conduct". In interacting with one another, persons have to take account of what each is doing. They use this information to deal with the situation. The activities of others either enter as positive influences on an individual person's behaviour or otherwise cause the individual to revise or alter their plan of action. The behaviour of each of us must fit one way or another with the behaviour of those around us. Mothers in the NICU interact with many individuals on a daily basis with whom they feel pressured to negotiate in a positive way. They recognise that the outcome of these interactions will influence how staff perceive them and may affect the care provided to their infant.

Interestingly, Mead recognized two levels of social interaction in human society and referred to them as "conversation of gestures" and "the use of significant symbols" (Manis & Meltzer, 1972).

The levels may be described as follows:

1. Blumer (1969) refers to the "conversation of gestures" as non-symbolic interaction, that is, response to others without interpretation, for example

reflex responses. Human beings engage in non-symbolic interaction as they respond unreflectively to each other's bodily movements, expressions and tones of voice.

2. "The use of significant symbols" is referred to as symbolic interaction by Blumer (1969). This is the characteristic mode of interaction involving responding to another after interpreting the meaning of an action.

   Symbolic interaction is a presentation of gestures by an individual and a response to those gestures. Mead (Morris, 1962) describes gestures as any part or aspect of an ongoing action that signifies the larger act of which it is a part. For example, a frowning face may be interpreted as indicating an unpleasant interaction. It provides an intention of a plan of action. The person who responds, organizes his response on the basis of what the gesture means to him. The person who originally gestured did so as an indication of what he is planning to do as well as what he wants the respondent to do or understand by his gesture. Gesture therefore has meaning for both parties.

"Mead's triadic nature of meaning" proposes the meaning of gesture flowing along the following three lines:

1. It signifies what the person to whom it is directed is to do
2. It signifies what the person who is making the gesture plans to do
3. It signifies the joint action that is to arise by the articulation of the acts of both.

He notes that, if confusion or misunderstanding arises along any one of the three lines of meaning, then the communication will be ineffective, interaction will be impeded and the joint action will be blocked (Blumer,1969).

Blumer (1969) added an additional feature to Mead's original analysis of symbolic interactionism. He felt that for successful interaction to take place, individuals involved in interaction must necessarily take each other's roles into consideration when determining what interpretation is wished from the

interaction. This mutual role taking is the root of successful communication. Human group life is therefore an ongoing process, a continual fitting together of the developing lines of behaviour with one another. This is achieved through the dual process of definition and interpretation which operates to sustain established patterns of behaviour or else open them up to change. Established patterns of behaviour are sustained through the acts of individuals which result from the same schemes of interpretation. If the schemes of interpretation are disrupted or undermined by the actions of others, established patterns of behaviour will change.

Within the theoretical perspective of symbolic interactionism, the meanings certain things have for mothers are, therefore, dependent on the social context. The newborn infant represents significant meaning to the mother. The mother will act in relation to the meanings the nurse, as a symbol, has for her. The encounters between healthcare workers and mothers may be based on the infant, but the infant as a symbol represents different meanings for each of them. The infant will represent different meanings for each of the healthcare workers. To provide an example, the newborn infant may represent an acutely ill post surgical patient requiring pain relief to the neonatal nurse whereas to the lactation consultant the infant may represent a newborn unable to establish feeding. The mother's representation may be of an infant who is unresponsive to her overtures. Likewise the infant will act in relation to the representation of the mother which develops during initial interactions. Positive interactions for the infant are those in which the infant's needs are satisfied. For example through feeding or being comforted through gentle touch.

Recognising that social interaction between these individuals may be based on incongruent meanings, in turn leads us to the possibility of negative social interaction. Faced with an infant who is unresponsive to her overtures may cause the mother to use inappropriate means to elicit a response from the baby. For example, she may stroke the baby vigorously or raise her voice close to the baby which may trigger a negative physiological response. The nurse caring for the baby may try to intervene quickly without providing the mother with the rationale for not stimulating the infant in this way. The mother may perceive her situation

as not being welcome at her infant's bedside. This interaction is negative for the mother, baby and the nurse. Had the mother been made aware of her infant's inability to respond to her and been advised of appropriate ways of touching her infant, the infant would not have responded poorly and the nurse would not have had to intervene. Successful social interaction will necessitate significant revision of gestures by both healthcare workers and mothers.

STUDY METHOD – GROUNDED THEORY

The rationale for using a grounded theory methodology

Over the years I have witnessed mothers display a wide variety of responses toward their newborn babies and to the NICU environment. These varied responses become more obvious at different stages throughout hospitalization. When determining which qualitative methodology to use I considered these facts together with the questions to which I was seeking answers. Hence, as indicated in this chapterr, symbolic interactionism was chosen to provide the theoretical perspective for studying how individuals interpret their world and how this interpretation leads to behaviour in specific situations.

The main questions being asked were: What is happening in the substantive area under study which is essentially the development of a human relationship built on interactions between mothers and their infant? How do mothers manage when faced with serious illness of their newborn? What happens when the maternal-infant relationship must develop within the context of a surgical NICU? What factors obstruct or alternatively facilitate the development of that relationship?

The aim of this study was to examine more closely the developing relationship between mothers and their newborn infants when faced with serious illness in the NICU. I had long ago become aware of the individuality, flexibility and fragility of this process. In determining the research method it was appropriate that the research questions guided the process of selection. My aim was to employ a methodology which would enable me to examine the mother's perception of their relationship with their newborn and the problems faced by these individuals qualitative methods of first-hand observation and in-depth interviews were considered suitable techniques for uncovering the nature of the

mother's experiences, as these techniques facilitate the discovery of intricate details of life experiences. A qualitative methodology derived from the symbolic interactionism perspective best suited the aim of this study by generating a grounded theory through a process of inductive reasoning (Hammersley & Atkinson, 1992),

Symbolic interactionism supports the notion that mothers of newborns behave in relation to the experience according to the meaning it has to them (Blumer, 1969). It seemed important to discover the meaning of this experience for mothers if I was to truly understand what was happening. The way to achieve this was to listen to their concerns and perspectives, and discover what motivated their behaviours. Grounded theory is a qualitative methodology which derives its name from the practice of generating theory from research which is "grounded" in data.

Glaser (1978, p. 94) describes grounded theory as a method which will enable the analyst to identify "the chief area of concern of the people in the substantive area under study and discover what accounts for most of the variation in processing the problem". Grounded theory methodology was developed as an alternative to other research approaches which rely on hypothesis testing, verification techniques and quantitative methods.

In order to provide family-centred care in the NICU, neonatal nurses require a greater understanding of how families manage in the face of serious illness. Grounded theory attempts to conceptualize and interpret what is happening in the substantive area. Since grounded theory is developed through detailed observation, people involved in the substantive area should be able to understand and utilize the developed theory. This factor was also taken into consideration in the decision to use grounded theory methodology.

The emergence of the grounded theory methodology

Grounded theory has become one of the most common methodological approaches in nursing research. It was developed from the theoretical framework of symbolic interactionism (Benoliel, 1996; Norton, 1999). The influence of symbolic interactionsim is reflected in the focus of the methodology on

developing theory "grounded in the data". In other words, discovery of the meaning results from the interaction of individuals.

Grounded theory methodology was initially outlined in the *Discovery of Grounded Theory* (1967) by Barney Glaser and Anselm Strauss. The theory was developed by these two sociologists during a collaborative research project studying the substantive area of "dying in hospital". Both men came from different universities and consequently different educational backgrounds. The Glaser and Strauss collaboration continued for several years and resulted in the co–authorship of several papers and the publishing of three books describing grounded theory methodology.

As the popularity of the methodology increased so did the need for clarification on specific details of the analysis process. This prompted subsequent publications by Glaser and Strauss. Writing alone or in co-authorship they outlined their individual perceptions of what constituted grounded theory. Among the most well known of these publications are Glaser's (1978) *Theoretical Sensitivity* and (1992) *Basics of Grounded Theory Analysis*, Strauss' (1987) *Qualitative analysis for Social Sciences* and Strauss and Corbin's (1990) *Basics of Qualitative Research: Grounded Theory Procedures and Techniques.*

The publication of Strauss and Corbin's (1990) *Basics of Qualitative Research: Grounded Theory Procedures and Techniques* highlighted to Glaser the important epistemological and methodological differences in their approaches. The two scholars were unable to resolve these differences regarding several procedural aspects of methodology. Glaser published *Basics of Grounded Theory Analysis*, (1992) for the purpose of critiquing the Strauss and Corbin work and refuting their description of grounded theory methodology.

Glaser maintained after reviewing the Strauss and Corbin book that "Strauss indeed has used a different methodology all along, probably from the start in 1967, and it was not obvious until our more recent articulations and formulations" (Glaser, 1992, p.122). He describes Strauss's methodology as one of "full conceptual description" which has all the problems of forcing the data (Glaser,

1992, p.122). Glaser describes his own as one of "emergence, discovery, and inductive theory generation"(1992, p.122).

Distinguishing the methodological differences in grounded theory attributed to Glaser and Strauss

Two distinct schools of grounded theory methodology have resulted from these identified methodological differences - the Straussarian and the Glasarian.
One of the recognized faults in many grounded theory studies is the researcher's failure to clearly articulate whose guidelines were used (Cutcliffe, 2000). I have therefore outlined the most obvious differences in an attempt to explain my choice of methodology.

Strauss's approach seems to be more concerned with rules and procedures for conducting grounded theory. Emphasis on retaining the "canons of good science" such as replicability, generalizability, precision, significance, and verification seemed representative of quantitative research principles rather than qualitative. An example of this is the description of axial coding which outlines specific steps to be followed within each phase. The phases are evaluated against research quality criteria of construct validity, internal validity, external validity and reliability. Glaser (1992) critiques this approach maintaining that it can result in researchers missing the relevance of the data by forcing it into a preconceived framework. In addition, Strauss and Corbin (1997) repeatedly emphasise verification and validation of theory and hypotheses as opposed to the Glasarian approach which emphasises theory generation as the central and recurring theme.

Glaser's approach to grounded theory is one which is guided by the data. He warns against the pitfalls of "forcing data" and encourages researchers to patiently wait for the emergence of concepts: "How the analyst enters the field to collect the data, his method of collection and codification of the data, his integrating of the categories, generating memos and constructing theory - the full continuum of both the processes of generating theory and of social research – are all guided and integrated by the emerging theory" (Glaser, 1978, p.2). Glaser's view of grounded theory is guided primarily by participants and their socially-constructed realities.

He insists the participant's world should emerge with little effort or detailed attention to process on the part of the researcher.

Finally, Strauss and Corbin suggest that "the research question in a grounded theory study is a statement that identifies the phenomenon to be studied" (1990, p.38). This is contrary to the Glasarian view that stresses that discovery of the research problem occurs through emergence as a natural by-product of open coding, theoretical sampling, and constant comparison. Ideally, the grounded study begins with the question "what is going on and how it is handled?" (Glaser, 1992, p. 22).

STUDY PROCEDURES

Ethics approval

The Ethics Committee of the Children's Hospital at Westmead approved the study proposal on the 21st December 2001. The study was approved under the umbrella of a larger study, named "A pilot study of developmental and behavioural outcomes following neonatal surgery" (BOS study). Several ethical issues were identified prior to commencement of the study.

The first ethical issue identified was how information divulged to me during the interview process would be managed. While confidentiality would be maintained, it was always possible that, given the emergent nature of care provided within the NICU and the numbers of clinicians with which mothers interact, issues regarding parental dissatisfaction with clinical care would arise. The ethical dilemma for me as a neonatal nurse was the knowledge that if I intervened on behalf of mothers, by informing staff of mothers' concerns, I would inadvertently alter the experience for mothers. I presumed that once staff became aware of parental dissatisfaction, provision of care would be altered. If I was truly to understand the experience of mothers whose infants required surgery, I could not intervene to alter that experience even though my intervention might improve the experience for mothers. In light of these concerns, I made the decision not to pass on maternal concerns to staff until the study was completed.

The second ethical issue identified was the safeguarding of mothers' psychological wellbeing. I was aware of the level of stress placed upon mothers of sick infants and felt it possible that I may become aware, during the interview process, of individual mothers need for support. Individuals deal with stress differently dependent on the experience and their emotional wellbeing at that time. With the consent of these mothers, I therefore made arrangements to refer them to a psychologist attached to Grace Centre for Newborn Care to offer counselling if this became necessary.

The infants of families who participated in the study would as a result of the range of assessments to be completed as part of the data collection would undergo a more comprehensive follow up than those who did not participate. This could be seen to be an advantage to families of infants with an uncertain prognosis.

Enrolling eligible participants into the study

Participants were enrolled into the larger BOS study by the chief researcher of that study. All families were informed of the range of collection tools being used including interviews conducted for this section of the study. Criteria for inclusion included: infants who were born at gestational age greater than 33 weeks, admitted to Grace Neonatal Nursery (GNN) within the first 28 days of life and who had undergone neonatal surgery involving entry of a major body cavity. Once enrolled into the BOS study, families were randomised into two groups.

The first group of families were supported through an individualised family support program. The program entailed routine developmental observations being carried out by staff trained in individualised developmental care. Infant care plans were developed incorporating recommendations developed for the infant by the specially trained staff. Care was carried out by clinical nursing staff utilising the recommendations.

The second group of families, while exposed to aspects of individualised care in the course of their infant's hospitalisation within Grace Nursery, were not routinely observed by the developmentally trained nurses. This group's care plans were developed by clinical nurses working within the unit.

Participants selected for enrolment into study under discussion

Contact was made with eligible families already enrolled into the BOS study early in the course of their hospitalisation for the purpose of developing a rapport with possible participants. It had been intended to interview couples together rather than individual mothers. Although all couples consented to the interview, only two fathers were available when the interviews were to be undertaken. As a consequence the data utilised for analysis were confined to that data collected from mothers.

The first two mothers interviewed were those who were immediately available. These initial interviews provided me with information on issues relevant to both groups which enabled me to decide which participants would potentially provide rich data. Throughout data collection I purposefully approached mothers who I thought could potentially provide me with the rich data I sought at that time. Decisions regarding what constituted rich data were dependent upon the emerging codes identified as important during previous interviews. Comparative analysis of data with previously collected data provided theoretical leads which were followed by interviewing participants who were thought to be able to support emerging concepts. All participants were enrolled into the larger umbrella study (BOS study). Individuals were selected for interview from this larger sample as they were needed. The choice of which individual to interview next were based on theoretical purpose and relevance (refer to theoretical sampling pge.)

Initially couples were approached regarding their willingness to be interviewed However due to the inability of fathers to be present interviews were predominately undertaken with mothers. Consequently data analysis was confined to that collected from mothers. Mothers who had undergone various experiences in the NICU were chosen for interview. Mothers who had received antenatal as well postnatal diagnoses for their infants were chosen. Mothers of infants with a variety of diagnoses and associated complications were chosen.

Couples were initially approached within the first two days after admission to the NICU. My usual routine was to monitor the progress of mothers and their infants through the unit, which involved referring to their hospital records, speaking to

the mothers themselves and the staff caring for them. As staff began formulating discharge plans, I purposefully approached mothers who could potentially provide me with the data I sought at that time. I approached the mother I wished to interview, usually within the week before their discharge, to negotiate an interview time convenient to them.

Thirty couples in total were approached regarding their willingness to participate in the study; of these, 12 couples were interviewed. Only one couple refused to be interviewed. Their reason for declining the interview was a culturally based fear that a member of their extended family might discover their child had been born with a congenital defect. Staff had been unaware that they had kept this information from their extended family. Despite being confident that all information would be kept confidential, I felt it inappropriate to request their participation as it was obviously of great concern to them. Seven other potential couples did not participate because of unplanned discharges or discharges to other areas within the hospital or units external to the hospital. Six couples were excluded from interview as it was thought these participants would not contribute anything new to the emerging theory. The remaining four couples were not required to be interviewed as data saturation had been reached prior to their discharge from the NICU. In total, 12 couples were interviewed. Contact numbers were provided to them for the purpose of providing additional information if required.

Research participants

Twelve mothers in total were interviewed; antenatal diagnosis of their infants was made for eight of them. Seven of these infants were diagnosed before the twentieth week and one at thirty weeks gestation. Post-natal diagnosis was made for four infants; two diagnoses were made at time of delivery.

Gestational ages of the newborns ranged from thirty-seven to forty-one weeks. Nine male infants and three female infants were included in the group. Eight infants were born with cardiac anomalies and four infants were born with gut anomalies. Four infants were transferred to theatre immediately after birth for surgery. The remaining infants were transferred to the NICU for stabilisation. Of

the infants transferred for stabilisation, five underwent surgery within 24 to 48 hours after delivery. Three infants underwent surgery within three to seven days after delivery.

Most mothers ranged in age from 22 to 40 years. Only one couple was substantially older - mother was 45 years and father 56 years. All couples were married and six mothers had other children. Only one infant's length of stay was less than one week; three infant's length of stay was greater than six weeks. The infants of five of the couples interviewed were readmitted within one month after discharge for further surgery or treatment.

Data collection methods - the interview process

Data were collected using an unstructured interview technique. Interviews were carried out just before the infant's discharge from the nursery. An unstructured interview format was used, as it was considered the least intrusive method of eliciting the personal viewpoint of mothers regarding their experience of developing a relationship with their infant. It also provided the flexibility to pursue specific aspects and clarify the information provided to me by mothers. The length of interview ranged from 1 hour to 3 1/2 hours and took place in a room situated away from the clinical area but within the NICU. The room was quiet and secure from disturbance. As I was aware that mothers might become distressed during the interviews as a result of reflecting on their experience, my aim was to help them feel as comfortable as possible. I initially interviewed several consenting couples for the purpose of familiarising myself with the interview technique and becoming comfortable with the recording equipment. Data collected from the first interview was not included in the collection as difficulties were experienced with taping. Data from the second interview was included and labelled for the purpose of maintenance of data collection records as the first interview. The interview flowed from an opening question of `Could you tell me the story of your infant's illness?" The interview was subsequently developed using a reflexive grounded theory approach which facilitated exposure of the meaning of events to mothers. Data from these early interviews was included in the analysis.

As mentioned earlier, provision was made for referral to a psychologist attached to GCNC with the parent's consent to offer counselling if this became necessary. However, to my knowledge this was not taken up by any of the mothers involved in the interview process. When asked at a later time what their feelings were about the interview, most suggested it had been cathartic. Several mothers suggested that all mothers admitted through the NICU should be offered a similar opportunity. All reported they were pleased to have been involved.

Data storage and management

Demographic data were collected from the patient record system with the participants' consent. Antenatal data were collected from the mothers during interview as in most instances this was not available in the patient record system. All data were de-identified and saved on my computer under security code. A copy was regularly updated and kept in a locked drawer in a separate area. I was the only person with access to participant interview data.

A case summary table was created for each couple using an *Excel* table format. The following data were collected on each participant: Identity code (interview code), infant's sex, length of admission, date of admission, diagnosis, delivery, gestational age, birth weight, surgeries undertaken, date of interview, date of discharge, date of readmission, record of contacts.

Audio and computer transcripts were labelled with an individual code for each participant. Contact date and times were recorded on all tapes and *NVivo* and *Microsoft Word* transcripts. This information was also recorded on an *Excel* spreadsheet along with the demographic data. Participant demographic data were kept in order of interview dates. Interview data were collected via audiotape and field notations were made directly after the interview. These notations together with the interview data were transcribed immediately into the *NVivo* computer program developed to manage qualitative data for analysis.

Each interview constituted a single *NVivo* document using the coding frame. Concepts related to the underlying meanings, uniformities and patterns which emerged during data collection were coded under conceptual labels. Codes

referenced to the labels given to concepts identified within the data. Each incident coded in an interview was automatically transferred as a narrative excerpt to a separate document labelled under that code. For example, the following incident was coded from an original interview document. This narrative excerpt was automatically copied into a code document labelled "pain".

> ***Researcher***
> *So was there any time when that was a concern to you?*
> ***LUCY***
> *Oh, only when I went to pick him up for the first time. I was very unsure about how to hold him and I just asked the nurse and ... (sarcastic tone) she was helpful. It'll be right sort of thing. She just said pick him up, she didn't really explain to me...*
> *It wasn't until I got back to Grace and they said 'don't pick him up under the arms and if you're patting him on the back he might not like that, it might be hurting him' and so they said to pick him up under the shoulders and bottom.*

Memos were used extensively throughout the analysis process. Memos are the theorizing write-up of ideas about codes and their relationships as they strike the analyst while coding. It is a constant process that begins when first coding data and continues throughout reading memos, literature, sorting and writing the papers (Glaser, 1978). A summary memo of each interview was included at the end of each interview document. This included my initial perception of what had been revealed during the interview. During later interviews, when confirmation of concepts was sought, results of these discussions were included in the summary memo.

The 12 interviews were transcribed and recorded as separate documents. These documents were then coded. Fifty-nine codes had been recorded in separate documents at the end of open coding. Memos pertaining to specific codes were included in corresponding code documents. Additional memos were recorded in separate documents.

During coding, narrative excerpts which would be used later in the write up to illustrate specific concepts or codes were dated and identified to correspond with the transcript from which they were taken. Similarly all memos referring to specific narrative excerpts were also dated and coded which facilitated tracking of all information.
As the volume of documentation grew, it became increasingly more difficult to deal efficiently with the data using the *NVivo* program. Moving between interview documents and the code documents became more difficult. As this was my first encounter with the *NVivo* program, difficulties were possibly due to inexperience. The decision was therefore made to copy the data to *Microsoft Word* documents for ease of use. The cut, copy and paste facility enabled the analysis to proceed more efficiently. I had also begun the write-up which I had always planned to complete using *Microsoft Word.*

Difficulty was also experienced envisaging the relationships between conceptual codes and conceptual categories using *NVivo.* I developed coding tables using *Microsoft Excel* to overcome this difficulty. Initially all level one codes were listed in a single column. As these codes were altered, subsumed or deleted during further analysis into additional coding levels I was able to use different colours to indicate linkages between individual concepts.

Coding levels were developed to illustrate the decisions made regarding the collapsing of similar concepts under the one conceptual code once the indicators for that conceptual code became clearer. I listed each coding level in order by number and date. Substantive and theoretical codes were listed separately. Memos regarding data analysis decisions were also dated and recorded on a separate *Excel* spreadsheet. Detailed memos of all categories and the properties of each were recorded, as were the regrouping of categories. Relationships between properties and then for each category were identified by using different colours for each category.

These strategies enabled me to develop an audit trail recording the steps taken and decisions made during the coding process. More importantly it enabled me to

visualise the interrelationship of the different concepts to the core concept more clearly. Chapter Three (Table 3.1) gives an example of conceptual codes listed under conceptual categories.

Subjectivity of researcher

I have worked as a neonatal nurse for many years. During this period I have become familiar in all aspects of neonatal intensive care nursing. I have completed tertiary studies in neonatal nursing , nurse education and infant mental health. Over the past ten years I have participated as facilitator for nurses new to the area of NICU. In addition, I completed the Level One Neonatal Individualised Developmental Care Assessment Program (NIDCAP) training reaching reliability in 2002 and re-reliability in 2004. In the process of gaining this qualification I have carried out numerous infant - family observations and developed plans and recommendations for care. This obviously involved close collaboration with families, medical and nursing teams.

During the period of data collection and analysis I was employed as Nurse Educator of NICU. I was conscious of the impact my background and interest in specific areas of neonatal nursing might have on the data analysis. I recognised my personal values and beliefs could potentially influence the study results. However, since it was my intention that all concepts would be developed directly from the collected data I embarked on data collection. I purposefully ascertained the validity of the emerging concepts by questioning participants regularly throughout data collection.

Although I was acutely aware of these difficulties I intentionally met with couples early in their babies' hospitalisation. I felt that although the mothers would see me as a neonatal nurse, they would feel confident that I understood what they meant when they talked about their experiences. As a result, they did not have to explain their opinions and experiences as thoroughly as they would have to someone new to the area. I therefore view my familiarity with the environment and culture as a benefit as it did allow me to understand the perception of the mothers' experiences as they relayed it to me within the interview.

DATA ANALYSIS

Glaser and Strauss (1967, p.261) originally developed grounded theory methodology specifically to ensure the generation of a theory which would fit and work and be grounded in the data. The methodology involves the investigation and identification of codes and properties which relate to the area under study. In this case the area under study was the experience of mothers whose infants had been admitted to NICU to undergo surgery for a congenital anomaly. Data collection and analysis occur simultaneously using a grounded theory method. In the following chapter I discuss issues related to data collection and analysis using a grounded theory methodology.

The analysis process

I began each interview with the same request of participants: could they tell me the story of their infant's illness? All mothers chose to begin at the same point, that of diagnosis of their infant's condition. If their infant had been diagnosed antenatally they began at that point in the pregnancy. If it was a postnatal diagnosis mothers began by describing their experience of receiving the diagnosis and the events leading up to it. Simple straightforward questions were used to prompt participants in the earlier interviews. These questions were added to and became more specific in the later interviews as issues arose requiring confirmation by participants.

Interviews were transcribed immediately into a computer file. Glaser (1998) does not recommend this technique in the belief that analysis might become delayed because of the length of time it takes for the researcher to transcribe data word for word. He also warns that much unnecessary data may be collected. He recommends field notes be made of interviews rather than transcripts, to capture the key concepts/ issues expressed by participants. Analyses of the field notes are made immediately after the interview, enabling immediate identification of all important incidents and memos to be recorded at that time.

I acknowledge Glaser's (1998) concerns; however, I found transcribing the tape recorded interviews within hours of interview enabled me to achieve the same outcomes. I was able to recreate a mental image of the interview interaction, the

facial expressions and physical cues which provided me with the additional insight needed to complete memoing. Hence initial analysis began with the memoing within hours of completion of the first interview which allowed me to prepare for the following interview in a timely manner. Preparation for following interviews involved identification of issues or concepts which might require confirmation.

Memoing

While codes conceptualise the data to which the analyst refers, memos serve as a means of revealing and relating by theoretically coding the properties of the substantive codes. A memo can be a sentence, a paragraph or a few pages (Glaser, 1978). Glaser proposes the writing of theoretical memos as a critical stage in the process of generating theory, arguing that without free memoing a theory will never be rich and ripe (Glaser, 1995). Memoing is designed to tap the initial freshness of theoretical notions, the goal of which is to "theoretically develop ideas (codes) with complete freedom into a memo fund that is highly sortable" (Glaser, 1978, p.83).

Theoretical sampling

Theoretical sampling was used to guide data collection. Theoretical sampling involves seeking out data sources to inform current theoretical analysis and commences from the beginning of data collection (Glaser, 1978). As data was collected and coded it was compared with previously collected data through constant comparative analysis.

Theoretical saturation of codes refers to the point at which no additional data are found which can contribute to the development of the properties of a particular category (Glaser, 1978). The various properties of conceptual codes were developed through a process of continual hypothesis until saturated. The process of continual hypothesis facilitated exploration of all aspects of the conceptual codes and their connection with other conceptual codes.

Data collection was controlled by the emerging theory. In other words, data were jointly collected, coded and analysed, thereby influencing decisions about which

data needed to be collected next and where to collect it, in order to develop the theory further. Glaser (1967, p. 42) proposes the basic question in theoretical sampling is: "what groups or sub-groups does one turn to next in data collection?" and "for what theoretical purpose?" The basic criterion influencing any decision regarding where to next collect data is the relevance for furthering the development of emerging categories (Glaser,1967).

At one point in the analysis a subtle difference in the shock experienced by the mothers whose infant's condition was diagnosed antenatally, compared with those diagnosed postnatally, was emerging, leading me to the decision to interview several mothers diagnosed antenatally. Suspicions about what was happening to them were confirmed in these subsequent interviews. Similarly, differences seemed to emerge in the progress of mothers through convalescence where infants were born with cardiac anomalies as opposed to gut anomalies. I therefore turned my attention to mothers whose infants were born with cardiac anomalies. I was able to confirm that for the participating mothers feeding as an issue, which arose uniformly in the cardiac group and impacted on their progress. Every interview was re-read and coded again after clarifying the concepts further. They were compared with each extract as done previously. Theoretical sampling on individual codes stopped when they were saturated, and integrated into the emerging theory as recommended by Glaser (1978).

Comparative analysis

The initial conceptual codes quickly became apparent within the data. As elements, incidents and behaviours were coded under conceptual codes they were compared with the elements, incidents and behaviours previously coded under that conceptual code. This process is referred to as comparative analysis (Glaser & Strauss, 1967) and illuminated the properties of each conceptual code. For example, indicators for the conceptual code **"shock"** were compared from each set of data. It soon became evident that many different emotional and physical symptoms of shock were displayed by the participants. Some of these were identified by mothers themselves while other obvious signs, such as disorientation were identified by myself. It also became obvious through the comparative analysis process that an episode of high anxiety was present in each event along

the continuum. These were not all coded as **"shock"**. Thus **"shock"** referred to more acute episodes. The degree of anxiety was variable along the diagnosis to discharge continuum. Eventually **"shock"** became a property of the **"distress"** phase of the **"maintaining equilibrium"** process. Theoretical memos were used to record the relationships between the properties of each conceptual code.

Glaser and Strauss (1967) proposed a method of continual comparative analysis to facilitate the systematic discovery of theory from data. Comparative analysis is a general method used for social units of any size (Glaser, 1967). Analysis initially involved reading the data for the purpose of identifying the preliminary codes and resulted in the identification of a range of conceptual codes. Thereafter each incident within the data was compared with existing conceptual codes. Eventually patterns within conceptual codes emerged and conceptual categories were able to be formed.

Comparative analysis is a strategic method for generating theory and is advocated for several reasons (Glaser, 1967). Firstly, comparative analysis facilitates the collection of data that can be employed for comparison between and within groups. Secondly, the generality of the theory is established as the boundaries of applicability are compared between groups. Finally, as the data collection continues, data are compared with the emerging theory to ascertain the relevance of the selected categories in relation to the emerging theory.

For example, the following conceptual codes thought to be involved in coping were grouped together under a general heading of *"**coping strategies**"* –

- ***acceptance of current capabilities***
- ***linking with others***
- ***comparing own situation***
- ***maintaining positive attitude***
- ***feelings of hope***
- ***ways in which mothers seek support***.

The properties of each category were determined and the context within which the category occurred was examined, as were the conditions under which it

functioned, thereby helping to clarify each category in relation to other categories. For example the condition under which "**shock**" arose was as a response to "**high anxiety**", this resulted in most cases with the exhibition of maternal distancing behaviours from the infant in order to decrease the anxiety. The concept, shock, was related to mother-infant availability, in that it decreased the mother's availability to her infant. The decrease in anxiety and her distance from the infant enabled her to reflect on her relationship with her infant within the context of the current crisis.

Memos were recorded on ideas, theories and questions which arose throughout data collection and analysis. All memos were recorded and were available to be used at a later time. Recording memos prevented valuable conceptual formulations being forgotten or mislaid in the volume of the data being analysed. This process was continued throughout data collection and coding.

As the categories evolved, relationships between many of them became evident and preliminary theories began emerging. It eventually became clear that "**distancing**" and "**handing over**" were short-term strategies used to decrease initial high anxiety. My early questions regarding the developing theory included questions about the emerging theories, for example:

> Is ***"distancing"*** a coping strategy or is it ***"the handing over"*** of parenting responsibilities or responsibility of "***infant's wellbeing"*** because this is ***"best for infant"***?

Coding

The initial collection of data was based on the general perspective of examining more closely the developing relationship between mothers and their infants facing serious illness in the NICU. Coding was confined to the transcribed interviews. It was carried out for the purpose of identifying the problem for mothers in the substantive area and the way in which mothers resolved the problem. The goal of coding was to generate a set of categories and their properties which fitted, worked and were relevant for integration into a grounded theory (Glaser, 1978).

The essential relationship between data and theory is a conceptual code. Concepts refer to underlying meanings or patterns identified within incidents (Glaser, 1998). These concepts were identified within the data and labelled using conceptual labels or codes. A grounded theory is developed by discovering the relationships between conceptual codes which have been generated from the data (Glaser, 1978). Two types of codes are generated – substantive codes and theoretical codes.

Substantive codes

Substantive codes conceptualise the empirical substance of the area of research. They identify the problem or behaviour being examined in the substantive area. Two types of coding are carried out in order to define the substantive codes – open coding and selective coding (Glaser, 1978). A description of each process follows.

Open coding

Substantive coding began with open coding or "running the data open". Initial coding was very broad. Glaser (1978, p.56-58) recommends that every element, incident and behaviour seen and heard be coded. It involves the breakdown, analysis, comparison, and categorization of data. Data were coded under coding headings reflecting the concept to which they were related.

Glaser (1978, p.57) recommends a set of questions being asked of the data during the coding process: "What is this a study of?" "What category does this incident indicate?" "What is actually happening in these data?" The questions act as prompts to maintain theoretical sensitivity. My own interpretation of these questions throughout coding was "What is going on here?" "What is the meaning of the situation to this mother?" "What is her major concern?" "How does she manage?" These questions were continually utilised during the processes of collection, coding and analysis of data.

In open coding, incidents or events are labelled and grouped together via constant comparison to form categories and properties. Open coding allowed the direction

in which to take the study to be identified and prevented sampling becoming prematurely focused on a particular problem. All interviews were coded sentence by sentence. Each incident was coded under as many conceptual codes as possible to achieve full theoretical coverage which was thoroughly grounded (Glaser, 1978).

Two types of conceptual categories emerged as the process of analysis continued. Glaser (1967, p. 107) refers to these as *sociological constructs* and *in vivo* codes. Sociological constructs refer to codes developed by the researcher which are usually highly descriptive and add meaning to the analysis. They are usually based on the researcher's expert knowledge of the substantive area under study. An example in the current study would be the conceptual code of "**parent–infant relationship**". In vivo codes are taken directly from the language of the substantive area. They tend to be the behaviours which explain how the basic problem is resolved or processed. For example, participants described their feeling of "**connecting**".

An incident can be coded for several categories. This strategy forces the analyst to use an incident as an illustration only once, for the most important among the many properties of diverse categories that it indicates (Glaser & Strauss, 1967). For example, this quote, in which a mother is referring to another mother with a infant whose diagnosis was the same as her own infant's, was initially coded under both the conceptual codes of "***comparing own situation***" and "***ways in which mothers seek support***".

> *PAULA*
> *I thought what a shame he had been transferred and we'd had no idea. I had seen her in the expressing room and she didn't say anything about it until they were getting ready to go. Not that there's a lot to say but it would have been nice if someone had said 'Look there's this Mum here' though I suppose it's that confidentiality thing too. You can't say too much about other parents but maybe it would be something to have on offer, wouldn't it?*

Table 3.1:Conceptual codes collapsed under conceptual category headings – fifth revision 24/10/05.

Stage	**Response**
Diagnosis	**Shock**
Admission into maternity/Birth	Parent's' perception of too many people
Surgery	Reliving previous experience
Convalescence / Feeding	Removal of self from situation
Discharge	Parents' feelings of helplessness
Maternal – infant interaction	Family needs
Maternal physical condition	Foreign place
Maternal emotional state	Feeling cheated
Infant's physical condition	Not seeing the infant
Parent-infant communication	**Initial response to coping – distancing – decreasing anxiety**
Interaction with others	Decision making process - hand over control to experts
Conflict	Keeping your distance – emotional and physical
Relationship with family	Material versus emotional needs fulfilled
Relationship with spouse	**Positive coping - approach - connecting**
Communication	Acceptance of current capabilities
Delivery of information to mothers	Coping strategy
System – Resources – environment includes name tags, book	Language
Being messed about	Linking with others
System –Staffing – experience level	Mothers compare own situation
System – Staffing collaboration with families	Mothers maintain positive attitude
Obstructing connection	Mothers' feeling of hope
Connection	Ways in which mothers seek support
Facilitating attachment	Trying to make contact
Still able to parent	Refocus on another plan
Physical connection	
Eye contact	

Soon patterns between conceptual codes began to emerge which enabled individual conceptual codes to be collapsed under a single conceptual heading. To provide an example, initially ***"staff – family collaboration"***, ***"obstructing connection"*** and ***"being messed around"*** were all viewed as individual codes

(refer to Table 3.1). However, it soon became evident that incidents coded under these headings were all similar and overlapped in several ways. They each provided examples of how the opportunities of connecting had been interrupted or obstructed and, more often than not, the interruption or obstruction was either avoidable or totally unnecessary. Hence they were all regrouped under ***"being messed around"***.

A concept may be generated from one incident, which then becomes one of many possible indicators for, and data on, the concept. These indicators are then sought for the comparative analysis (Glaser & Strauss, 1967). For example, one theoretical category ***"shock"*** may affect the meaning of a mother's relationship to her infant. The category of ***"shock"*** can be generated from either the observation antenatally of how mothers react to the diagnosis or at confirmation of preterm labour or postnatally when an anomaly is obvious. Irrespective of when the event occurs, be it confirmation of diagnosis or surgery, it is likely that ***"shock"*** is a category related to the relationship between the mother and infant.

Selective coding

Selective coding, as opposed to open coding, applies to that which is carried out after the core category has emerged. Whereas previously during open coding all data were coded, during selective coding only incidents relevant to the core category were coded. Selective coding for a core category means delimiting coding to only those variables that relate to the core category in sufficiently important ways to be used in a theory. The core category becomes a guide to further data collection and theoretical sampling. The goal of grounded theory is to generate a theory that accounts for a pattern of behaviour which is relevant for those involved. The core category accounts for this variation in behaviour of individuals. The generation of theory occurs around a core category.

Data collection stopped when it became evident that no new data related to the core category were being found. Glaser and Strauss (1967) refer to this as the point of theoretical saturation. Once theoretical saturation was reached, theoretical coding focused on identifying the relationships between subcategories and properties and the core category for the purpose of theory development.

Memoing continued throughout this process. I made notes regarding issues for which I might need to return to the literature to resolve. Throughout the process I continued to reread the grounded theory methodology. I did this several times during the project to ensure I stayed true to the Glaserian method.

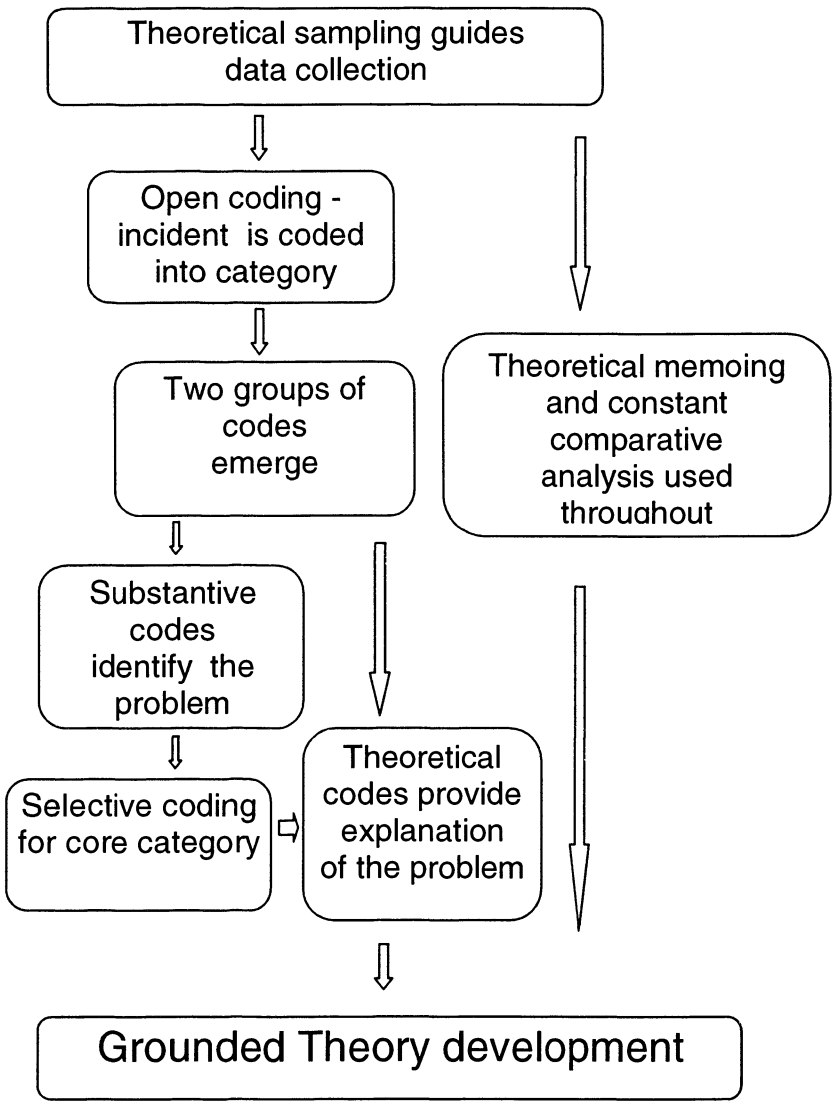

Figure 3.1: Flow chart of steps involved in developing a grounded theory.

Table 3.2: Theoretical families identified by Glaser (1978).

1	The six C's	causes, context, contingencies, consequences, covariances, conditions.
2	Process	stages, phases, progression, passages, graduations, transitions, steps, ranks, careers, orderings, sequencing, shaping, cycling.
3	Degree family	limit, range, intensity, extent, amount, polarity, extreme, boundary, rank, grades, continuum, probability , possibility, level, cutting points.
4	Dimension family	dimensions, elements, division, piece of, properties of, facet, slice, sector, portion, segment, part, aspect, section.
5	Type family	type, form, kinds, styles, classes, genre.
6	Strategy family	strategies, tactics, mechanisms, managed, way, manipulations, manoeuvrings, techniques, ploys, means, goals, arrangements, positioning.
7	Interactive family	mutual effects, reciprocity, mutual trajectory, mutual dependency, interdependence, interactions of effects, covariance.
8	Identity /self family	self image, self concept, self worth, self evaluation, identity, social worth, self realization, transformations of self, conversions of identity.
9	Cutting point family	critical juncture, cutting point, turning point, breaking point, benchmark, division, tolerance levels, point of no return.
10	Means - goal family	end, purpose, goal, anticipated consequence, products.
11	Cultural family	social norms, social values, social beliefs, social sentiments.
12	Consensus family	agreements, opinions, conflict, descensus, differential perception, cooperation, homogeneity-heterogeneity, conformity, non conformity.
13	Mainline family	social control, status passage, social organisation, social order, social institutions, social interaction, social worlds, social mobility.
14	Theoretical family	parsimony, integration, relationship to other theory, interpretive. Inductive/deductive, multivariate structure, theoretical codes,
15	Ordering or elaboration family	structural, organisational, temporal and generality.
16	Unit family	collective, group, nation, organization, aggregate, situation, context, arena, social world, behavioural pattern, society, family.
17	Reading family	concepts, problems, hypotheses.
18	Models	pictorial model, the theory.

Theoretical codes

Theoretical codes conceptualise how the substantive codes may relate to each other as hypotheses to be integrated into a theory (Glaser, 1978). They provide a link, cause or explanation of the problem or behaviour. Theoretical coding is achieved by comparing different theoretical memos to each other. For example, a theoretical code was used to describe the initial behaviours exhibited by mothers on experiencing high levels of anxiety or "**shock**". It was labelled "**distancing**".

Glaser (1978) recommends the grounded theorist refer to many theoretical codes in order to be sensitive to rendering explicitly the subtleties of the relationships in the data. Table 3.2, above, lists 18 item theoretical families identified by Glaser (1978) to utilise during theoretical coding. He advocates the use of the coding families with theoretical sensitivity in the generation of grounded theory. Several different families may be used to analyse individual concepts (1978, p.73-82). The theoretical coding families outlined simply provide different ways of analysing each concept. They stimulate the researcher to look for the patterns, similarities, grading, consequences, conditions, and interactions in their data (1978). In this way the properties of concepts emerge and the relationships between the concepts become clear.

These theoretical families were utilised during analysis to review emerging concepts. Examples of the utilisation of theoretical families in the study are given in the following analysis of the concepts of anxiety and communication.

"**Anxiety**" was recognised early in coding as a prominent concept. It was analysed in terms of being a consequence of another factor which was the realisation of the threat to the mother's relationship with her infant. It was also examined in terms of being the cause of the behaviours displayed by mothers. The conditions under which anxiety evolved were examined. It became obvious that anxiety was a property of each event along the diagnosis to discharge continuum. It was therefore also examined in terms of degree of anxiety exhibited across the continuum.

The concept "**interaction with others**" was examined in terms of the interactive theoretical coding family since the basic component of communication is interaction between two individuals. This concept was also analysed within the mainline family of traditional sociological perspectives of social interaction and social worlds. All concepts were similarly analysed utilising one to several families.

IDENTIFICATION OF THE PARTICIPANTS PROBLEM , EMERGENCE OF CORE CATEGORY AND MAJOR THEMES

Initially many factors appeared to impact on both the mother and her infant. It was obvious from the beginning of analysis that the mother's priority was her relationship with her infant. Maternal focus was the wellbeing of the infant and maintaining contact with the infant throughout all events from diagnosis to discharge.

I identified the problem for these mothers as being the threat to their ongoing relationship with their infant. The diagnosis of a congenital anomaly requiring surgery altered the meaning of the relationship with the infant, previously perceived as certain to uncertain. I therefore labelled the participant's problem as "***preserving a relationship while enduring a crisis***" quite early in the analysis process. The meaning of the relationship for these mothers before diagnosis had been that of a live healthy infant capable of sharing a long, loving relationship with them. Potential threats to the relationship could therefore comprise both physical and emotional aspects. Carol was aware that she might possibly not take her infant home. The threat was related to the infant's physical condition.

> *CAROL*
>
> *I mean we came in here thinking um we could be here for months and we were prepared for a fight. Um and if he was going to fight as hard as he can well we would do whatever we can and we were pretty realistic. Because we were given a 50 /50 chance of him surviving, as much as we didn't want to look at the down side, we had already discussed you know, if we did have to have a funeral which way we wanted to go and so on.*

In addition to her concern regarding her infant's intellectual prognosis Paula was also concerned about the emotional aspect of her relationship with her daughter. She felt she needed to support her infant and continue to hope for the future.

> *PAULA*
> *No not a lot, but I am aware of it but I want to be positive for her too. She doesn't need me to have negative vibes about worrying how she is going to be learning and functioning. To us she's ... we were just so proud of her getting through the heart side of it and anatomically like physically, she's got the heart sorted out um and like with this webbing so there the biggest things I suppose and they are going to look into this palate or whatever. But they're big things and I suppose we're just happy she can walk and talk and her heart 's beating and we love her for the little girl she is and that's the best you can do for her, she needs all the positive stuff.*

I was aware of the pressure to identify the core category as it explains how the main concern or problem of participants is being resolved. In this case it would explain how mothers were able to preserve a relationship with their newborns while enduring the crisis of diagnosis of congenital anomaly and subsequent surgery. I learnt from the grounded theory literature that this concern not unusual among beginner grounded theory researchers.

Glaser developed the following criteria for core categories (Glaser, 1978, p. 94). The core category: must be central, must recur frequently, take more time to saturate, connect with other categories; it must come quick and richly; must have clear and grabbing implication for formal theory; must have considerable carry through; does not lead to dead ends; can be any kind of theoretical code - a process, condition, dimensions or a consequence.

I had answered the preliminary questions of "What is going on here?", "What is the meaning of the situation to this mother?", "What is her major concern?". The next step was to address the question "How does she manage?" At this point in the analysis I had two possible categories which fitted the core category criteria in addition to many subcategories. Both categories were closely related. I began the

process of reviewing the relationship between these two major categories with the other subcategories. I made the decision to go with the category related to the majority of subcategories and began the process of selectively coding for that single core category. The core category was coded ***"maintaining equilibrium"***. Mothers were able to decrease the perceived threat to their relationship with their infant by utilising strategies to sustain that relationship. Initially I was under the impression there were two processes at work. A process represents movement from one point to another over time. Participants were in the process of becoming new mothers. In addition, they were either pregnant or had just given birth when receiving the diagnosis of their infant's congenital anomaly. The process of transitioning from diagnosis to discharge was imposed on the process of becoming new mothers. Events occurring during their transition from diagnosis to discharge appeared to intersect the process of becoming new mothers.

At this time, I felt the need to look for further examples of grounded theory studies, including research papers and theses. This reading provided me with a broader insight into how I might continue the analysis. However, it was not until I read Blumer's (1969) insights into Mead's work a second time that I felt I truly had an understanding of exactly what I needed to identify. Until then I think my understanding of the process I had been witnessing was superficial. I then analysed the series of events experienced by mothers and infants along the "***diagnosis to discharge***" continuum using the Process and the Degree theoretical coding families.

The interval beginning at diagnosis and ending at discharge was described as a continuum because it referred to a degree of change. The intensity or change in the level of anxiety experienced by mothers changed along the continuum. Earlier in the continuum "acute intense" anxiety was experienced about the potential mortality or morbidity of the infant. Later "acute intense" anxiety changed to "chronic" anxiety around the infant's uncertain physical prognosis, feeding issues and the developing emotional relationship with the infant. The diagnosis was the first and one of the most anxiety-provoking of the events along the continuum.

Mothers were not in the process of becoming new mothers - they *were* already new mothers. They were in the midst of developing a relationship with their infant and experiencing difficulty functioning within their role as mother. Mothers were in a state of conflict between wanting to halt versus continue their relationship with their infant. The meaning of the situation for them was that they were facing a crisis which threatened their relationship with their infant. It was this difficulty that accounted for the fluctuation between distancing themselves from and then approaching towards the infant at different times that I had been witnessing.

A process often implies positive movement toward a goal, which in the case of these mothers did not always occur. Movement along the continuum from diagnosis to discharge did not always result in a positive movement and therefore did not constitute a positive process. Mothers artificially dissected the continuum into discrete events. They were able then to focus on preserving their relationship within each event rather than face the entire continuum. Mothers did however, utilise a process within each event along the continuum. They utilised a process of "***maintaining equilibrium***" to preserve their relationship, when faced with the challenges that determined each of the discrete events along the continuum.

As comparative analysis continued it was obvious that the "***maintaining equilibrium***" process was mediated by three factors - "***interaction with others***", "***interaction with the health system***" and "***mother and infant interaction***". Many of the concepts previously identified fitted into these three themes. The common premise between themes was that they all influenced the mother's perception of her ongoing relationship with her infant. These three mediating factors - "***interaction with others***", "***interaction with the health system***" and "***mother and infant interaction***" - were all interrelated. They all impacted on the mother's perception of the situation during each crisis event along the "**diagnosis to discharge**" continuum. The way in which each theme impacts on the mother's perception of the situation alters as they progress along the diagnosis to discharge continuum.

The theoretical analysis begun during open coding continued throughout the selective coding process. Ongoing data collection and analysis was guided by the

core category of "***maintaining equilirium***". Many of the existing categories were found to be directly related to the core category. The developing theory emerged as these relationships became clearer. This process was facilitated through sorting and analysing memos relating to each category.

A concept map was also developed to illustrate the relationships between categories and the developing theory. This acted as a precursor to the write–up. The concept map was repeatedly reviewed and adjusted during theoretical analysis. It was helpful to use this strategy to demonstrate how each conceptual category included within each of the three major themes was able to be integrated with the core category in order to develop the substantive grounded theory of how mothers preserve a relationship with their infant in the NICU.

CONCLUSION

The importance of symbolic communication is evident in both Mead and Dewey's (Manis & Meltzer, 1972) viewpoints. Dewey (1967) contended that symbolism expressed in language is the element that differentiates humans from other species and that linguistic communication makes human society possible. The pragmatist approach views living beings as attempting to make practical adjustments to their surroundings. Symbolic interactionism extends this view to meanings not simply residing in the object but emerging from social interaction processes, such as the relationship developing between parent and infant in the NICU context.

Blumer's (1969) perspective is that society is composed of individuals interacting with the objects they encounter, such as mothers' interactions with their infants, with their immediate family and with individual health workers within the hospital institution. These interactions are undertaken within the context of the hospital situation which imposes routines, rules and policies upon them with which they must interact. Actions may take place as a result of interactions between individuals, between collectives or on behalf of others. Despite this, action remains the property of the individual and is carried out within the context in which the individual carries out the action.

Blumer (1969) emphasized that groups were individual collectives working together. Eventually, group action will result in cultural and societal formations, maintenance or change, just as mothers might learn to respond in pre-defined ways to the cultural and social expectations and boundaries placed on their developing relationship with their infant in the NICU environment. Joint actions, networks and social functions take on a character that separate the collective group of mothers with infants in the NICU from the individual parent and infant; but these actions do not operate automatically. Individuals must make them work. Society is continually renewed by the actions of individuals and groups, and this is achieved by the communication and negotiating processes occurring in any situation people find themselves.

Symbolic interaction provides a suitable theoretical perspective for studying how mothers interpret the objects and rituals of the NICU and the actions of other people, such as other parents and health staff, and how this process of interpretation leads to a particular way of behaving towards their infant in this specific situation. This perspective views behaviour as a dynamic process and, as such, requires an understanding of how the parent interprets their environment and redirects their behaviour accordingly. It is imperative to understand what mothers know about this particular world, or experience, and what they believe to be important in developing a relationship with their sick infant. Symbolic interaction is an appropriate theoretical approach in interpreting this experience.

The Glaserian methodology was chosen for this project as it provides the flexibility required to capture what is occurring in the area under study. I believe that the Glaserian grounded theory approach reflects more closely the theoretical framework of symbolic interactionism in that the theory is guided by the participants. This is important in this particular study as the substantive area under study involves the interaction between infants and their mothers in the NICU context.

The Chapter provided rationales for the decisions made regarding the study process. The steps taken within the study process outlined included those involved in gaining ethics approval, enrolment of participants and data collection,

management and storage. The next Chapter presents a detailed discussion of the major results of the grounded theory analysis.

CHAPTER FOUR: PRESERVING A RELATIONSHIP WHILE ENDURING A CRISIS

INTRODUCTION

This Chapter provides the context within which the mothers managed to preserve their relationship with their newborn. The participant's problem identified as "***preserving a relationship while enduring a crisis***" was experienced by mothers as they transitioned the ***"diagnosis to discharge continuum***. The ***"diagnosis to discharge continuum***" was composed of crisis events that were able to be developed individually as major conceptual categories. Mothers found themselves propelled along the continuum of crisis events. The way that mothers managed to move along the continuum is explained by the basic social process of "***maintaining equilibrium***". The "***maintaining equilibrium***" process helped mothers regain some control of the situation which in turn enabled them to maintain contact with their infant and participate in care. ***"Maintaining equilibrium***" comprised several different phases. As mothers moved along the "***diagnosis to discharge continuum"***, three mediating factors, "***interaction with others***", "***interaction with health system"*** and "***mother and infant interaction***", impacted on their perception of the situation during each crisis event.

The problem for mothers is first described and then the process of the core category "***maintaining equilibrium***" is explained The way in which mothers create the meaning of a situation, the alteration of this meaning during the experience of delivering an infant with a congenital anomaly, and the way in which they manage to sustain their relationship with the infant is explained.

"Diagnosis to discharge continuum" is described in this chapter as it provides the foundation for "***maintaining equilibrium"*** as described in chapter five. Each event along the continuum is discussed in turn, with the similarities, differences and interrelationships between each event outlined. The process of "***maintaining equilibrium***" illustrates how the mothers managed to move through each of the events along the continuum. The three factors which mediated this process are presented in Chapter Six.

THE PARTICIPANT'S PROBLEM

The "chief area of concern" (Glaser, 1978) or problem for mothers was identified through the grounded analysis of data collected during interviews as described in Chapter Six.

Mothers in the study experienced extreme distress when they perceived their relationship with their infant was under threat. This level of distress confirmed to me the importance of the developing maternal-infant relationship. The "chief concern" reported by mothers in this study was the problematic interactions they encountered while trying to preserve their relationship with their infant. The experience from the time of diagnosis of their infant's congenital anomalies through to their infant's discharge from hospital was described by mothers as a crisis with which they had to deal. Therefore the problem for mothers was identified as **"preserving a relationship while enduring a crisis".**

According to the theoretical perspective of symbolic interactionism there is an interrelationship between human activities, interpersonal interactions, experiences and creation of meaning. The problematic interactions encountered by the mothers while trying to preserve their relationship with their infant has great descriptive, but limited explanatory power. In other words, the problems mothers in my study encountered, and the impact of these on their relationship with their infants, can be described but the description does not provide us with insight into how the mother-infant relationship continues within that context. A more complete level of understanding is gleaned from understanding how they manage to preserve the relationship. The process the mother uses to manage specific kinds of problematic interactions which impact on her relationship with her infant is the key to how she manages. Identification of the problem for mothers facilitated the "discovery of what accounts for most of the variation in processing the problem" or the core category "***maintaining equilibrium***".

Symbolic interactionism theory states that individuals act on the meaning objects hold for them, for example, reacting to a situation based on the threat to something to which they are committed. Their perception of threat is based on the meaning of the situation. Individuals create meaning during social interactions.

An individual may or may not have previous experience on which to organise their perceptions and attribute meaning to situations. Individuals will cope according to their perception of the possible outcomes. Symbolic interactionism acknowledges that the meaning a mother attributes to her relationship with her infant is unique, that it will influence her perception of that relationship and in turn, her behaviour within that relationship. The meaning of a mother's relationship with her infant influences how she will respond during interactions with the infant. This meaning also influences her responses to the health system and with other individuals during social interactions.

In this study the mothers created meaning during interactions with their infants, with the health system and with others (refer to Figure 4.2). The meaning of these relationships were altered during these interactions. They provided numerous examples of possible threats to their ongoing relationship with the infant. One mother (Alice) interviewed in this study perceived her infant as not becoming "attached" to her for the first week after delivery because the infant preferred to look at her husband. She assumed this was the case because she had required an emergency caesarean section to deliver the baby which meant her husband alone had accompanied the newborn infant to theatre for cardiac surgery. This perception changed once she was able to breastfeed her son. She recalls the exact moment when he appeared to really connect with her. The meaning of the situation is different for each individual and is dependent on their perception of what is happening.

The perception of a threat to the relationship with the infant is based on the meaning of the situation, which may range from the initial obstruction of emotional and physical connection with the infant owing to acute illness, or in the worst possible scenario, the death of the infant. The range of possible meanings in developing a relationship with the infant undergoing major surgery has the potential to represent a threat to the mothers' perception of the ongoing relationship.

In the following example, Alice had previous experience of the NICU with her firstborn son who had been diagnosed with the same condition as the son she was

about to deliver. Her firstborn son had died at age four. The meaning this experience held for Alice was a continuing threat to the ongoing relationship with her newborn. This infant, like her firstborn, had several setbacks while in neonatal intensive care and this had extended the length of his hospitalisation. So, despite expert advice to the contrary, her present expectation was that the infant might not survive. Her past experience in a similar situation influenced her perception of the present situation.

ALICE

And there I was on the table thinking I don't want him to come out, I didn't want him to come out because I really was not looking forward to the aftermath, I really was scared about it, I was scared about losing him.

RESEARCHER

So what were you scared about immediately after birth

ALICE

Just after birth and his future I was scared I would lose him I mean it still scares me now. Because no one can give me guarantees and that's fine I mean I understand that um but having been through it once I know that anything can happen.

In the following example Susan's focus on her ongoing relationship with her daughter had moved from one surrounding the survival of the infant to concern regarding her ability to bond with her daughter. Susan was concerned that the necessity for physical distance due to surgery may have affected their ability to develop a relationship. In this example she is referring to the positive effect of close skin to skin cuddling (Kangaroo cuddles) between a mother and her infant.

SUSAN

I think the cuddles are very important. Especially the Kangaroo cuddles yeah that was very important to me because at one stage when she was in ICU and wasn't able to be cuddled I was a bit worried that a bond

wouldn't happen but as time has gone on that hasn't been a problem at all.

The mother's perception of the degree of threat to her relationship with her infant was related to the context of the situation in which she found herself. For example the perception of mothers in this study of their relationships with their infants at birth differed considerably depending on the health status of the infants. If the infant was acutely ill the mother tended to perceive a long-term relationship with her infant as under threat (because of the need for hospitalisation and the uncertain prognosis), whereas if the infant was well the mother's expectation was of a long-term relationship with her infant.

The perception of threat differed according to the point they were at on the "***diagnosis to discharge continuum***". The mothers' earliest priorities focused on treatment options and expert care which reflected their fear regarding the physical sequelae of the infant's condition. These ranged from the fear of the infant dying, or of sustaining physical handicap. Later during convalescence and as they neared discharge, their priorities focused more on the emotional needs of the infant and the consequences of the situation for their ongoing relationships with their infants.

Mothers attempted to resolve this threat by altering the meaning of the situation from one of crisis, where they were faced with little hope in regard to their ongoing relationship with the infant, to one of a challenge to be faced by employing a number of options for preserving the relationship (see Figure 4.1). They achieved this through their efforts to preserve the relationship while moving along the "***diagnosis to discharge continuum***". The core category and the basic social process used by mothers were therefore labelled "***maintaining equilibrium***". The process of "***maintaining equilibrium***" accounts for the change over time in the meaning of the situation for mothers. A change in the meaning of the situation for the mothers occurred within each event along the continuum, in addition to the change in meaning of the relationship which occurred between diagnosis and time of discharge.

To cope successively with each new crisis they were facing the mothers artificially dissected the ***"diagnosis to discharge continuum"*** into the discrete events of "***diagnosis***", ***"birth"***, ***"surgery"***, ***"convalescence"*** and "***discharge from the neonatal unit"***. Each event along the ***"diagnosis to discharge continuum"*** was composed of many interactions which influenced the meaning of the mother's relationship with her infant.

A maternal perception of the developing relationship with their newborns was altered through interactions with the infant, others and the health system. These interactions occurred within the context of the situation within which the mothers found themselves, attempting to preserve a relationship with their sick infant.

"Mother and infant interactions" refers to verbal and non-verbal interactions which occurred between the mother and her infant from the time of diagnosis to discharge (see Figure 4.2). ***"Interactions with others"*** refers to interactions between the mother and other individuals, such as care staff, regarding her infants care (see Figure 4.2). ***"Interactions with the health system"*** refers to the many facets of the health care system which influenced the ability of mothers to sustain a relationship with their infant (see Figure 4.2), including the schedules of healthcare professionals and availability of resources.

The strategy used by mothers to sustain their relationship with their infant was to achieve equilibrium at each event along the ***"diagnosis to discharge continuum"*** which facilitated their connection with their infant. The process of ***"maintaining equilibrium"*** comprised four phases: ***"distress"***, ***"response"***, ***"achieving equilibrium"*** and ***"connecting"*** (see Figure 4.1). Mothers move through the ***"maintaining equilibrium"*** process during each event along the ***"diagnosis to discharge continuum".*** The process enables them to sustain the connection with their baby as they move from diagnosis to discharge. The process is best described as the process by which mothers are able to amend their initial response to each crisis experience through reflection and consideration of other possible outcomes. The process of *"**maintaining equilibrium**"* is discussed in more detail in Chapter Five.

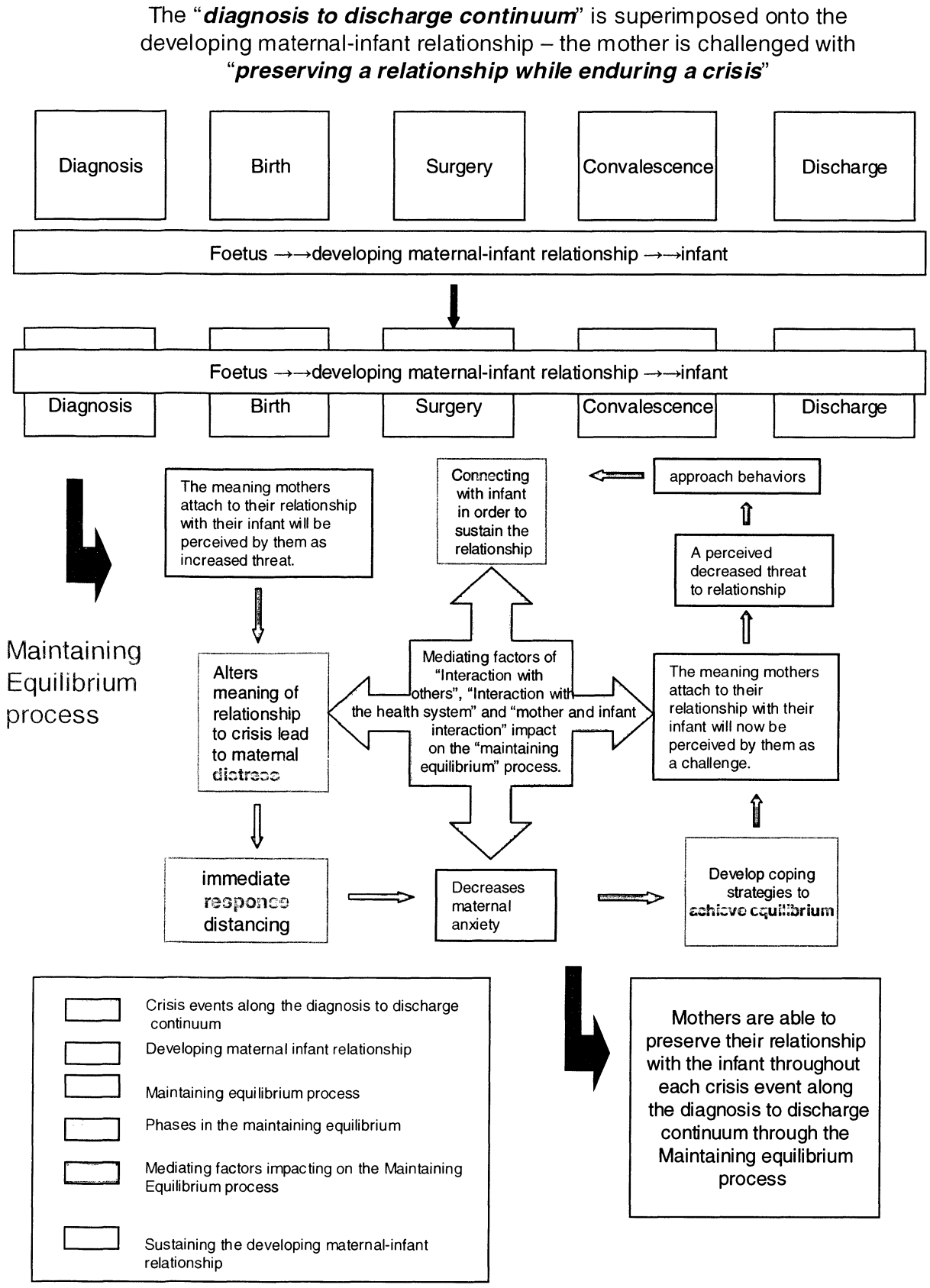

Figure 4.1 Flow diagram of the"Maintaining equilibrium" process

THE DIAGNOSIS TO DISCHARGE CONTINUUM

Mothers were propelled along the ***diagnosis to discharge continuum*** by forces which, for the most part, were out of their control, such as hospital schedules, staff and resource availability and the infant's physical condition. They had no real control over when the birth of their infant would occur, when surgery would be performed or when their infant would be discharged. These events occurred whether or not they were psychologically ready for them.

The events along the continuum developed individually as the major conceptual categories of "***diagnosis***", "***birth***", "***surgery***", "***convalescence***" and "***discharge***". Mothers who had received their infant's diagnosis antenatally experienced each event along the continuum. Mothers who had received their infant's diagnosis postnatally, although beginning the continuum at "***diagnosis***", had already given birth. However, this when they were asked at interview to tell their story they described the "***birth***" and then the "***diagnosis***" events.

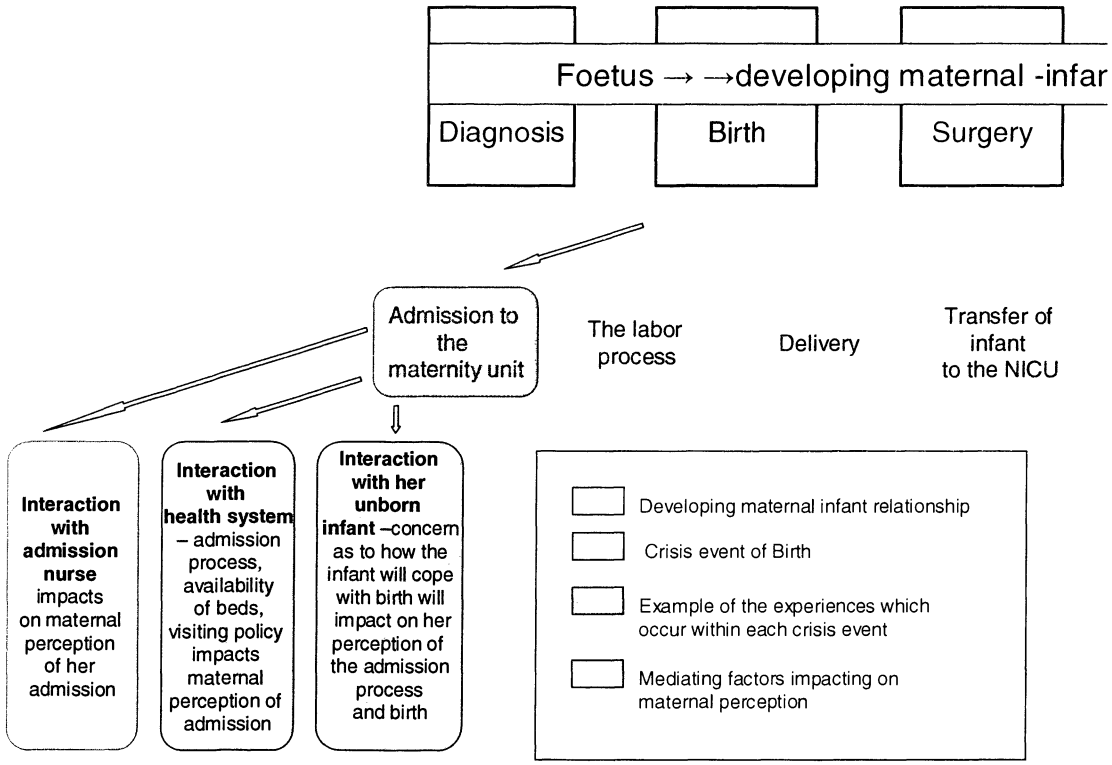

Figure 4.2 Interactions impacting on maternal experiences within each crisis event.

Each event included many individual experiences for mothers. For example in the event labelled "***birth***", mothers were faced with admission to a maternity hospital, the labour process, the actual delivery and then the transfer of their infant to the NICU. Each experience required interactions with other people and with health system factors (see Figure 4.2). These interactions impacted on how mothers perceived the meaning of the situation in regard to their future relationship with their infant (see Figure 4.1). Mothers referred to these events along the continuum in terms of distinct crises they needed to overcome in order to maintain their relationship with the infant.

Differences in the degree and type of connection made between mother and infant depended on the event. The ***"maintaining equilibrium"*** process was common to all events along the continuum. "***Interactions with the health system***", "***interactions with others***" and "***the mother –infant interaction*** influenced the strategies used by mothers to sustain their relationship with their infant by altering the meaning of the situation for the mothers (see Figure 4.1). These mediating factors also affected the situational factors such as the beginning, the end and the length of each event.

Mothers reported experiencing varying levels of emotional and physical control along the continuum. A description of each event and the associated difficulties faced by mothers follows.

Diagnosis

A diagnosis of congenital malformation that required urgent treatment at birth threatened the pregnant woman's ability to sustain her relationship with her unborn infant. The event of ***"Diagnosis"*** began with the actual communication of the diagnosis to mothers and extended up to admission to hospital. Antenatal diagnosis normally occurs between 16 and 20 weeks gestation. The mothers described their initial reaction as "**shock**". They either used the term "**shock**" or used descriptors of physical, psychological responses which implied a shock reaction, such as blurred thought patterns, disorientation, uncontrollable crying, and the initial disbelief despite credible sources of information.

The behavioural responses displayed by Lucy and Alice were typical of those displayed by all mothers in the study. These symptoms of distress reappeared in response to challenges the mothers experienced along the diagnosis to discharge continuum.

LUCY

Um I suppose I found out at the 19 week ultrasound so I had plenty of warning but I suppose I was in shock because I'd had four children who'd had no problems. .So those first few weeks after I found out I was very emotionally upset. I couldn't think clearly and I cried.

ALICE

I would just cry and cry and cry in disbelief and shock and just can't believe it and why has this happened to us and all that.

The following example refers to the experience of a mother whose infant was diagnosed in emergency after becoming ill at home. Despite symptoms occurring over several days at home, being urgently referred by the community nurse to her Paediatrician and then in turn urgently referred to the emergency department this mother was still unable to comprehend the seriousness of the situation.

PETA

And going to emergency. It was just such a shock. We went to the early childhood centre and I thought they were going to say here's a drug or something, this will make him eat you know. Not that I would speak to Dr W and he would give me a choice of hospital where do you want to go , I'm at Westmead. So we just came into emergency and they were waiting for him and they said is this the baby from Y and we said yep and they just grabbed him from me and we were in emergency and there were ten doctors working on him and that was scary.

RESEARCHER

So what were you thinking then?

PETA

I wasn't thinking it was just more shock. I mean he was in the car and the day before he was fine and I think. You have no idea what I was thinking but more so shock. It was shit - reality check. But never a question of them, what are they doing. Ten doctors on one little baby was just.

The maternal perception of their infant's diagnosis and subsequent prognosis was influenced by interactions with health professionals and interactions with the health system in the form of support services. The interaction surrounding communication of the diagnosis was perceived as poor by mothers. Often there was a delay between ultrasound confirmation of an anomaly and discussion with cardiologists and surgeons.. In Laura's case it was only two weeks.

LAURA

And even then even when they told me it looked like that I still didn't really believe it. I just thought that once I go to this specialist...I think I had an appointment with my Obstetrician on the Monday fortnight. I thought once I go to see him he'll have another look and it'll be OK ... because I suppose I was hoping that it was something other..

Yeah. So I wasn't really phased when I initially heard the news because I was hoping it was wrong. But then I had the appointment on the Monday after. He basically confirmed the diagnosis. I think I was in shock because that confirmed it for me then once he had said it doesn't look quite normal. Like obviously he couldn't see as well on his machine as on the ultrasound but he could still see it wasn't quite right. And that confirmed it. So Oh I suppose I just sank. I had a sinking feeling, reality hits and it is the right diagnosis.

Several mothers were given the diagnosis alone, without a support person present. It was evident from the mothers' emotional and behavioural responses when given the diagnosis that they were ill equipped emotionally or cognitively to take in all the information. Several mothers reported experiencing sleep disturbances, imagining what could go wrong during labour and what their infant might

experience at birth. One mother continued to have nightmares from diagnosis to delivery.

The inability to visualise what would happen at the time of delivery appeared to be very important to several mothers diagnosed antenatally. Consequently they experienced the remainder of their pregnancy as extremely stressful because of their inability to prepare themselves for the delivery as was Hazels experience.

> *HAZEL*
> *I was just worried mainly about um lack of oxygen when the baby was born that it would cause brain damage and problems like that and I didn't know what sort it would have to be a special delivery or anything like that but then I saw my obstetrician and he said oh no it should be just a normal delivery which it was.*
> *And then I was just imagining, trying to imagine what would be happening to the baby when it was born and all of that cause I hadn't really. And that wasn't really explained exactly what would happen to the baby when it was born. So I didn't, I was having nightmares actually.*

The majority of mothers who were given a diagnosis antenatally reported a continuation of anxiety throughout the remainder of the pregnancy, which heightened towards the expected date of delivery. This period of incapacity appeared to extend from several weeks to months. The uncertainty around what would happen when they delivered their infant hindered their ability to view their relationship with their unborn child in a positive way. Whereas previously they had been able to look forward to a normal delivery and imagine themselves interacting with a healthy infant, they were now faced with a very different scenario.

In the following example Alice and her husband Todd were offered termination of the pregnancy once the diagnosis had been confirmed. This couple had previously lost a child with a similar diagnosis. She had expected a healthy baby from this

pregnancy. Alice describes her emotional state as she considers her ability to cope with the life of her unborn child.

> *ALICE*
> *Anyway it was a case of the next couple of days just a hugh rollercoaster of emotions. Just um do we, don ' t we, do we, don ' t we it was horrible. It was the second most traumatic thing to happen in my life next to losing Daniel. It was that horrible. And then I was wishing before the amino results came in and this is before we decided hoping, hoping, hoping that there was a major abnormality thinking that that would make my decision alot easier. Huh that would have only made things more complicated. Todd and I were at different ends of the pendulum at different times and then a couple of days afterwards it just came to us like a bolt of lightening No we are having this baby and going to give him the best that we can. And we just felt that the world had been lifted off our shoulders once we decided. I mean when it boiled down we wouldn't have been able to do anything anyway because I would give birth and then we would let this little person die in my arms. I just knew I couldn ' t do it. I mean I would have Daniel back in a flash a million times over and here I was put in this situation where I would end a life knowingly and my baby ' s life - no we would go ahead with it.*

Thus, the mother's initial response was shock and they were unable to comprehend much of the information given to them. They perceived the poor diagnosis as a threat to their developing relationship with their unborn child over which they had no control. In response, mothers distanced themselves from the relationship.

One strategy used by mothers to cope once diagnosis was confirmed was to informally hand over the responsibility for decision-making regarding their own care and the care of their unborn child to the health experts – to the obstetrician, cardiologists and surgeons. They did not see themselves as being able to contribute to the physical wellbeing of their child so therefore left it to the experts. Other mothers refused to make plans for the birth of their infant.

Several mothers used approaching behaviours which enabled them to move forward. However, other mothers continued to hope the experts had been wrong throughout the pregnancy, although they admitted they knew cognitively that the diagnosis was correct.

> *LUCY*
> *And he confirmed that he thought the diagnosis was correct. Thought there was still a part of my husband and me that hoped it was wrong you know. I think we were hoping right to the end or well we were praying. We had alot of people praying and in fact. I think you go through thinking the worst otherwise.. Yeah.*

An additional coping strategy used by mothers was the seeking of further information or making arrangements for the delivery of their infant. These strategies appeared to enable mothers to anticipate the birth of their child in a more positive light, preserving their developing relationship. Some mothers sought out information form the internet, books and other sources, as in Susan's case while others sought out further information from other people.

> *SUSAN*
> *Initially when I started looking on the internet and seeing photographs and all those sorts of things yeah that was on my mind more and more but quite soon after I started having discussions with surgeons and seeing ICU and all those kinds of things at about 20 weeks. So that happened quite early. Yeah so I felt I was really quite well prepared for it.*

Allison sought out information from a trusted relative which she was then able to use to plan for the delivery of her baby.

> *ALLISON*
> *One of my husband's uncles is a cardiologist so that night. I was really, really upset and his uncle he' s like my "go to" person when its anything to do with healthcare When my Mum, my mum has lung fibrosis so when ever she had a problem with that and she was hospitalised he was my go*

to person I would call him and say Oh what does that mean and what do I do? And he has been an excellent support all the time. The first thing he said was Don ' t worry I' ll be there to support you during the delivery and at least for a week after I'll be there. Then he explained the whole thing again in a purely layman terms so I' d understand and um he said things like it will be OK. But it was just the uncertainty at that time um I think that it helped to think it was TOF at that time. It didn't really prepare us so much but it helped us in planning. We are from Canberra and we had to plan the whole delivery.

Despite using these strategies, most women continued to experience some level of anxiety and depression throughout the remaining pregnancy. Mothers gradually began to take control of the situation in ways in which they were able. Although initially having handed over decision-making responsibility to their obstetrician, the mothers reported that they gradually took back this responsibility as time of delivery drew near.

Several mothers reported that they focused on maintaining their own physical wellbeing in preparation for the birth of their child. Most mothers reported that they focused on confirming birth arrangements. They wanted to ascertain that the hospital personnel knew their histories and would be prepared for them when they began to labour. Carol made the trip from her home on the south coast weekly to ensure she received best care and her delivery plans were in order.

CAROL

From that point on they referred us to X and the care there was just fantastic. The atmosphere there made you feel really good, you didn't feel like you were left alone which was good. Um I was in visiting, going out for weekly visits from probably 35weeks. I suppose it was a bit of travelling but , well we work at Marrickville so I'd go to work on the day I had the appointment and then go out after work so it wasn't too inconvenient. I just preferred to go there because they knew the case history much better and they have the experience that Y just don't.

Alice required support to enable her to visualise what would happen after the delivery of her baby. This helped her cope initially however despite providing relief initially as delivery approached her anxiety heightened.

> *ALICE*
> *After I was booked in and the midwife was very nice and I met L who is the nicest lady and she just put me at total ease and said well we will look after you. She told me the total process of what would happen with the baby and what would happen afterward. She really did make me feel OK about it so that initial period afterward I wasn't worried I sort of knew it was taken care of.*

Mothers wanted to be able to picture their infant but the foreignness of intensive care treatment made visualisation impossible for them and seemed to increase their anxiety about the birth.

Birth

Admission to the maternity hospital signalled the beginning of a stressful experience both for women admitted antenatally and for those admitted postnatally. The ***"birth"*** event began with admission to hospital and extended to the newborn's transfer to neonatal intensive care.

The admission process itself was especially difficult for mothers whose infants had been diagnosed immediately after delivery; as they were still experiencing shock having not had time to become accustomed to their infant's diagnosis. These women seemed to be admitted routinely through the emergency department with little consideration being shown to them despite the obvious trauma they were experiencing.

At that time mothers were in shock, unable to make decisions and act independently. Paula describes her admission to the emergency department of the hospital to which she was being admitted after having given birth. Her baby had deteriorated immediately after delivery and had been transported down to Sydney. She and her husband had travelled several hours by car to be with their baby.

Information about the reason for her admission to the maternity unit had been provided by the birth hospital; however, she was forced to wait in the emergency department until the admission process was completed. This obstructed them in their efforts to be with their baby and contributed to their anxiety.

PAULA

No, No we came down and went to the adult hospital. That was probably the worst experience. We had a room there but they made us go through casualty to get admitted to the hospital. It was all organized over the phone that we would stay at Westmead public- all done every thing was organized but we still had to wait in triage for about an hour and a half with drunks and weirdoes. Midnight Saturday night so you can imagine what it was like? It was just awful and Rob (her husband) his concern was me being there and I'm in tears and carrying on and the paperwork. Oh the paperwork we had left that in the car and Rob asked the night desk to look out for me while he went to get the paperwork and she was just "I'm not a nurse I can't do that" What's she going to do? as if I was a danger to her as well? It was weird. It was really cold. Yeah that was awful.

Mothers reported the confusion about locating the hospital and, once there, about the disorientation they felt. Once admitted to the maternity unit the mothers reported being left to find their own way to the NICU at the Children's Hospital at Westmead. On entering the neonatal unit they were faced with the disturbing image of their unresponsive infant connected to a ventilator.

Women diagnosed antenatally were also disappointed with the admission process. Despite having made every effort to organise the delivery of their infant so as to avoid unnecessary problems and facilitate a safe delivery, several mothers experienced difficulties with the maternity system and staff on their arrival to maternity for admission.

HAZEL

I turned up for the induction and happened to get a cranky nurse and there are not many of these cranky nurses around but I got a cranky

nurse, everyone else I've dealt with has been nice but this midwife, she was at the end of her shift, she was a bit of an older lady and she said... well your doctor doesn't deliver here, you're not supposed to be here and this and that and the induction's not booked in and hasn't been ordered... and I'm like, I was terrified anyway...

These poor interactions altered the mothers' perception of the impending birth of their infant from a challenge to a crisis. These women were fearful because of their anticipation of the infant's condition being poor at birth. They were admitted to hospital facing an event they had been dreading, sometimes for months. Most expressed feelings that indicated they had been emotionally ill equipped to face delivery.

Under normal circumstances the birth of an infant is a joyous occasion. In the case of an infant diagnosed antenatally with a congenital anomaly requiring surgery, this is not the case. The anxiety levels of these mothers appeared to increase as the time of delivery grew nearer. They had tried to prepare for the delivery by controlling all the factors which could impact on the delivery of their infant. Several women expressed feeling as though they had been under considerable pressure to "do well" in labour. As they approached labour and delivery they believed it was their responsibility to deliver a live infant in the best condition possible, believing the physical wellbeing of the infant a higher priority than their own.

LUCY
No It was just that the baby was breech and I didn't have alot of liquid so it was unlikely it would turn and having known the problems and I would have been too stressed out knowing that there were problems and knowing the extra risks with the breech deliveries it would have been too much pressure on me I think - get that baby out! So when I first found out that it was breech and a caesarean might be necessary I was disappointed because I have relatively good births but once I got used to the idea.

Despite their best efforts, the process of labour and the final delivery often proceeded quite differently to the way they had previously imagined. The birth experience for most couples was very frightening. They reported feeling the situation had been out of control and of feeling terrified during labour that something was, or would, go wrong. However, as the physical and emotional strain of labour intensified, several mothers could not maintain their control of the situation and deferred the decision-making regarding pain relief and delivery to the experts.

CAROL

That was a Monday night at about 7 o'clock um with the gel
It didn't really do very much so they put me on a syntocinon drip the next morning and that starting my contractions really getting going at about one thirty but I put up with the pain for three hours and then I had the gas for about two or three hours and then I was exhausted so by about seven o'clock I couldn't do any more at night I was just absolutely exhausted so then they um said you haven't progressed and my husband said look she can't do any more she has to have an epidural so I had that .

But it about another still another 12 hours to fully dilate and then I started pushing for an hour and his head was too big. His head was too big to come out but we wanted to have a natural birth because they suggested that would be the best way for him to be born. Because it 's you know it releases the right hormones and whatever so we were happy to do that but by they eventually said to be look you'll have to have a caesarean he's not coming out so we did that was a bit of a shock.

RESEARCHER

How did that make you feel?

CAROL

Um By that stage I probably thought that I just wanted to get him out but I was also -- I felt a bit of a failure.

The mothers who had received an antenatal diagnosis reported being extremely anxious at the birth of their infant. All the fathers accompanied their babies to the NICU with the neonatal team, while mothers were left alone, physically disconnected from their infants immediately following the birth.

> *ALLISON*
> *He went across to see him and get a picture and all that. Um, so after that I couldn't really think about it because I passed out. I had a postpartum haemorrhage and they had to give me drips and the catheter and the whole thing. I was very weak and everything, so they put me in observation down in the delivery area itself until about 1am. My husband took pictures of him and brought them across so I had them at the bedside but it was horrible not having him with me. It was like I just gave birth to him but he wasn't with me. The next day around 12pm I went over to see him.*

These mothers reported finding interacting with staff, others and, indeed, their infants to be difficult. They reported being preoccupied with memories of the birth, feelings of loss, guilt, isolation and having a sense of impending disaster. Despite the infant being alive at birth they knew there was no guarantee that their child would survive. These feelings influenced the mother's perceptions of how her relationship with her infant would continue. It is in this state they were faced with the challenge of entering the NICU in order to reconnect with their infant.

Surgery

Interactions with the health system impacted on mothers' perceptions of their relationship with their infants. Mothers experienced a considerable degree of uncertainty about what management would be undertaken, and when. These perceptions obstructed maternal efforts to connect with their infants. The infant's condition and availability of theatre time dictated the timing of surgery. Emergency cases were taken immediately.

For most mothers, anxiety about surgery began the day before, when preparations began. Mothers described feelings of conflict. They knew that survival of their infant entailed surgical correction; however, they wanted to protect their infants from hurt. A common thought was that they could be handing their infant over for the last time. Mothers faced their reality that their relationship with their infant might end prematurely with the infant's death during surgery. This knowledge hindered mothers' attempts to connect with their infants until they were certain the infants were well.

In the following example Carol explains her fear of touching her newborn after surgery. She implies that she is still careful believing him physically vulnerable despite him being deemed ready for discharge. Her continued relationship with him must therefore remain uncertain.

> *CAROL*
>
> *I was very scared of, just the thought of picking him up scared me. I had this fear of touching him. But now I'm , I mean I'm still abit tentative but I'm certainly..... (didn't elaborate). Especially when they've had something wrong with them. You don't want to upset them or pull a cord out or Yeah*

However, several mothers whose infant's surgery was postponed for several days after their delivery perceived that they had begun to connect with their infants through breastfeeding. Mothers referred to breastfeeding as a bonding behaviour, indicating their intention to sustain their relationship with their infant. Lucy's infant didn't go to surgery until one week after birth. She feels she had begun to connect with him but to her this was not necessarily a comfort.

> *LUCY*
>
> *I was worse the day before the operation than the day of the operation. I was just very teary. I suppose just the thought of having to hand the baby over to the operator and I didn't want him to have the operation but I knew he didn't have a chance at life without it and um the thought of having to hand that baby over once I'd formed that bond was hard, and*

although you know its a very successful operation you think well I may be handing my baby over for the last time. You know you've got to go through all those things too. You have all the reality checks and you know there I thought well you're baby could die. Go through the doors and not come back. It's all abit of a blur my husband came in early the next morning and we bathed the baby. Then we had a final nurse in the waiting room.

Lucy had breastfed her infant between birth and surgery. She had been concerned during her pregnancy that perhaps the infant would not be able to breastfeed. She appeared to connect breastfeeding with bonding. The only physical contact Lucy had with her son during this time was when breastfeeds were attempted once or twice a day. Nevertheless, her perception was that because she breastfed she had sustained her relationship with her infant.

Lucy's experience contrasts with Allison's. Allison had experienced a particularly difficult pregnancy – difficulty in sleeping, nightmares, mood swings and a delivery complicated by a postnatal haemorrhage. However, at delivery, she had been surprised at how good her son looked and began to consider that perhaps surgery would not be necessary. The difficult delivery prevented her from visiting her son in the NICU for over 24 hours whereupon it was evident to her that his condition had deteriorated. Despite her acknowledgement that he was not well, Allison still held on to the hope that surgery might not happen until it was confirmed by the cardiac surgeon that the surgery would go ahead. When her worst fears became reality she was emotionally shocked. She described several hours of complete disorientation. When asked whether she felt connected to the infant at that time Susan admitted initially considering whether or not she should connect with her son.

ALLISON

To be honest I was thinking whether I should really totally start allowing him in or not, you know because I was… (Susan didn't complete this sentence, she simply looked away)

After this period of considerable shock within one day of delivery Allison went on with the support of her family to attempt to connect with her infant. She spent every waking moment with him, involving herself in much of his daily care routine. However, this involvement made it extremely difficult for her to hand him over for surgery. She broke down at the theatre doors.

> *ALLISON*
> *I didn't know how he was going to come back and I was trying to be positive but I was scared as well.*

Mothers who had time to connect with their infants between birth and surgery appeared to experience similar levels of stress postoperatively to those whose infants were taken to surgery immediately. Their perception of the risk to their infant during surgery was not altered by making emotional and physical connections with their infant before surgery.

All mothers reported imagining their infant would die during surgery. The perception that their infant would not live influenced mothers' behaviours in their efforts to sustain their relationship with their infants before surgery. While several mothers felt strongly that they should connect with their infant as this might be their only opportunity, others distanced themselves from their infant in an effort to reduce their own emotional hurt if the infant died.

Several women commented on the intensive care area in which they found their infant after surgery. Their own infants look frightening to them. The babies were usually either medically paralysed or heavily sedated. This resulted in a non responsive infant. Mothers described the infants as "not looking real" or else "looking dead". Mothers were hesitant to touch or hold their infants. The underlying reasons for this hesitancy were explained by mothers as – fear of hurting their infant, fear of disrupting monitoring and fear of being in the way of the experts. . Many mothers felt guilty because they were afraid to touch or hold their infant, while also fearing that they might hurt the infant, if they did touch them.

PENNY

Well he was just in a crib hooked up to about 10 different things and he was muscle relaxed, sedated, not responsive. So there was no point. But once they started to reduce his medication and he started to open his eyes which was about the time he was beginning to stabilise they let me have a cuddle. Which wasn't a real cuddle just holding on a pillow but it was better than anything before. Yeah I could hold his hand. When he finally got a cannula out of one hand I could hold his hand.

Penny did not perceive her emotional and physical contact with her newborn as being helpful to his condition. She perceived him as being out of reach in terms of emotional connection. Her infant was sedated and unable to response to her. She perceived him as being physically, extremely fragile and requiring technological support. Like other mothers, Penny was not concerned about disrupting the staffs' schedule, but simply did not want to obstruct the care being provided to her newborn

At this point along the continuum, what was most important to mothers was the expert medical care being provided to their newborn. They would overlook the brusqueness of busy staff as they saw the technical care as being the most critical thing in keeping their infant alive.

LUCY

One night I went to bed worried. Oh it was just that she had a different temperament to mine but I mean it was just her way I mean she wasn't awful but she was just alittle harsher than I would be. She didn't really need me there. I was tired I just had to go to bed and I wasn't concerned that she didn't know what she was doing. As a parent what you value more when you first come out of the operation is the experience because that's the time when a lot's happening and you don't really want just a nice nurse with a good personality you want someone with expertise.

A live infant increased the likelihood of preserving their relationship. Infants should experience comfort from their mothers when distressed, and the

developing maternal-infant relationship begins with these brief interactions. Nonetheless, several mothers did not touch their infant for many days post-operatively, as they believed this was best for their newborn. They thought they would harm their infant as they were not confident of their ability to comfort their infant. This perception was influenced by interactions with staff and the health system.

Convalescence

Once the infants' condition improved they were transferred to the extended care nursery of the neonatal unit. Infants in this area of the NICU although still very unwell, did not require the same level of medical care as they had immediately post-operatively. Although staff worked in both the intensive care area and the extended care area, the extended care area was staffed by less experienced nurses. There was also less observable routine in the extended care area and patient staff ratios were higher.

Transfer to extended care created a dilemma for mothers when they compared the care their infant received in the extended care area with that received in the neonatal intensive care. Mothers preferred neonatal intensive care because of the increased level in expertise of staff. Although the physical care of infants in NICU was seen to be primarily the domain of nursing staff and mothers were not encouraged to participate in the physical care of their babies, mothers felt their infants were safer in the NICU. This feeling impacted on their ability to develop their relationship with their infant as they became focused on their infant's physical safety rather their interactions with the infant.

> *SUSAN*
>
> *Um I think yeah the thing that upset me most was that you couldn't, you couldn't hold your infant and um there were certain ways you had to touch your infant which I understand why um and they were explained to me quite clearly but sometimes it was repeated often by some of the nurses and I must admit that sometimes I felt that they were coming and telling me off, you know, but in the most polite way. At the time it felt like hard work yeah. Yeah it was day five when I got my first cuddle, yeah.*

Although the infant was physically better and mothers felt more comfortable about accessing close contact with their infant, the extended care environment remained foreign to them. Whereas in the neonatal intensive care area mothers perceived staff as experts concerned primarily with the technical aspects of supporting the infant's physical wellbeing, in the extended care area staff were perceived as being focused upon moving the infant toward discharge. Mothers were now expected to participate in the practical care of their infant and found themselves being supervised while undertaking parenting tasks especially infant feeding. This considerably decreased the opportunities for maternal-infant interactions to take place. Although the philosophy of the unit was family-centred care, practical involvement in their infant's care was dependent on the philosophy of the individual staff member. Staff interactions with mothers in my study were powerful determinants of the level of their involvement with their infants.

> *PETA*
>
> *When he was in NICU I slept OK alot better than I have when he's been in ECU. I think NICU is more regimented so that they know when the Morphine goes down this is what they do. It's not the level of care you have down in ICU obviously. It's not worse. It's not one on one. Whereas up in ECU if he screamed it was "well it could be this or it could be that". You know it's different.*

Although some mothers had difficulty participating in their infants care, others did not. The majority of mothers reported their infant's convalescence in extended care being the period when they were finally able to experience the physical contact they had been unable to experience in the neonatal intensive care area. While the convalescence event did not involve life or death situations, it continued to remain a threat for mothers in their relationship with the infant for precisely that reason - this was where they had envisaged connecting with their infant. Mothers experienced a great deal of anxiety about their ability to parent their sick infant. This is evident in Carol's description of her experience of bathing her infant for the first time.

> *CAROL*

I'm not confident, not really, I mean um the first bath he had was two days ago. And I can't remember who got the bath for me but they basically said just bath him which I, I was thinking what do I do? I didn't know what to do! I just, you know, just washed his head and so I didn't realize that you really didn't need to do a huge amount to them, it was more

Feeding in particular seemed to play an important role in determining their ability to parent. It appeared to be intimately involved in mothers "connecting" with their infant. Some mother's confirmed that for them feeling connected occurred when they were able to hold and feed their infant. The significance of feeding is clear when considered within the context of the infant's emerging social relationships. Feeding episodes offer opportunities for social interaction between mother and infant. Infants soon learn that they are able to initiate these interactions through signalling their need. The mother responds to these signals and the interaction begins.

As discussed earlier, some mothers felt the need to establish feeding before surgery. They believed feeding would develop a connection with their infant that would sustain their relationship during the crisis of surgery and the immediate post-operative period when they would have minimal contact with their infant. However, this practice often led to disappointment when, despite establishing feeds pre-operatively, the babies had difficulty attaining full feeds post surgery.

Most of the infants with cardiac diagnoses experienced difficulties in consuming incremental amounts to full feeds during the convalescent period. Mothers found this time particularly difficult as they had believed they had moved through the worst stages of the crisis. They had difficulty coming to terms with the fact that the surgery had not resulted in their babies being as robust as a healthy infant. Concern over the survival of the infant continued to impact on the developing mother-infant relationship. Emphasis on the task of feeding interrupted smooth interactions between mothers and their infants. Mothers became focused on the quantity of feed ingested, perceiving this to be the measure of the infant's

wellbeing. These concerns inadvertently increased the threat to the mother's perception of her relationship with her infant.

PAULA

We've had a bit of a struggle with feeding , well not a struggle but um we started breast feeding and S wasn't coping and um I was getting stressed and anxious. She was actually just screaming and irritable, She would latch on really well but would stop and cry and she wasn't enjoying it ,and she wasn't putting on weight although I know that happens alittle after .....

And we both all along we both wanted to express and put it in the bottle and feed her that way. She went really well on the bottle and the nurses had said she really loves her bottle. But there was always the suggestion of putting her onto the breast. And no matter when you tried with the bottle there was this constant you know why don't you put her to the breast. So I was thinking am I doing the right thing by not putting her to the breast, maybe there is a reason they are all saying this maybe I'm not doing the right thing by S Oh it was just awful.

But we gave it a good go and then a nurse said to us we are going to have a new plan we are just put her on the breast no bottle because she was having a bottle, a breast. But in our opinion that was a step backwards because she was already having 50 ml on the bottle and then maybe only 10 down the tube. And then we were told after a week of trying, to stop that and they wanted us to go backwards.

So there were a few individual that preferred the breasts. But it seems to me that the nurses don't want to give you a set rationale. Like I think from S's point of view right from the beginning it was clear breast wasn't happening for her, bottle was and I think we should have been given and I know maybe this breastfeeding thing is a very , people don't want to form an opinion but I think in S's case a cardiac baby it should have been said from the beginning go bottle.

Emphasis on successful feeding was reinforced during interactions with staff and was a prerequisite for discharge. Mothers focused on gathering information from staff in order to construct some meaning in their relationship with their infant. Mothers were often in conflict regarding which advice to follow, and whether they would be able to care for this infant themselves. Establishment of feeding was therefore crucial to mothers in preserving their developing relationship.

Discharge

The major challenge faced by mothers in the "***discharge***" event was perceived by mothers as their ability to undertake mothercraft skills and develop a relationship with their infant. Mothers obviously looked forward to the discharge of their infant; however, they were at the same time faced with the sole responsibility for the infants physical wellbeing. Previously this responsibility had been shared with a number of experts, therefore taking on the responsibility alone was a source of distress for mothers.

Preparation for discharge home occurred gradually over many days, if not weeks. However, the progress was usually dependent on the infant's physical wellbeing. Often infants experienced setbacks, such as feeding difficulties, which extended their hospitalisation. Once these difficulties were resolved mothers perceived discharge as being arranged with little advance notice provided. Mothers whose infants were to be discharged with little notice often had difficulty altering their perception of their infant from sick to healthy. Often their immediate response to the news of impending discharge was distress. Although previously looking forward to their infant's discharge, mothers would occasionally cope with this distress by attempting to delay their infant's discharge for a day or two by requesting longer periods of rooming - in. This delay enabled them the time they required to prepare emotionally for their infant's homecoming.

As the time of discharge approached most mothers experienced an increase in the level of apprehension about their ability to cope once home. However, several mothers described their upcoming discharge in terms of their emotional connection to the infant. Having felt unable to connect with their infant while still hospitalised, these mothers described their infant's upcoming discharge as a "rebirth".

HAZEL

Once we get her home it will be and because we haven't had.... besides my mum and dad and my two children with me I said no other visitors to anyone else. I just wanted to keep it very intimate and then when we come home and I feel happy with myself and she's doing well that I can share that with everyone else. And I haven't even wanted to talk to people on the phone, I just wanted to wait until its all .. its like a rebirth I think.

CONCLUSION

The experience of carrying and then delivering an infant requiring surgery in the newborn period was viewed by the mothers participating in this study as a series of crises which they had to overcome. Their chief concern was the problematic interactions they encountered while trying to preserve the developing relationship with their infant. The level of distress mothers encountered was evident within each event along the ***"diagnosis to discharge"*** continuum. This distress was exacerbated by poor interactions with both the health system and health professionals. which in turn impacted on the mothers' ability to interact with their infants. The way in which the mothers managed was to deal with one major event at a time.

Maternal distress experienced in the earlier events along the continuum surrounded the survival of the infant, whereas in later events distress surrounded the emotional relationship between mother and infant. Although in later events survival was probable, it remained a concern for mothers until discharge. In addition, mothers began to focus on the emotional wellbeing of their infants in later events and their ability to fulfil the maternal role.

The technical expertise of health professionals in intensive care was valued highly by mothers and perceived as ensuring their infant's survival. Mothers were prepared to forfeit physical contact with their acutely ill infant during these earlier events, ignoring their own emotional needs as they perceived this as necessary for their infant's wellbeing. Mothers did not develop confidence in their own ability to comfort or care for their infant until the point of discharge. These perceptions were reinforced during mothers' interactions with the health system and staff.

This chapter has presented the "***diagnosis to discharge***" continuum as the context within which mother's attempt to preserve the relationship with their newborn. The basic social process of "***maintaining equilibrium***" discussed in the following chapter describes the process used by mothers to deal with each event along the continuum.

CHAPTER FIVE; THE BASIC SOCIAL PROCESS OF "MAINTAINING EQUILIBRIUM"

INTRODUCTION

In the previous chapter, I described the emergence of the problem for mothers as ***"preserving a relationship while enduring a crisis"***. Mothers provided numerous examples of possible threats to their ongoing relationship with their infant. Possible threats ranged from the fear of physical handicap, fear of the infant dying, or the inability to connect with their infant after separation during hospitalisation.

Mothers in the study attempted to resolve this problem by altering the meaning of the situation from one of crisis where they were faced with little hope for their ongoing relationship with the infant, to one of a challenge which they needed to overcome to sustain their relationship with their infant. Therefore the basic social process used by mothers to resolve the problem was named "***maintaining equilibrium***".

As discussed earlier mothers in the study artificially dissected the "***diagnosis to discharge continuum"*** into discrete crisis events. Many individual experiences were involved within each event, each of which was composed of interactions which impacted on the way mothers perceived the meaning of the situation in regard to their future relationship with their infant.

The process of "***maintaining equilibrium***" illustrates how the mothers managed to move through each of the events along the continuum. The process of "***maintaining equilibrium***" is composed of four separate phases: ***"distress", "response", "achieving equilibrium"*** *and* ***"connecting"***. Each phase will be explained and examples provided.

THE PROCESS OF "MAINTAINING EQUILIBRIUM"

The events along the "***diagnosis to discharge***" continuum represented multiple crisis experiences for mothers. At each event mothers moved through each of the four phases of the "***maintaining equilibrium***" process. Dissecting the continuum allowed them to deal with the experiences within each event individually, one distressing experience at

a time. For example, initially during the "***diagnosis***" event (in the antenatal diagnosis continuum), mothers were physically and emotionally connected to their expected baby. On being given the diagnosis mothers found themselves in a state of "***distress***". In this phase they experienced both physical and emotional symptoms of shock and stress. Their need to overcome the emotional and physical distress triggered them to respond to the stressor, moving them into the "***response***" phase. At that point, mothers did not wish to become too connected. Becoming connected was too emotionally challenging while they were experiencing the initial shock of the diagnosis. They simply used whatever coping strategies they required to regain their equilibrium. Once they moved into the phase of "***achieving equilibrium***" they were better able to reflect and process the situation. Movement into this phase did not imply total control of the situation, merely that they had reached a point where they were able to consider what was best for their baby. Preoccupation with their unborn child eventually moved them onto the "***connecting***" phase. In this phase they attempted to maintain some connection with their unborn child, no matter how slight.

Although each event along the "***diagnosis to discharge***" continuum comprised many individual interactions, each held a major challenge for mothers. For example, in the event labelled "***birth***" mothers were faced with admission to a maternity hospital, the labour process, the actual delivery and then the transfer of the infant to NICU. However, the challenge for them within the "***birth***" event was the actual delivery of the infant. Whereas in the event labelled "***diagnosis***" the major challenge was the interaction surrounding the diagnosis. In the event labelled "***surgery***" the challenge for some mothers was their infant's transfer to theatre while, for others, it was the experience of seeing their infant post-operatively in intensive care. This was the period in which mothers found themselves in the most distress.

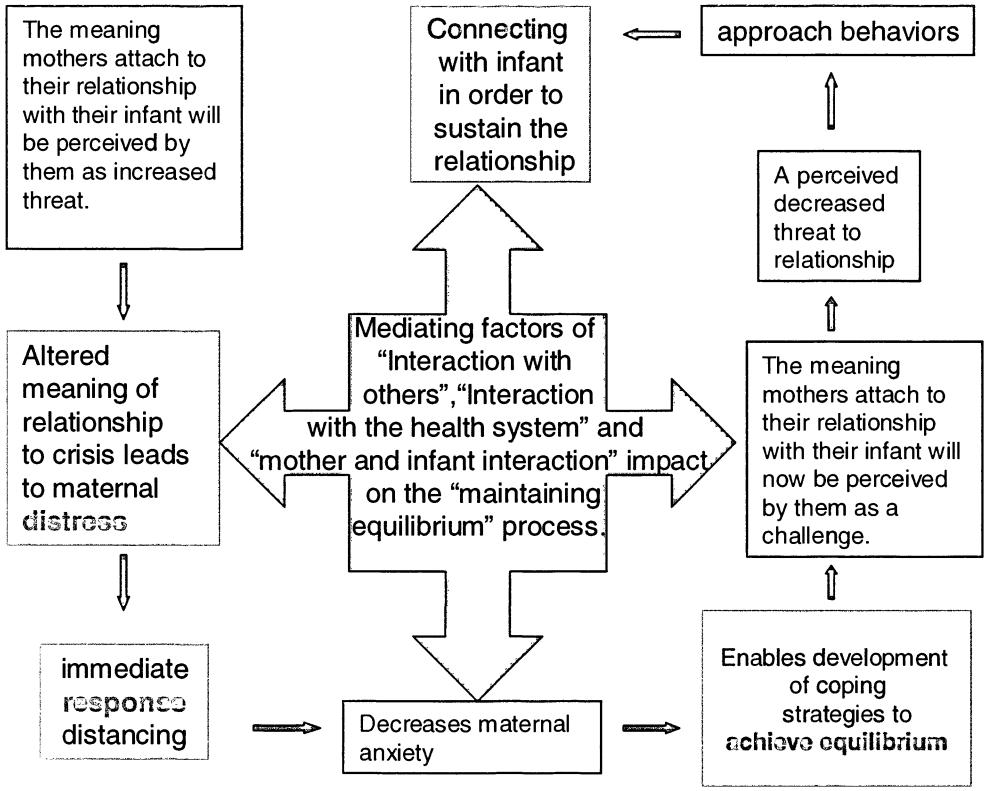

Figure 5.1: The process of "Maintaining Equilibrium"

Distress phase

The first phase of the "***maintaining equilibrium***" process was the "***distress***" phase in which mothers initially experienced some appreciation for the situation they faced. This initial recognition often overwhelmed them. Their feelings of anxiety were directly related to their perception of the situation. The meaning they attached to the situation was perceived by mothers as a threat to their ongoing relationship with their infant.

"***Distress***" was present in each of the events along the continuum. In the events of "***diagnosis***", "***birth***" and "***surgery***" mothers perceived the distress as so great they used the term shock rather than stress. In the later events of "***convalescence***" and "***discharge***", in which there were stressful challenges, distress was described as anxiety or stress rather than shock. The intensity of the stress appeared to change over time and according to the level of threat perceived by the mother.

During periods of "***distress***" which was perceived as shock, mothers described themselves as being incapacitated, unable to function cognitively and emotionally. When required to be involved in the care of their infants at these times mothers often deferred decision-making to staff who they thought of as the experts – obstetricians, midwives, NICU staff, surgeons. The following is an example of the confusion mothers endured around these crisis episodes. Hazel describes her first visit to the NICU immediately following the birth of her daughter.

HAZEL

> *Yeah well I came straight down pretty much, I went to my room at Westmead and then I got dressed straight away because I wanted to see the baby and Nick brought me down and we went to see her but I was not really ready for it because I was very, you know, dizzy and but I saw the baby and then and she was stable at that time so that was good and I got introduced to a lot of people that I've got no idea, that just went all over my head... I think that was a bit much for me. Too many people at once. People were coming up to me and saying I'm so and so and I'm so and so and that was a bit much. I think it, it probably should have stuck to two people being introduced rather than, I'm sure there was at least twenty people or it could have been more I don't know...That was all a blur. A bit too many people at once, especially because I'd just had the baby so maybe if the baby was a few days older and I was, and even in the days after more people kept coming up. I'm thinking how many people am I going to be introduced to? Which I could cope with perfectly now but that would have been the hardest thing.*

Mothers described feeling disoriented, experiencing difficulty in sleeping, imagining dreadful outcomes at birth and surgery, crying uncontrollably and experiencing mood swings. These shock reactions were sometimes delayed as Zena and Hazel explain in the following examples:

ZENA

I don't know um I think you're running on adrenaline and a lot of still being in a state of shock, part denial and partly with me I've got such a big extended family. I was on the phone conveying what doctors were telling me I didn't have time to think about how it was affecting me emotionally.

HAZEL

Yeah. That's when I got a bit upset. I think it was day three I actually got upset. I think infant blues hit day three and because I checked out of the hospital that day and all of a sudden I didn't know where I was and then I got upset for about twenty minutes.

Hazel literally didn't know where she was and was forced to ask for help from a receptionist. Unfortunately, her partner was not with her at the time. She panicked and could not remember where she was supposed to be going.

Allison described her shock when she saw her infant after surgery. She had seen her infant briefly at birth, then again many hours later with her husband on the infant's return from theatre. It wasn't until the next day, when she saw the infant, that she became really upset. Her infant had gone to surgery for repair of an omphalocele, unfortunately complete closure was not achieved. On the second day, when she was finally able to spend time with her infant, she went alone. What Allison was faced with was a frightening picture. Her infant was lying supine, non-responsive, with abdominal contents suspended within a plastic silo from a frame above the infant's open abdomen. It was as though the reality of the situation hit her only then.

The infant lying in the crib did not at all resemble Allison's perceived image of how her infant would look. Despite being told how the anomaly would appear and how it would be managed, she had not been able to truly picture her infant. Allison could not comprehend how she had carried and delivered this infant. Although she was aware the infant was well sedated, this did not prevent thoughts of the infant being unaware of her presence, of appearing dead. She could not

foresee that this anomaly would ever be corrected or that the infant lying in the crib would ever look normal. At that point she could not envisage how she would be able to connect with the infant.

The distress for several mothers was so great they were unable to recall seeing their infants for the first time. While they were able to recall being shown their infant, they could not visualise them. Their inability to visualise their infant was an emotional coping strategy. If they were unable to visualise their newborn they did not have to deal with the reality of losing them. They distanced themselves from the emotional distress. These mothers reported finally "seeing" their infants hours, sometimes days, after initial contact.

CAROL

> *I couldn't actually see him. I saw this thing wriggling but that was about it and they brought him past when he was going to, um, down to intensive care and I just held his hand and that was nice but I didn't really get to meet him until the next day after his operation.*

The high levels of anxiety experienced by mothers in the "**distress**" phase of the process prevented them being able to contemplate their next moves. They were unable to see past the crisis.

In the later events of "***convalescence***" and ***discharge***", the distress phase occurred around the challenges within each of the events. In the ***"convalescence"*** event, the greatest challenge was the progression of infants to their full quota of feeds. The greatest challenge for mothers in the ***"discharge"*** event was the transition to being totally responsible for their infant's wellbeing. Mothers reported feeling high levels of anxiety regarding their infant's long-term prognosis and their ability to care for them at home. Interactions with others and the health system influenced mothers' perception of what was happening and therefore altered their understanding of the degree of threat posed to their ongoing relationship with their infant. Interactions with others, the health system and with their infant will be discussed later in greater detail under mediating factors (refer Chapter Six).

Response phase

The second phase of the process identified was the ***"response"*** phase in which mothers responded emotionally to the distress they were undergoing. Behaviours displayed by mothers included distancing themselves emotionally and physically from their infants and appeared to be a primarily self protective strategy. Distancing facilitated mothers' attempts at regulating their emotional response to anxiety. The rationale for behaviours displayed by mothers in this phase was therefore the reduction of anxiety.

In the following example Hazel was experiencing conflict between her need to see her infant and the fear of what would happen next.

HAZEL

> *I can't really remember the first ... I can remember seeing her but because it was all a bit too much at once it's a blur. Which is probably just as well it's a way of coping I guess. Things become a blur. You just cut it all out. Even when she was just firstborn um I didn't really want to look at her too much which is... Even though it was my baby I didn't want to. I think part of you when you're having a baby it's like get the baby out of me and that's a relief and then you don't really want to cope with what's happening next. You just want to, part of you just wants to enjoy the fact that you've got the baby out...Yeah because that's always a big deal, that's always hard and then I don't know I just didn't want to be, too much a part of that. I wanted to see her but I didn't want to be too attached to her. No. Yeah in a cold way.*

Penny was hesitant to form a relationship with her infant because she feared he would not survive. She was frightened of being hurt.

> *PENNY*
> *So I think during that time it was difficult for me to form any kind of bond because - one I was removed physically but the other was I didn't want to let myself get too attached if I thought he was going to die. Because that was the reality of the situation they pretty much told me.*

RESEARCHER

Did you think that at the time or now on reflection.

PENNY

At the time I thought that too. I thought 'Oh no I'm going to lose him and I barely even know him' but thank goodness we didn't.

Other mothers responded by handing over their infant's care to the "experts". The following mother seemed to need the emotional support of being one half of a strong couple. She seemed not to consider her presence necessary in relation to her infant's emotional needs.

PAULA

One of us could have gone in the helicopter but we were with each other and we knew S would be in the best of care. We knew she had a doctor and a nurse and we knew she would be in the best of care and with my caesarean I didn't know whether I would cope with a helicopter flight and um we just needed each other too and it was the best thing we could have done that journey leaving the hospital. It was just really calming for us. We just talked together and relaxed and thought well S is in the best of care now it's out of our hands.

The following mother found herself unable to manage at several points during her infant's hospitalisation. When this happened she would arrive obviously emotionally upset and then deliberately remove herself from that situation. In this example she was referring to a prearranged meeting with a member of the care team with which she was emotionally unable to manage.

LAURA

That day was hard. You are in there for a reason and there are so many people at you for their different aspects of S's condition and I just went off. It's just part of the situation and it can't be changed and there are people that want to speak to you. And some days I had to just remove myself from the situation.

The proportion of distancing to approaching coping behaviours exhibited varied considerably within each event along the continuum. Over time mothers moved from using more distancing behaviours to using more approach behaviours. An example would be the period immediately after birth when mothers used a greater proportion of distancing behaviours as they were unable to approach physically and emotionally. However, further along the continuum when establishing feeding, mothers tended to use a greater proportion of approach behaviours.

Achieving equilibrium phase

The "***achieving equilibrium***" phase incorporated the time frame between the mothers' behavioural responses to distress and their ability to consider the best course of action. As mothers' anxiety levels decreased they were able to reflect on the effectiveness of the behaviours they had used in the "***response***" phase in terms of altering the true meaning of the situation.

While the behavioural responses were successful in reducing their anxiety, mothers realised the situation remained unchanged. Therefore, they needed to focus on the most appropriate action to fulfil their needs in terms of their relationship with their infant. If they were to preserve their relationship they needed to focus on the relationship rather than the crisis.

> *ALLISON*
>
> *I knew the whole thing but still my brain was not accepting it...I didn't even know whether I wanted to go back and see him and I was really scared about what was going to happen and everything. And then I collected myself up and thought OK these are all stupid thoughts. Let me go see him and I saw him...So that was the time that I decided I wasn't going to sit in the wheelchair anymore. It got me up and thinking well I can't be sitting any more there are more important things to do than all that.*

This phase of cognitive reflection has been labelled "***achieving equilibrium***". Movement into this phase did not imply total control of the situation. It simply referred to mothers reaching a point where they were able to control their

emotional and physical state to a level which permitted them to make decisions regarding their actions rather then simply reacting as they had done previously in the "***response***" phase.

In this phase alternative actions were weighed and considered until the best possible strategy was determined. The best possible strategy was one which would allow them to focus on their relationship with their infant. Strategies used included being hopeful, focusing on the positive, seeking support and comparing their situation to that of others. Utilising these strategies empowered them to participate in the care of their infant.

The following example refers to an infant whose prognosis was uncertain. Despite this uncertainty, the mother maintained a very positive outlook for her infant's future. Mary based her behaviour on her previous experience. She referred to herself as an optimistic person implying that this state of mind helped her to move on, however she does acknowledge her fear..

> *MARY*
> *It was a constant worry at the back of my mind the whole time which I was trying to put, usually I'm a very optimistic person so I was looking at it at that time in a very positive way hoping that everything would go well.*

In the next example, Allison maintained positive communications with her infant as suggested by her partner and parents because she felt it would ensure a good outcome. She utilised her support network in order to sustain her relationship with the infant.

> *ALLISON*
> *I don't know whenever I was with him I would totally forget all that. I kept talking to him because my husband was a good support and he was saying and everybody around me was saying 'Don't show your grief to the baby because he will feel it'. That was my mum who said that. So every time I was around him I was trying not to cry. Both my parents and my husband were saying be very positive - talk to him in a positive way. And my*

husband would talk to him and say 'Hey you're going to be alright champ. We are there for you. You are going to come out hail and healthy.'

Mothers admitted using the strategy of comparing their own situation to that of other people. They reported that the comparison helped them see they were not the only ones experiencing difficulty, allowing them to put the situation into perspective and return to focus on their infant.

ALICE

I don't like to see people suffer after seeing some of the other mothers up there and they have their own issues I can't help but feel sorry for some of the other mothers up there even though we've got what we've got ahead of us I still feel sorry for the other mothers. It's just unfair to see people suffer to know what they have ahead of them. And even walking the corridors here in the hospital and seeing the older children with IV poles dragging behind and you think to yourself and you sort of think of the future of that child and how much the family have gone through and still have to go through.

PAULA

She's just and I'm so proud of her , we're both proud of her, she's just gorgeous and when you look at what other parents are going through you think well gee they'd give anything to have..... you know some are losing their children some have already lost a child.

Mothers' often focused on the positive aspects of the situation, usually on how well their child coped.

ZENA

He's been really great. What a great little fighter. Every week he was going to theatre to have something done. It was like a great step backwards and in between he was coming leaps and bounds feeding from me having breast milk and then again he would go to theatre and come

back with all these things, these attachments. Mm. Yeah. But he's a real fighter.

These strategies, used to alter the meaning of the situation from one of hopelessness in terms of their relationship with their infant, to one of hopefulness, resulted in various levels of connection.

Connecting

The "***connecting phase***" was the action phase in which mothers attempted to sustain the developing relationship with their infant, no matter how slight. Mothers were acutely aware of "***connecting***". When Zena's son was critically ill and unable to be handled, she maintained contact at a level he was able to tolerate.

ZENA

Yeah once you start.. and what you can do and what's allowable. Well you know you don't want to interfere with his care so like if a doctor or nurse was busy doing something with my baby I'd want them to have access to him and not be in thier way. Eventually I was able to take temperatures and bath him

Levels of connection with their infant in some instances included physical connection, in others emotional and in some instances both physical and emotional connection. The nearer to discharge, the more likely the connection included both physical and emotional connection. Examples of physical connection included sitting by the bed, touching, feeding before surgery and holding. The improvement in the infant's physical status enabled mothers to have increased physical contact. Where previously they were concerned lest they increase the infant's discomfort, they were then more confident that the infant was not in pain. Emotional connection included being with the infant during procedures, making plans for the future and becoming involved in decision-making regarding the infant's wellbeing.

Mothers appeared, at times, to fluctuate between the "***achieving equilibrium***" and "***connecting***" phases. In fact, movement between phases facilitated the trialling

and altering of strategies throughout the event, enabling mothers to determine which would provide them with the outcome they sought. Susan moved to connect with her baby by visiting alone once her partner had gone home to their other children. However, she experienced a great dealt of distress on seeing her baby. To relieve this distress she responded by cutting her visiting short, thereby distancing herself from the cause of her distress. She was then able to achieve equilibrium and recognised she would need support to visit. She moved toward connecting by ensuring someone was with her during her visits to the NICU.

> *SUSAN*
> *Yeah even though I was prepared for it, it was still a shock. It was hard to see her um and funny enough I didn't get really upset until the second night I saw her. I did it by myself S had gone home to our other three children we have at home and I had the porter bring me over the second night. And I was just dropping off milk funnily enough but I popped in to see her and I got really upset. I suppose because I had to do it by myself. Yeah and um it was hard so I didn't stay very long. Um and I must admit for a couple of days after that I was always with S when I saw her. Just so I had someone else there to kind of help me through it.*

Movement between phases was essential as the meaning of the situation changed throughout the crisis event. A changing meaning required alteration in ways of managing the situation. For example, the meaning of the event of "***diagnosis***" would be altered for the mother of a baby diagnosed with a cardiac anomaly if she then went into premature labour. The meaning of "***diagnosis***" altered for her from the birth of a fulltime baby with a cardiac anomaly to that of the added risk of a premature birth. Whereas she had previously responded to the meaning of the initial diagnosis and moved to the point of maintaining equilibrium the altered diagnosis would move her back to the "***distress***" phase. The altered diagnosis would increase the mother's anxiety in the "***distress***" phase which would in turn alter the behaviours she displayed in the "***response***" phase forcing her to alter the way she coped with the "***diagnosis***" event and then the "***birth***" event.

Each phase of the process was influenced by the phase before it and the current meaning of the situation to the mother. The self protective distancing behaviours displayed in the "***response***" phase resulted from anxiety experienced in the "***distress***" phase. As a consequence of behaviours exhibited in the "***response***" phase mothers experienced a decrease in anxiety. Their decreased level of anxiety facilitated maternal cognitive appraisal in the "***achieving equilibrium***" phase.

The meaning of the experience for mothers was in this way altered from the experiences of hopelessness during a crisis to the hopefulness of a challenge. They were then able to determine a course of action, which would enable them to sustain their developing relationship. Interactions with the infant, the health system and others, influenced the dimensions of each phase of the process (refer Chapter Six).

CONCLUSION

The "***maintaining equilibrium***" process comprised four phases along the "***diagnosis to discharge***" continuum. For example, on being given a diagnosis for their infant of a congenital anomaly, mothers found themselves in the "***distress***" phase of the "***diagnosis***" event. In this phase they experienced both physical and emotional symptoms of shock and stress. Often symptoms temporarily incapacitated mothers. The need to overcome the emotional and physical distress triggered them to respond. The focus of the response phase was the reduction of their distress.

Mothers utilised whatever strategy necessary to regain their equilibrium. As their anxiety levels began to fall they were able to move into the phase of "***achieving equilibrium***". Once decided on a particular strategy they felt would work, mothers moved onto the "***connecting***" phase. This was the action phase in which mothers attempted to sustain the relationship with their infant no matter how slight. In reality, connection may have meant simply acknowledging the need to prepare for the birth. In other cases, mothers displayed a need to regain control of the situation by confirming birthing arrangements or viewing the NICU. Mothers trialled a number of strategies, moving backwards and forwards between the

"achieving equilibrium" and ***"connecting"*** phases in order to determine the most effective strategy to sustain their relationship with their infant.

This chapter has described "***maintaining equilibrium***" as the process used by mothers to deal with each event along the ***"diagnosis to discharge"*** continuum. The "***maintaining equilibrium***" process helped mothers regain some control of the situation which in turn enabled them to participate in care and maintain contact with their infant. The ***"maintaining equilibrium***" process was mediated by three factors - ***"interaction with others", "interaction with the health system"*** and ***"mother and infant interaction***". As mothers made the transition along the "***diagnosis to discharge***" continuum , these mediating factors impacted on the their perception of the situation during each crisis event (refer diagram 8.1). These three mediating factors are discussed in the next chapter.

CHAPTER SIX: MEDIATING FACTORS

INTRODUCTION

In Chapter Four the context within which mothers dealt with the problem of preserving their relationship with their newborn was described. This was the "***diagnosis to discharge***" continuum which consisted of multiple crisis events. Mothers dealt with the continuum by dissecting it into discrete crisis events which enabled them to deal with each event separately.

Mothers dealt with each crisis event by using the "***maintaining equilibrium***" **process** discussed in Chapter Five. This process was essentially a coping process composed of four phases; ***"distress", "response", "achieving equilibrium"*** *and* ***"connecting"***.

In Chapter Seven, the three mediating factors which impacted on the "***maintaining equilibrium***" process described in Chapter Six are presented. "***Interaction with others", "interaction with the health system***" and ***"mother and infant interaction"*** influenced the dimensions of each phase of the process.

INTERACTION WITH OTHERS

During analysis several subcategories were collapsed within the mediating factor of ***"interaction with others"***. These were "**relationship with others**", "**relationship with healthcare workers**" and "**communication**". "**Relationship with others**" refers to mothers' relationships with their spouse, children, extended family or other significant people in their lives. Relationships with these individuals influenced how mothers perceived and coped with their infant's diagnosis and subsequent management. While in some instances these individuals provided support, in other instances they were a source of guilt if mothers were unable to care for them because of their preoccupation with their infants.

Similarly their "**relationship with healthcare workers**" also influenced how mothers perceived and coped with their infant's diagnosis and management. The term 'health worker' refers to midwives, obstetricians, social workers, surgeons, neonatal nurses and consultant specialists such as cardiologists and neonatologists. Obviously, mothers' relationships with healthcare workers were

not as strong as relationships with relatives and friends; however, the opinion of healthcare workers often held greater weight. In most instances, mothers in the study viewed healthcare workers as the experts, relying on their advice, support and technical expertise to manage their infant's care. This level of trust placed healthcare workers in the very powerful position of either facilitating or obstructing the ongoing maternal–infant relationship.

These original subcategories were interrelated. Mothers' relationships with others was either favourably or unfavourably influenced by communication interactions with staff. Their perceptions of their infants' illness and consequently the decisions made regarding care were coloured by both the opinions of others and of healthcare workers. Hence my decision to collapse the subcategories of "**relationships with others**" and "**relationship with healthcare workers**" into the mediating factor "***interactions with others***".

The subcategory "**communication**" was also interrelated with "***interactions with others***". Verbal and non verbal communication provides the method by which perceptions are developed. The social interaction of communication has a direct effect on how we each perceive the world in which we live. Our perception results from the way in which we sense, interpret and comprehend each experience. Ineffective communication exposes mothers to ambiguity and confusion.

The importance of communication to the mothers and the transference of information between themselves and others was evident across the entire continuum of their experiences. "***Interactions with others***" influenced how well mothers were able to face the challenge within each event along the "***diagnosis to discharge***" continuum.

Mothers utilised the strategy of close observation of body language and speech patterns in their observation of staff. Close observation of staff provided mothers with cues which enabled them to determine the progress of their infant and to establish the experience level of staff. When they entered the nursery, mothers described a sense that everything was running smoothly, so long as the nurse caring for their infant appeared calm. Alternatively, when staff appeared anxious or concerned, mothers immediately looked for the cause. They were very astute at

picking up signals that all was not well either with their own infant or other infants in the nursery. They confirmed that this knowledge was especially important when their infant was in the intensive care area as it enabled them to prepare themselves when things were not going well.

Mothers also observed staff in the intensive care area to determine whether they "knew what they were doing". Mothers made it clear during interviews that they were not as concerned about staff members' years of experience as they were with staff being able to elicit help when they obviously needed it. They were happy for their infant to be cared for by a junior nurse who had a mentor at hand. The strategy of close observation of staff effectively provided mothers with information about the situation they were experiencing and added to the meaning of the situation for them.

In a busy surgical unit, multiple teams of healthcare professionals review each infant's case. Effective communication of information to mothers becomes more difficult as the number of individuals involved in the process increases. Several mothers described how they became suspicious upon discovering they had not been fully informed about their infant's progress. In Alice's case she feared the team was keeping something from her.

> *ALICE*
> *Its very easy to read into things especially when there are so many rounds and things through the day its really difficult to keep up with who ' s who and what they say and you are sought of trying to pick up and find meaning in what they say and hoping that when they come they are not just saying what they are saying and then walking away and saying poor child hasn't got a chance - do you know what I mean? I am just secretly hoping that everybody has been up front with us that he ' s well and that they truly mean it and it ' s not a case of enjoy it while it lasts.*

As a consequence the mothers then began to actively seek out all information, fearing something was being kept from them. This in turn altered their perception

of healthcare workers, resulting in a level of mistrust which impacted on the developing relationship between mothers and healthcare workers.

The context of the situation in which mothers find themselves, the ***"diagnosis to discharge continuum"***, equates to successive crisis experiences. It seems reasonable, then, to expect mothers to experience a heightened sense of awareness of the physical and verbal cues of others. They are in a state of anticipation in terms of the threat to their developing relationship with their infant.

In the following example, Paula and her partner experienced poor communication about additional tests undertaken on their daughter. They were forced to try and piece together information which resulted in them discovering their daughter was being investigated for a possible diagnosis of a syndrome as opposed to a solely cardiac diagnosis.

> *PAULA*
> *No, here yeah, we knew, someone said oh we have to get some blood tests done but we won't talk about that until we get the results back and we just thought in the back of our minds. Oh OK*
> *Mm. Yeah and then we asked Dr X in the rounds oh how are the blood tests going and he said oh some of those blood tests won't be back for a couple of weeks they take a lot of time , that's the T cells and B cells and we said no the ones about the syndrome. And he said oh I'll come back and talk to you about that and then we knew. And you should have seen everyone's eyes.*
>
> *RESEARCHER*
> *So you tricked him?*
>
> *PAULA*
> *Yeah, Yeah. I think he was quite happy to tell us when he was ready. And then we sort of mentioned the syndrome because the genetic people had come round and began checking things, veins and ears and stuff. So we*

basically put two and two together. That was the first time the word syndrome was used.
So that was on the 22nd we had an idea but because you are so happy about her getting through the operation and then her recovery you sort of forget about that, yeah,so we sort of knew from about then that there was something else but didn't really know the extent.

Mothers actively sought out as much information as they could regarding their infant's management and the situation in which they found themselves. They utilised any means open to them to collect this information. They described how they studied the facial expressions of staff. They made enquiries of staff, specifically looking for hints during the ensuing conversation. Some mothers reported deliberately eavesdropping on the conversations of others. The value of providing information to mothers cannot be overestimated. The information they gathered enabled them to then analyse their situation and adjust the way they managed the situation in order to obtain the best outcome. Without all the facts they were unable to determine which course of action to take.

Often the infant's prognosis did not become evident until well into the admission. Mothers were left feeling as though information had been kept from them. In addition, many professionals avoided discussing possible problems with mothers until they were able to confirm a likelihood of the problems arising. These mothers were then understandably suspicious of staff whom they felt did not inform them fully.

Difficulties also arose when infants were born with anomalies spanning multiple systems. Further testing became necessary. This made it difficult for mothers to keep track of the evolving diagnosis. Again, these mothers were often cared for by multiple teams, a situation which inherently posed communication challenges. So the experience was, for mothers, often governed by the infant's health status.

The way in which information was imparted to mothers also affected their perception of the experience as it influenced their ability to analyse the information they had been given. The quality of the interaction enabled mothers

to analyse the information received, make decisions and behave appropriately. Overloading occurred when too much information was provided, or information was provided too quickly, or the type of language prohibited full understanding (shared meanings).

In the following example, Alice reflected on the context in which she came to the realisation that her unborn child would be born with a cardiac anomaly. Initially she was unaware of where the conversation was headed so when informed of the result she became very distressed.

> *ALICE*
> *I was just lying there and the lady was quite nice but looking back in retrospect um I didn't pick up on it nor did Mum but she was all over the place she was on the heart then she was here and then she went to something else and she was asking me a million and one questions about Daniel and his heart problem (Daniel was her firstborn son who had died several years earlier as a result of a congenital heart anomaly) and when he was diagnosed and when I was scanned and just all sorts of questions and I didn't twig I thought she was just interested in his history and anyway having seen a lot of ultrasounds of hearts over the years um when they brought up the colour thing like the blue and the red um I was looking at it going mm that doesn't look right. I saw something shoot across but I didn't think it should be shooting across. It just went out of my head then but within seconds of that she froze that section of that picture and lent across and said its the same. It is the same as Daniel and I just said what do you mean it's the same as Daniel? And she said its a double outlet right ventricle and with that I said its a boy isn't it and she said yes and that was it. It was just horrible I mean she had to stop the scan there and then it was just futile going any further and within a short space of time um the head of the unit came in. They gave us our options ...we could end it if we wanted to, we could go ahead with it if we wanted to, it was entirely up to us.*

Overall, healthcare professionals appeared to underestimate the power of their communication techniques to influence meaning of the experience for mothers. They were at times unaware of having communicated particular meanings to mothers which resulted in miscommunication. In the following example inadequate explanation regarding the use of Prostin resulted in Mary's misunderstanding of the meaning of the commencement of a Prostin infusion. She had interpreted this as an indication of deterioration rather than the usual course for infants with her son's diagnosis and had become extremely anxious.

MARY

After he had his septostomy he wasn't on any medications and his sats (blood oxygen saturation level) *were OK but then they started plummeting. So initially I heard the doctors talking, they were handing over and she said well at what point do we start this medication?*

RESEARCHER

Prostin?

MARY

Yeah well if his sats are this stage for 10 mins or whatever and the doctor said we probably won't have to start this but we're getting this plan ready in case he deteriorates overnight. And that was fine we got through that but then over the next couple of days he was de-saturating so they had to start Prostin.

I came over from X (birth hospital) this day and he was on Prostin and I was really emotional about that because I thought that was a backward step and then later on that day the cardiologist came round and said that he wasn't in any danger when he was de-saturating (fall in oxygen saturation measured and displayed on monitor).

When I first came in that morning I was crying and the nurse got me some tissues and then by the time the cardiologist came round and I said 'well he's had a hard night' and he said 'well no he didn't it was just more of the same'.

What they should have done the day before when his sats started falling was to explain that this happens and it's not a backward step and we fully expect to put up Prostin.
I think it is just me I would have liked for him not to have had to go onto the Prostin. I suppose I found that hard to take the course he decided to take. When he was de-saturating to the 40s I was thinking 'Oh NO!'

Staff often do not realise that mothers take literally every word communicated to them regarding their infant, whether or not they are personally involved in the conversation. Mary was eager for the information she overheard; however, the result for her was an increase in her distress due to a misunderstanding. If the plan and rationale had been discussed with her this unfortunate result may have been avoided.

The mothers' perceptions of the situation were heavily influenced by interactions with neonatal nurses. Mothers were confident their infant would receive lifesaving treatment in the intensive care unit. Mothers saw neonatal nurses as experts. Initially they were satisfied that the nurses were able to fulfil their infant's need for physical stability. The experts, in whose technical expertise mothers had confidence, often had a negative influence on maternal perception of the situation because they failed to support them in other ways.

As the mothers made the transition along the "***diagnosis to discharge***" continuum their focus altered from simply keeping their infant alive to caring for their infant in an effort to sustain their developing relationship. However, by this time confidence in care provided through the health system had been shaken for many mothers. Communication breakdown was common in the system. The expert nursing staff strongly influenced the unit's culture which focused on the technical work of the NICU. The culture of the NICU resulted in nurses determining the level of involvement of mothers. In this way, mothers' interactions with others influenced her interactions with the health system.

INTERACTION WITH THE HEALTH SYSTEM

There are many facets of the health system which influence the ability of mothers to sustain a relationship with their infant. Subcategories included within this mediating factor included "**resources**", "**confidence in care**" and "**being messed around**".

The subcategory "**resources**" refers to the quality and type of resources as well as parental access to resources such as operating theatres, NICU beds, accommodation, parenting and technical equipment.

The subcategory "**being messed around**" referred to the negative interactions with the health system experienced by mothers. Some negative health system influences were seen to be unavoidable. For example, the necessity to transfer the infant immediately after birth to the NICU. This type of system impact is usually well recognised by those involved but they perceive change in practice as beyond their control. However, other avoidable interactions with the health system which negatively influenced the mother's relationship with her infant occurred. These included poor organisation, unplanned changes in care management, or poor communication.

The sub-category "**confidence in care**" referred to the level of confidence mothers had in the care their infant received. Mothers' "**confidence in care**" was influenced to a great extent by their interactions with staff and the availability of resources. These three sub-categories contributed to the mediating factor "**interacting with the health system**".

Within the context of a diagnosis of congenital anomaly requiring surgery, mothers experienced anticipation in regard to each of the events along the continuum from diagnosis to discharge. They tried to organise themselves for the anticipated threat or challenge to their relationship with their infant. In an attempt to manage the situation, some mothers maintained internal control by visualising what would happen and how it would happen. They attempted to anticipate what would happen at delivery, for example and surgery. Mothers went to great lengths to maintain control in an attempt to prepare themselves. It is understandable, then,

that mothers became extremely anxious when, despite all their best efforts, something unexpected occurred and reality did not match their anticipation of what was to happen. They found themselves unprepared for the reality of the situation and the altered meaning of the situation.

In the following example Hazel recalls becoming extremely anxious that she would be admitted to hospital without the support network she required for the birth of her baby. An already distressing situation was made worst for this mother because the obstetrician failed his obligation to confirm admission arrangements. He obviously did not recognise this confirmation as an important issue in her antenatal care.

> *HAZEL*
> *it was all a bit crazy , my doctor told me he couldn't deliver at Westmead because he's not, he doesn't deliver there so he was going to line me up with another doctor who would deliver and just before he set up the appointment and just before I was about to go and see this doctor he said to me 'Oh good news I can deliver at Westmead now but the paperwork and everything has to go through so I won't get you to go and see the other doctor now, we'll hold off'. So we kept holding off and he kept , every time I ' d see him he would say um 'It's still not official because of all the paperwork and everything' so I wasn't booked into the hospital and then I was in my own little panic about that and I ended up ringing."*
>
> *I was thinking they don't know who I am , nobody knows who I am, I'm going, if I go into, then I started thinking if I go into premature labour and he kept saying well just go straight to the hospital and I'm thinking 'I'm going to get there and nobody will know who I am' so I ended up ringing the hospital myself a week before she was due for induction and they were horrified that he hadn't booked me in but they did it all over the phone, they were very very helpful.*

As stated above, in this anxious state of anticipated threat or challenge mothers need to feel that everything is in order for them to remain in control of the

situation. Important aspects are familiarity with both their surroundings and familiarity with individuals whom they perceive as important to the experience. When admitted to the NICU area, they are exposed to a new environment and staff, and the cultural norms are unknown to them. The mothers are not known to staff and therefore, staff may not perceive the situation in the same way as the mother expects. Mothers admitted to feeling as though they did not belong and were often left unsure of what was expected of them and what they would be permitted to do.

PAULA

Well that was the other thing we weren't happy about, we didn't see a doctor the whole time we were there. So the last time I saw a doctor was when I left the operating theatre. That's right but because we'd chosen to go like to get enough health cover to go private we were assured that the obstetrician would see me every day and that sort of went out the window. It probably just wasn't what you expected like you go to the classes at the private hospital and they tell you this is going to happen and that's going to happen so..

RESEARCHER

Yes

PAULA

And then you get the other end of the spectrum. And the other thing was the medication too. The medication didn't follow on from the private hospital they just took it upon themselves to give me this Endo, oh and I was hallucinating and I was on Morphine basically. These Morphine tablets and I just said to them 'just look at my charts, that's why they had sent them with me so you would know what to give to me, and that was really traumatic. I just wanted what I'd had before and um these Endo tablets I'd try to rest and I'd be jumping, and jolting and jerking and I'd be seeing things it was just awful. And then we had the big trek across here.

Paula had endured an unpleasant experience when admitted through casualty of a large public hospital. In addition, her perception was one of very few staff available to deliver care and that the orders from her own private hospital not being carried over. She experienced a bad drug reaction, which worsened the situation. She felt abandoned in a foreign place with strangers. The receptionist in casualty did not welcome this couple at all after their traumatic journey to the hospital; instead she increased their stress and their feeling that things were not good. No-one offered reassurance.

Despite having had knowledge of the parental need for information for many years, often staff provided information very poorly. Poor communication contributed to, rather than prevented, the negative impact on the mothers' ability to sustain a relationship with their infant.

Other very obvious needs of mothers which required recognition included both physical and emotional needs. In the case of mothers who were about to or had recently delivered a sick infant, the basic physical needs of pain relief, preparation for breastfeeding, exhaustion, postnatal checks and medication administration required attention. The emotional needs of mothers were dealt with sporadically by individual staff rather than dealt with systematically.

The maternity experience left almost all mothers reporting feeling as though they were not seen as important, that they were just a number. No relationship was made with them despite the fact that maternity staff were sharing one of the most important developmental experiences of these women's lives – the birth of their child. Likewise mothers reported the same type of feeling when cared for by some of the nurses during their intensive care experience. They felt they were in the way, not needed, helpless. The most distressing experience for these mothers was not being able to hold their infant or touch the infant in the way they wanted.

The offer of a cuddling experience to mothers was often contingent on the staff on duty. If the unit was extremely busy or the nurse caring for the infant was inexperienced, it would require a level of organization to bring the infant "out" for

a cuddle. The overriding factor in this decision is the nurse's perception of the importance of the cuddling experience for the infant and the mother.

Some nurses would determine whether the provision of a cuddling experience was a reasonable request based simply on the physical status of the infant, ignoring the emotional needs of both the infant and the mother. The cuddling condition of "you can have a cuddle if the infant is stable" was routinely offered to mothers. The implication of this was that the infant was expected to achieve physiological stability, an almost impossible task within the context of NICU. In some instances, using the "stable" condition was a reflection of how confident the nurse was in her own ability to move the infant out for a cuddle. However, for others this was one way of avoiding interacting with the mother and infant. The unfortunate consequence was that mothers often interpreted not being permitted to cuddle their infant as meaning the infant was "unstable", which altered their perception of the situation and increased their anxiety about connecting with their infant.

Alternatively other nurses worked with the philosophy that contact between mothers and their infants was imperative to the wellbeing of the infant. The cuddling condition for these nurses was. Only infants who were medically paralysed or who had a physician's order to remain in bed would be classified by these nurses as extremely unstable. Guiding the cuddling experience provided these nurses the opportunity to develop their own relationship with the mother in addition to providing an interaction opportunity for mother and infant.

The way in which mothers reacted to individual staff members was dependent on their perception of the situation. If mothers perceived their infant as not being able to tolerate touch they did not touch the infant. Ultimately, the infant's needs were put before their own needs. Mothers' perceptions were influenced by the staff member's advice, health system interactions and interactions with the infant.

In the following example Hazel recalled her feelings about cuddling her infant after surgery. While one staff member would have supported her, several others disagreed, insisting that the infant was unstable. It was obvious that Hazel was

anxious that she might have hurt her infant if she attempted to hold her. It took very little to convince her she should not. However, with support, Hazel might have successfully been able to hold and comfort her child. The positive effects of a cuddling experience for Hazel, her infant, and their relationship were not considered by staff.

> *HAZEL*
>
> *I was cuddling her every day. But after theatre? no. And I didn't want to because I didn't want to make her uncomfortable in any way. She just looked like too delicate. One of the nurses suggested it but I was too nervous and then a couple of the others said "oh no, no she's too sensitive" and there was a bit of a conflict between them." Part of me felt a little bit maybe I should because I'm the mother but most of me didn't want to do it because I just felt that she wasn't … I would hurt her. So it wasn't until I got back here.*

During the course of their infants' hospitalisations, many healthcare professionals passed through the lives of each of the mothers. It was extremely difficult for mothers to develop relationships with so many people. However mothers perceived that it was the staff 's expectation that they should trust them implicitly. A degree of familiarity was expected, despite the fact that staff themselves did not invest in developing a relationship with mothers Mothers reported that individual staff members appeared not to trust them to attend to simple aspects of care unsupervised. Mothers repeatedly reflected on how healthcare professionals implied they could not adequately care for their own infants.

> *PAULA*
>
> *The number of time some particular nurses have asked and are you happy with what you are doing? And like we've decided. And they ask again and again as though they are trying to put that little bit of doubt there in my mind. Hoping I'll change my mind.*

The paternal attitude of individual staff undermined the confidence of mothers in their ability to care for their infants. They were exposed to many differing opinions from individual staff members on aspects of their infant's care. These

incidents occurred from time of diagnosis to discharge of the infant. Frequently, mothers were inappropriately interrupted by staff while spending time alone with their infant.

If infants were not permitted to come out to be cuddled, mothers were instructed about how they should touch them. The importance of touch and handling to mothers cannot be underestimated as the following example illustrates:

PENNY

> *Yeah. I wasn't allowed to stimulate him so you naturally want to rub and that provides a stimulus. So you could just put a hand and touch him, so we did that. And talked to him which I'm sure he thought 'shut up' but that's great. He probably didn't hear a word I said but anyway.*

The other factor that was recognised as extremely important was the support provided to these mothers by nursing staff. As previously discussed, nursing staff were very influential in regard to how mothers perceived the situation. In the following example, two nurses trained in developmental care were able to support Alice.

> *ALICE*
>
> *Oh they have been really supportive of that I mean I've been very hands on with R. I just say Oh I will do that and they have let me do everything. They just respected the fact that I wanted to be involved with him. That was when I went and told the nurse I wanted to give him a bath and I wanted to learn how to bath him. She was very good. There were two nurses helping me out. J and N were fabulous. J showed me how to do the football hold to hold the head and then what I should do to give the rest of the body a wash. She would just hold and show me and then lay the infant down and I would actually do it. That was very good because then it really helped me learn. And I knew she was right there next to me so if anything was wrong she would show me. That was very helpful.*

Mothers felt, when faced with a decision regarding the care of their infant, that they needed the approval of staff. Negotiations regarding decision making were difficult for mothers with so many staff offering individual opinions. Mothers reported that dealing with conflicting advice was a persistent issue, which was especially evident about feeding, as will be discussed under **"convalescence".** Mothers would come to a decision which satisfied some staff, or with which some staff were happy, but still had to deal with other staff who were not happy with the decision. This obviously created unnecessary confusion, conflict and distress for mothers.

Mothers usually decided on a course of action by gathering information from multiple sources. These sources included verbal advice from health care professionals, written and internet resource material. They assessed which verbal advice to follow in terms of the healthcare professional's familiarity with their infant's needs. In addition, they at times considered the experience level of the healthcare worker.

Once their decision was made, mothers expected to be able to put their plans into action. However, many examples were provided in which the mothers' plans were obstructed by staff with differing opinions. Often the mother's wishes in relation to a particular care intervention were ignored if they differed from the healthcare worker's wishes.

Another common occurrence was the continual offering of an alternative option to mothers after they had already decided on a course of action. Mothers were made aware that these staff felt they had made a wrong decision. Some mothers perceived this as a deliberate ploy to undermine their confidence. Others reported feeling as though their opinion were not being considered by staff. These feelings clearly impacted on staff – mother collaborative processes.

Mothers felt as though they had no control over what happened to their infant. This powerlessness was particularly distressing when they were concerned about the competence of individual staff, or the way in which an individual staff member practised. These concerns usually surrounded staff attitudes. Mothers

handled these concerns in several different ways. They avoided leaving their infant alone with these staff or, alternatively, developed relationships with staff they felt they could trust.

Staff consistency was an important support for mothers and facilitated collaboration between staff and mothers. Deliberate efforts were made by staff in charge to ensure consistent staff allocation. However, pool staff were a particular concern to mothers. Mothers perceived them as not being accountable to the ward. They managed this dilemma by staying all night in the nursery rather than leaving their infants in the care of these staff.

Paula recalls particular nurses who inspired her confidence. She admitted that she had favourite nurses and tried to arrange that they were allocated to her child.

> *PAULA*
> *Oh L was one of the first nurses she had and she was beautiful, very special and that was nice to continue to see her around. And you know I think there is also a family of nurses we've become attached to. We have our favourites , we do...you know we'd ask 'Are you back again today?' 'Can you try and get S tomorrow?' you know. I love the way the hospital does that though you do manage to see who's having who.*

Mothers experienced great discomfort when they were faced with the issue of staff competence. Several mothers described incidents when they were forced to approach clinical managers about the matter. There was a degree of conflict involved in this decision for mothers. They were obviously concerned for the wellbeing of their own infant but worried about loosing the support of the clinical staff if they complained. Ultimately the clinical manager solved the following dilemma by dealing with the situation tactfully. Interestingly, Alice was a nurse herself and had practised for many years yet she still felt care for her infant might be compromised if she became involved in a conflict with staff.

ALICE

There was one particular girl who was looking after him who I don't personally have a problem with but um she was not very big on hand washing. I would just stand by his isolette and cringe. OH my god she didn't wash her hands, she didn't wash her hands. She wouldn't wash between infants or even use the antibacterial gel. It got to the point one night when I watched her go from a infant across from R I was just compelled when she pulled the sheets off him I asked her if she had washed her hands, knowing full well she hadn't cause she had just had them in the crib. She pulled them out and I followed her around and I said look I'm really sorry but I'm really big on hand washing and she asked me if I had had a bad experience. I said I don't want to talk about it or go there but just trust me I'm big on hand washing. I thought that that would be enough to snap her out of her slackness or whatever it was. The next day she brought him back from surgery and I was just having kittens watching her with the blood gases etc. The day before I had watched her pull a tissue out of her pocket wipe her nose put it back in her pocket and didn't wash her hands. Anyway that night he came back from surgery I said something to somebody and the next day I bumped into C in the corridor and asked her if she was on. She said don't worry you will be happy with the girl who is looking after R tonight and I burst into tears and C was totally cool about it. It was everything this girl did… she contaminated everything! I mean the last thing I wanted to do was make enemies up there or here comes Mrs B she's crazy!

RESEARCHER

Why was that an issue for you to worry about?

ALICE

I think you have got to have a good relationship with the nurse looking after your child and if you don't it could compromise the care they give your child and I didn't want that to happen. I am very happy with the care but it was just that one girl.

Several mothers complained they were not happy with a particular nurse in PICU who they described as being harsh with their infants. They all commented that she was not incompetent but was uncaring, which prompted me to ask whether they preferred the technically expert nurse or a more caring nurse. These mothers responded that initially there was no choice because their first priority, when the infant was in ICU, was a live infant. However, they stressed, as did other mothers in later discussions regarding staff competency, that the level of experience was not a concern for them if they could be sure the nurse would recognise when they needed help from senior staff and seek out this help.

Mothers were also aware of the nursing shortage, both in the maternity and the NICU. Their response on the whole was sympathetic toward nursing staff; however, they were concerned regarding infants being left unattended because of staffing loads. This was a concern for mothers simply because they were well aware that most of the infants had recently undergone surgery and would tire easily if left crying.

Confidence in the care their infant received was also one of the most powerful positive impacts on the meaning of the situation to mothers. Many mothers described the expert care provided, especially in the NICU.

> *PAULA*
> *Well in ICU especially when he was on a lot of support - well I don't know anything about that so I just had to leave that up to them and trust that they are doing the right thing and some seem they tell you more than others so their knowledge is higher but they were fabulous.*
>
> *Every day it was great because we knew that everything was computerised and the rounds twice a day, we were so impressed with these people these teams coming around twice a day and taking such an interest in each individual case and knowing so much about it and the nurse explaining things, the communication was great, same as in here but really full on in there so we knew if anything came off that it had definitely been consulted within the team it wasn't just the nurse or one person making the decision.*

Mothers identified staff they preferred on the basis of the way they treated their infant. Lucy discussed the first nurse she encountered when the infant returned from the operating theatre. She valued the nurse's level of concern and the nurse's ability to answer her questions. Other mothers stressed they would prefer experts without the caring aspect, versus caring nurses without the expertise, in the NICU. Lucy was fortunate to experience a nurse who was technically expert in addition to being experienced and caring enough to support the family.

LUCY

The first night he came out of theatre I had this lovely nurse. She was just lovely.

RESEARCHER

What made her lovely? What made her different?

LUCY

Oh well it was just her personality I think. She just talked to my baby, called him darling and Yeah and I asked her lots of questions, what's this, what's this, what's this and she explained everything to me and um and she wasn't fazed by you knowing stuff.

Healthcare workers external to the unit communicated their confidence in staff to mothers which appeared to have a positive impact on the meaning of the situation for mothers.

PETA

The paediatrician said 'look you are in the best care'. You speak to the neonatologists and the surgeons and they don't leave a doubt in your mind that they know what they are doing.

Hazel's cardiologist made her feel confident in the care provided at the hospital as he quoted statistics regarding success with this particular type of operation.

HAZEL

And he said that we've got the best um team of people here and a very high success rate and that type of thing. He drew a diagram to show us what the problem was.

As with ***"interaction with others",*** the subcategories of "***interaction with health system***" were all interrelated. "**Confidence in care**" and "**being messed around**" described opposite views of aspects of the system which influenced the mother perception of the situation. For example, the hospital routine of offering tours of maternity and the NICU antenatally **"confidence in care"** positively influenced maternal perception. However, the hospital routine of maternal postnatal transfer admissions occurring through emergency **"being messed around"** negatively influenced maternal perception. Nursing culture both positively and negatively influenced maternal perception of the situation.

The mother's perception of her relationship with her infant and her perception of the situation she is experiencing is influenced by the system. As the situation changes so does the meaning of the situation change for the mother.

MOTHER AND INFANT INTERACTION

The subcategories within this theme included "**needs of mother**", "**needs of infant**" and "**connection"**. The "**needs of mother" subcategory** referred to the physical and emotional capacity of the mother to interact with her infant. Similarly, the **"needs of infant"** referred to the infant's capacity for physical and emotional interaction. **"Connection**" referred to experiences which the mother perceived to be successful in connecting with her infant. These three concepts are interrelated. The infant's capacity for interaction directly influenced the mother's capacity for interaction.

As previously discussed, mothers underwent a substantial level of distress within each crisis event along the "***diagnosis to discharge***" continuum. Mothers also complained of being exhausted because of lack of sleep and anxiety. These factors impacted on their ability to be emotionally available to their infant during periods of interaction. Mothers reported not being able to "see" their infant immediately, despite being shown their infant at delivery. Although they

remembered being shown their newborn, they could not visualise the infant. Their inability to visualise how their infant looked the first time they saw them may have been due to their high level of anxiety at that time.

Admission of newborns to the NICU also resulted in mothers visiting within hours of delivery while experiencing physical discomfort. They were often confined to a wheel chair as they were too weak to walk across the campus unaided. On occasions mothers were confined to bed and unable to visit as soon as they would have wished.

Maternal and infant emotional and physical availability was necessary for successful interaction to take place. The interaction between the infant and mother provides the context for the relationship to develop. The infant and parent both contribute to the interaction by providing behavioural cues and responding to these cues (Als, 1979). Initially, an infant works toward neurobehavioural organization and a parent works toward learning how to read and respond to her infant. Co-regulatory interactions provide the structure for enhanced development of the parent-infant relationship.

The mother's level of awareness of her infant's cues provides the basis on which she responds and supports her infant (Als, 1979). As the infant's need for support changes, the mothers adjust their strategies to match. In this study, making eye contact appeared to be an important factor in the mothers' eagerness to approach their infants and take control of their care. Eye contact was most often achieved through cuddling and breastfeeding the infant. However, in the initial period after birth and initially after surgery, these opportunities were often either not provided by staff or not taken up by mothers.

> *HAZEL*
>
> *In a way it felt like she wasn't born straightaway. It did feel like she was born but not born and it wasn't until um I guess just recently that I felt like and even now that she's not connected to the machine its like that umbilical cords been cut and she's now mine. Still I have been sharing her with a lot of people.*

Many mothers with healthy newborns experience difficulty interpreting their infant's cues. Mothers faced the dilemma of interpreting the cues of tired, sick and sedated infants. Opportunities for mother-infant interaction were limited in the intensive care nursery, hence the mothers found it difficult to become familiar with their infant's behavioural repertoire.

RESEARCHER
Were you worried at all at that stage about his comfort level?

LUCY
Um. No because they said he was zonked. They told us that before the operation so I wasn't thinking that he should be in pain he just had all the tubes. Although he looked a bit worse for wear I didn't think he was in pain.

RESEARCHER
So was there any time when that was a concern to you?

LUCY
Oh only when I went to pick him up for the first time. I was very unsure about how to hold him and...

Lucy recognised the infant was uncomfortable but did not see it as needing attention as the staff had informed her that her infant was well sedated. She did not feel confident in her ability to recognise his cues. Remembering these infants had received sedation and were experiencing some level of discomfort, it is unlikely mothers would be exposed to clearly defined behavioural cues, making interaction with the infant all the more difficult.

The meaning of the mother's relationship with her infant influences the mother - infant interaction. Mothers strived to successfully connect with their infants and therefore sustain their relationship while making the transition along the continuum. They interpreted making eye contact and successfully feeding as

essential in connecting with their infant. The importance of facilitating the maternal-infant interaction cannot be overestimated. Impaired interactions place the infant at risk for developmental delay, social and cognitive, and linguistic limitations, and failure to thrive. Parent-child interactions form the foundation of a trust-building relationship which enables a child to progress through the stages of normal growth and development (Leitch, 1999).

CONCLUSION

The first theme, "***interaction with others***", surrounded the issues of delivery and receiving of information. Difficulties in communication and the perception of mothers regarding the situation repeatedly arose. The impact of the theme "***interactions with others***" in relation to interactions with healthcare professionals changed with movement along the continuum closer to discharge. Mothers by that time had often developed a relationship with healthcare workers or at least felt more confident in their interactions with them. Closer to discharge mothers had also usually determined how their relationships with friends and family would fit with their ongoing relationship with their infants. Whereas earlier in the continuum, when there was a degree of ambiguity surrounding the ongoing relationship with their infant, mothers could not visualise how the other relationships in their lives would continue.

Similarly, mothers were able to deal more confidently with the impact of "***interactions with the health system***" on their perception of their relationship with their infants. Many facets of the system remained out of their control but increasing familiarity with the system over time allowed them to manage the practical difficulties more easily. "***Interactions with the health system***" referred to the impact of the healthcare system which influenced the mothers' perceptions of their relationships with their infants. These factors primarily surrounded healthcare workers and resources.

The third theme, "***mother and infant interaction***", referred to both maternal and infant factors which impacted on the mother's perception of her relationship with her infant. The "***mother and infant interaction***" continually changed as they moved along the continuum. As each crisis event represented a different threat to

their ongoing relationship with their infants, mothers fluctuated between distancing and approach behaviours, depending on which they perceived would ensure the most appropriate outcome.

These three mediating factors - "***interaction with others***", "***interaction with the health system***" and ***"mother and infant interaction"*** were all interrelated. The way in which each impacted on the mothers' perception of the situation during each crisis event altered as they moved along the "***diagnosis to discharge***" continuum.

CHAPTER SEVEN: INTEGRATION AND COMPARISON OF THE THEORY WITH OTHER RELEVANT THEORIES

INTRODUCTION

In this chapter the way in which the emergent theory satisfies Glaser's criterion for substantive theory development is discussed, and compared with related theories and the literature. As identified in preceding chapters, the key concept of the emergent theory, "***maintaining equilibrium***", accounts for the variability in the behaviour of mothers who have experienced the birth of an infant diagnosed with congenital anomaly requiring surgical repair. The theory explains the variations in maternal behaviour across the time continuum from diagnosis to discharge of their infant.

GLASER'S CRITERION FOR SUBSTANTIVE THEORY FULFILLED

According to Glaser: The goal of grounded theory is to generate a theory that accounts for a pattern of behaviour which is relevant and problematic for those involved (1978, p.93). A grounded theory should be parsimonious while still having sufficient scope and should meet four central criteria: fit, work, relevance, and modifiability. (Glaser, 1978, p. 4).

"Fit" refers to the participants' recognition of the agreement between the theory and the phenomenon they are experiencing. Concepts which are generated directly from the data ensure fit and relevancy. Throughout data collection, I therefore deliberately ascertained the validity of the emerging concepts by questioning participants.

"Work" refers to the ability of the theory to explain what happened and predict what will happen within the context of the participants' problem. The participant's problem was identified as "***preserving a relationship while enduring a crisis***". It was solved by "***maintaining equilibrium".*** This basic social process was based on an underlying rationale that the meaning of a mother's relationship with her infant was influenced by interactions with others, the health system and her own interactions with the infant. When faced with a crisis situation which threatened her ongoing relationship with her infant, the mother used various strategies which altered the meaning of the situation for her,

from one of crisis to one of challenge. In this way she moved her focus from the crisis to her relationship with her infant, which satisfied her natural instinct for primary preoccupation with her infant. In order to alter the meaning of the situation, mothers initially took measures to decrease their anxiety levels to a point at which they were able to focus on preserving their relationships with their infants.

According to Glaser (1978), "relevance" is achieved when the theory both fits and works. As "***maintaining equilibrium"*** both "fits" and "works", the criterion for "relevance" is achieved. "Modifiability" refers to the criterion that the structure of the theory should accommodate variation. The component strategies within the "***maintaining equilibrium***" process are able to accommodate new data as it emerges. The substantive area will change as a result of the interactions which occur within individuals and the environment.

INTEGRATION AND COMPARISON OF "MAINTAINING EQUILIBRIUM" WITH OTHER RELEVANT THEORIES

The continuum

The ***"diagnosis to discharge continuum"*** was the time continuum along which mothers transit from the time they received their infants' diagnosis until the discharge of their infant from the NICU. The continuum was artificially dissected by mothers based on the major challenges they faced along the continuum. Each of the events along the continuum impacted on the mother's perception of her ongoing relationship with her infant. Interactions with the system, with others and her interactions with the infant occurred throughout each of the events along the continuum. The dissection of the continuum supported mothers in their ability to cope with successive threats to their relationships with their infants by enabling them to deal with a single crisis event at a time.

A literature review undertaken at the completion of data analysis to identify previously developed theories that explained this process revealed none in which a framework of a continuum was used to describe the experience of mothers whose infants were admitted to a NICU. Considerable research has identified the transition to motherhood in the healthy birth experience, also for women experiencing emotional disruption prenatally

and postnatally, and for women who have delivered preterm infants (Ammaniti, 1991; Cronin, 2003; Goulet, et al., 1998; Lawhon, 2002; Malnory, 1996; Pinelli, 2000; Rubin, 1975; Singer,et al., 1999; Singer, et al., 2003; Tilokskulchai, et al., 2002). However, there is little research which endeavours to understand the experience of women whose babies are born with a congenital anomaly (Doering, et al.,1999; Franklin & Rodger, 2003; Ward, 2001). Therefore, this concept within the grounded theory makes a valuable contribution to the literature.

Coping along the continuum

The process identified as being used by mothers to preserve their relationship with their infant was the process of "***maintaining equilibrium***". The process was used by mothers to manage the challenges they faced at each event along the continuum. It enabled mothers to manage threats within each crisis event. The process consisted of four phases – ***"distress phase", "response phase", "achieving equilibrium phase"*** and ***"connecting phase".***

Sudden alteration in the mother's perception of the ongoing relationship with her infant resulted in initial disequilibrium which gave way to symptoms of increased anxiety. Several authors have reported similar levels of maternal anxiety surrounding the hospitalisation of a preterm infant in the NICU (Affleck, et al., 1991; Affonso, et al., 1992; Fenwick, et al., 1999; Miles, et al., 1999; Nystrom & Axelsson, 2002; Van Riper, 2001). Mothers in my study used the coping strategy of distancing to give them time to come to terms with their altered perceptions. They were then able to move to a point where they were able to approach their infants, viewing the threat as a challenge rather then a crisis.

Mothers described the process of "***maintaining equilibrium"*** as a coping strategy to deal with crises they encountered. Coping has similarly been described as a process by Lazarus and Folkman (1984). The rationale underlying this terminology is that process denotes a change in the individual's thoughts and acts as the stressful experience unfolds: "The dynamics and change that characterise coping as a process are not random; they are a function of continuous appraisals and reappraisals of the shifting person-environment relationship" (Lazarus & Folkman, 1984, p.144). Other authors have discussed coping in terms of a staged process (Kubler-Ross,1969; Klinger, 1977). They have discussed an initial response phase followed by at least one cognitive or appraisal phase which leads

to the action or behaviour phase, which indicates progressive movement or improvement in the ability to cope with the situation.

Other authors have discussed the vulnerabilities of individuals in regard to initial stress responses and the coping strategies they utilise. These findings recognise that the vulnerability of the individual influences the meaning of the situation for them. Vulnerability in this context refers to the physical, psychological and social resources available to the individual to deal with adaptive demands. As previously discussed in Chapter Six, these factors influence the interactions with self, environment and others.

Lazarus and Folkman (1984) discuss person-factors and situation-factors as influencing one's appraisal of the situation. The "situation factors" to which they refer are the characteristics of the stressful experience in which individuals find themselves. Lazarus and Folkman's (1984) stress theory accepts that the threat of the situation is dependent on the appraisal made by the individual of the threat. In symbolic interactionism, one's appraisal of the situation/threat equates to the meaning of the situation being influenced by the individual's interpretation of the characteristics of the experience. Thus the strategies used and behaviours displayed will change as the situation changes.

The shortcoming of using a stage concept to explain the process of coping is that it may lead inadvertently to a perception that individuals do not move forward or behave rationally if they fail to move through stages in a logical manner, or reasonable timeframe. A prime example would be the Kubler-Ross (1969) stages of dying. Individuals are often expected to ultimately move through the stages outlined, although not necessarily in the particular order in which the theory proposed. By relying strictly on these theoretical propositions, some individuals would be perceived as not coping using conventional definitions of coping. More recent explanation of these stage theories of coping suggest they were originally defined this way in an effort to identify systematic ways of coping. However, this is not always the case: the strategies individuals utilise to manage in stressful situations are as varied as the possible stressful situations (Lazarus, & Folkman, 1984, p.7-12).

Although using the term 'process', Lazarus and Folkman's theory (1984), accounts for the variability between individuals and stressful experiences. The theory recognises the ability of individuals to reflect on their situation and alter their behaviour accordingly. It describes a process which involves an initial cognitive appraisal followed by a reappraisal which may lead to change in behaviour. In symbolic interaction this encapsulates Mead's theory of self (Morris, 1962; Strauss, 1956) and Blumer's (1969) thesis concerning the process of interpretation and the importance of meanings.

The findings of this study reveal that mothers used different coping strategies depending on the context of the situation in which they found themselves. The choice of coping strategy utilised depended upon environmental, situational and personal variables. The mothers employed different strategies until they were found to be unsuccessful in achieving desired outcomes. Other strategic options were then reviewed and implemented. Throughout this process the impetus for utilising coping strategies remained unchanged. The primary focus for mothers was preserving their relationship with their infant.

The nurse-mother-infant triad

The nature of the maternal-infant relationship is complex, influenced by many factors, not the least of which is the presence of the nurse within the context of the NICU. The natural maternal-infant dyad is artificially increased to a triadic relationship. The mother is placed in the position of sharing the care of her infant with the nurse. The feeling of regret in having to share the care of their infant with others was confirmed by several mothers and has been supported by other researchers (Bialoskurski, Cox &Wiggins, 2002; Jackson, Ternestedt & Schollin, 2003). The nurse is placed in a very powerful position, being able to assert influence on the maternal-infant relationship which may be either facilitating or obstructing to that developing relationship.

In a recent paper which reported findings on mothers' responses to unsatisfactory nursing care, Fenwick (2001) refers to a "withholding" strategy used by mothers to smooth over a perceived disruption to their relationship with staff. In order to

cover up how they really felt, mothers in Fenwick's study physically withdrew from the nursery. The rationale provided for this behaviour was the pursuit of maintaining a positive relationship with staff responsible for the care of their infants. Similarities exist between Fenwick's "withholding" strategy and the behaviours reported by mothers in the current study. Behaviours displayed by mothers in the "***response***" phase in the process of "***maintaining equilibrium***" included distancing themselves emotionally and physically from their infants. These behaviours were self protective, facilitating a reduction of anxiety which provided an opportunity to refocus to ensure the continuation of care. In relinquishing care to the expert nurse ensured their infants received care and were physically safe, and in doing so, they were also ensuring the continuity of their relationship with their infant.

Several other similarities were evident between Fenwick's results and those of the current study. Fenwick (1999) noted the focus of nursing interventions was task-oriented rather than relationship-based. This was particularly interesting considering data had been collected in special care nurseries rather than intensive care nurseries. In my study, the mothers described nurses as being experts, particularly in the intensive care area. They explained that this was less evident in the extended care area. This confirms that neonatal nursing care is seen to be technically focused despite recommendations for change (Byers, 2003; Gilkerson & Als, 1995; Hutchfield,1999; McGrath & Conliffe-Torres, 1996).

Fenwick (2001) reported the nurse-mother relationship as having the potential to substantially affect how women perceived their mothering experience. This was specifically illustrated through the analysis of the communication patterns between nursing staff and mothers. Communication was similarly identified as an integral component of the interaction between mothers and others in the current study. "***Interaction with others***" was a mediating factor on the ability of mothers to sustain a relationship with their infant. Nursing staff were very influential in the way mothers perceived the situation. Fenwick (2001) noted that nurses' responses, both verbal and nonverbal to mothers, their infants and their families, affected how women approached their mothering role. Data in my study also suggest that mothers approached their role according to the meaning of their

relationship with their infant, which was altered as a result of their interaction with staff and the system.

Models of communication

Social interaction, manifest through communication, is not a straightforward process. It involves the ability to receive, evaluate, and transmit messages. Communication is affected by perception, memory, past experiences, value systems and the transmission quality of the message (Kneisl, 1988) in respect to the amount, speed and efficacy of the message. The symbolic interactionism model of communication focuses on this transaction. Social interaction is a presentation of gestures by an individual and a response to those gestures. The person who responds to language or gesture from another organises a response on the basis of what these mean. The originator of the language and gesture does so as an indication of what he/she is planning to do, as well as what he/she wants the respondent to do or understand by this gesture. Language and gesture, therefore, have meaning for both parties and influences the meaning of objects and situation for the individual (Blumer, 1969).

Hulett (1966) constructed a communication model according to the principles of symbolic interactionism. The model identified five phases in each person's communication sequence: input, covert rehearsal, message generation, environmental event and goal response. The communication process was described as the way in which individuals run through a series of internal trials in the process of organizing a message (intrapersonal process). They select and transmit the message they feel will have the most success in that particular situation (interpersonal process). Similarly, when the other person receives the message, a second interpersonal feedback loop occurs. The first individual then determines the most appropriate response and so the interaction moves forward. This process was borne out in my study. Mothers provided numerous examples of how they would observe staff carefully and then approach individuals in a particular way to elicit a positive response. This strategy permitted them to remain on good terms with staff which in turn enabled them to maintain their relationship with their infant.

In the process of communication some events take place intra-personally. Other events are interpersonal as they take place between individuals (Morris, 1969). Successful communication depends on the accuracy and completeness of the cognitive appraisal of the environment and the accuracy and efficiency of the intrapersonal and interpersonal processes. Mead (Blumer, 1969, p. 9) notes that if confusion or misunderstanding arises along any one of the lines of meaning then the "communication will be ineffective, interaction will be impeded and the joint action will be blocked".

In order for communication to take place, meaning between individuals must be shared (Kneisl, 1988). It is common for particular groups to have shared meanings for words. It allows them to use language in highly personal and private ways. However, attaching meaning from a sole perspective may result in inaccurate interpretations of events by those outside the group who are likely to be exposed to shared meanings they do not understand. Numerous anecdotal examples are found in the healthcare arena whereby meanings and abbreviations of medical terms can be misunderstood if overheard by the general population.

Individuals may develop different perceptions of the same experience. The development of different perceptions is influenced by the meaning of the experience to each individual. For instance, the neonatal nurse may have the perception that an infant's condition is no longer critical. However, the mother's perception may be that her infant is extremely sick and fragile. She is not familiar with the NICU or the normal convalescent course of infants with a similar diagnosis. She has no previous experience to measure this experience against. The nurse's and mother's perceptions of the infant's condition may be quite different and may lead to misunderstanding and misinterpretation of verbal and nonverbal cues during communication interactions.

An individual's perception may also be influenced by their own personal values (Hulett, 1988). Different individuals will have different values dependent on variables such as age, culture, life experience and role. Successful communication depends upon the participants taking into consideration their own perception when attempting to impart meaning to other.

Several researchers have reported problems with communication between parents and nursing staff which increase stress and anxiety (Bialoskurski, et al., 2002, Curran, et al., 1997). MacKean, Thurston & Scott, (2005, p.79) cited good communication skills as important for effective parent/staff relationships: "Parents valued health- care providers who would not only openly share useful information with them and invite and listen to their perspective, but who would then continue to work collaboratively with them in developing a plan of care that would best meet the needs of their child and family".

MacKean, et al. (2005, p. 79) also identified relational competencies of healthcare providers as being an important contributing factor to families' experiences with the health-care system: "Families did expect health-care providers to be technically competent: that is, they expected the health-care providers caring for their children to have good diagnostic and treatment skills as well as current, knowledge about developmental problems. It was relational competency however that dominated parents description of their experiences with the healthcare system".

Cescutti-Butler and Galvin (2003) concluded from their grounded theory study that parents viewed competency in a health professional as not solely involved on skills and tasks but in many caring behaviours. The four themes they considered as reflective of staff competency for parents included the following approaches:

- parents are facilitated to integrate into the unit and do not feel a burden
- parents feel in control whilst in the unit
- parents have a choice to opt out from observing tasks and procedures on their infant
- parents and the inter-professional team communicate well and provide appropriate information.

In Cescutti-Butler and Galvin's (2003) study, the neonatal nurse was recognised as the expert in the NICU playing an integral role in the infant's physical wellbeing. Mothers were conscious of this and geared their interactions with nurses accordingly. They recognised nurses as the technical experts who were

initially essential for the infant's physical wellbeing and so they surrendered their infants' care into the hands of the neonatal nurse.

In this study, the neonatal nurse working in the NICU functioned quite comfortably in the role of technical expert. As a consequence, the nurse rather than the mother had greater input into the infant's care in the acute phase of hospitalisation. In this scenario the nurse focuses on providing acute care for the infant. This work is tangible, measurable and controllable. Developing a relationship with the family is not necessary to provide acute care and sustain life. As the infant's condition improves, mothers wanted and were able to provide greater input into the care of their babies. However, in order to become confident they required information and advice from nursing staff. Consequently, the demand for the technical expertise of nursing staff decreased while the need for expertise in relationship-based care increased.

This development places the expert nurse in an uncomfortable situation. In their prime focus on the sick infant these nurses are often unable to provide the support required by mothers. My findings indicate that the nurses found it difficult to deal with the anxiety and distress displayed by mothers. Similar findings have been reported by Brown and Ritchie (1990), and Fenwick, (1999).

As mothers begin to initiate care based on their own perception of the infant's needs, the nurse may feel awkward within this situation. As a consequence, the nurse may attempt to control the situation by imposing her perception of how care should be delivered. At times nurses appeared to view themselves as protecting the infant from the mothers. For example, nurses would set time limits on infant handling with the rationale of not tiring the baby, rather than supporting the mother to pace the infant through handling or helping her to identify the infant's cues of being tired. Similar findings have been reported as undermining the attachment between the parents and their medically fragile infant (McGrath, 2001).

McGrath (2001) suggests the Guarded Alliance Model be utilised as a framework to improve the family-professional relationship in the NICU. The model describes

the stages which families of infants admitted to NICU undergo as they develop relationships with health professionals. McGrath makes the following recommendations regarding strategies that could be utilised to facilitate a trusting relationship between families and professionals:

- The need for recognition of the emotional needs of parents
- Working alongside parents to see the human features of their babies through the recognition of their cues and behaviours
- Providing families with the information they require, repeated as often as they need in a consistent manner

Maternal identity

Fenwick's (2001) research focuses on the nurse-family interaction; however, this is not the only factor which influences maternal-infant interaction. Anything that influences the meaning of the situation for the mother will affect the maternal-infant relationship. The development of a maternal identity and the subsequent attainment of a maternal role are influenced by the infant's characteristics, as well as the woman's self image and support from significant others (Fowles, 2005). Mothers in my study faced the dilemma of being unable initially to interact with their infants. Their first images of their infant after delivery included those of an infant who appeared lifeless, connected to a ventilator, infusion lines and drains, surgical wounds post surgery. Mothers underwent a substantial level of distress which impacted on their ability to be emotionally available to their infant during periods of interaction.

Similarly, Barclay, et al. (1997) reported that "becoming a mother" was mediated by the nature of the infant and the mother's reactions to her infant's behaviour and the nature of the social support available. Singer, et al. (2003) reported maternal and infant interactions were affected by infant risk status. In a descriptive study of 212 NICU infants, the mothers' perception of the severity of their infants illness was the strongest factor related to their parental stress scores (Shields-Poe & Pinelli, 1997). In my study, mothers perceived their infants as physically fragile. This perception influenced maternal efforts at interacting with their infant and was reinforced by the reluctance of staff to facilitate maternal infant interaction. Mothers normally used their infant's nonverbal behavioural cues to guide the pace

of their interaction. These mothers were challenged to interpret the cues of sick and sedated infants.

Nonverbal cues are important aspects of communication exhibited by individuals (Kneisl,1988; Grover, 2005). Nonverbal forms of communication include body language and posture, facial expressions and eye movements. These provide cues about persons and their feelings toward objects (environment and others). For instance, foot shuffling and hand wringing give us cues that the individual is uncomfortable, perhaps agitated. The recognition of these cues assists in gaining a perception of that individual, and in examining the environment for signs of danger which may have triggered this anxiety. In my study, mothers confirmed that close observation of body language and speech patterns of staff enabled them to determine the progress of their infant and consequently influenced the coping strategies they used. They confirmed that this information was important in the intensive care area as it enabled them to prepare themselves during events they found particularly stressful.

Eye contact in particular is an important cue for social interaction (Glass, 2002). Interaction is invited by making eye contact with another. If the other person returns the gaze the invitation for interaction has been accepted. Mutual eye contact between individuals signals a meaningful interaction and will therefore often be witnessed between persons who have a close relationship (Kneisl, 1988; Grover, 2005). The mothers in this study confirmed this as they described their feelings of connection to their infants once they were able to maintain this mutual eye contact. Gazes of longer duration also signal a more meaningful interaction than that of the usual short, intermittent gazes during a conversation. Mothers reported not feeling connected until they had experienced this mutual eye contact with their newborn.

In many cultures gaze aversion is used as a signal of rejection. However, in the case of the newborn, gaze aversion has long been recognised as being used to regulate the interaction (Als, 1979; Als, et al., 1982; Brazelton,1973; Tilokskulchai, et al., 2002). The newborn uses gaze aversion as a strategy to interrupt an overwhelming interaction. Several mothers in my study spoke about their infant's inability to sustain mutual eye contact. Their interpretation of this

inability differed. For example, one mother interpreted it as a sign that she had not bonded with her son because she had not been able to spend enough time with him, while another saw it as a reflection of her daughter's physical state. The newborn's intention will be interpreted according to the perception of the person receiving the cue.

New motherhood in the general population is often characterised by profound change, a strong sense of loss, isolation and fatigue (Rogan, Schmied, Barclay & Everitt, 1997). Although the birth of an infant is a normal developmental transition for most couples, the process involved is complex, sometimes stressful, and extends over a long period of time. It has been described as a life-altering event for mothers. Developing a maternal identity contributes to a woman's psychosocial development (Mercer, 2004). The infant's arrival may be anticipated with joy, or with anxiety and dread. The mother's own childhood and early relationships, life experience and satisfaction in her present situation will influence her reaction to the pregnancy and to the actual birth of the child (McFayden, 1997).

If we accept the theory of the establishment of the maternal–foetal relationship during pregnancy, we must then consider the possibility of mothers, whose infants were diagnosed antenatally, being placed at risk for attachment disorders, such as those mothers in my study. Mothers faced the event of "**birth**" with mixed feelings of wanting to deliver their infant but not wanting to face their infant's uncertain prognosis. Several mothers admitted they avoided attachment with their foetus and newborn.

Rubin (1984) described the process of maternal role attainment in stages which begin during pregnancy and continue well past delivery. She described the formation of maternal identity and the woman's attachment to the infant as separate entities of the same process. Rubin defined maternal identity as the end point in maternal role-taking with a woman having a sense of being in her role, along with a sense of comfort about her past and her future (Mercer, 2004). Rubin presents this process as occurring naturally in every maternal-infant dyad; however, this theory does not consider the other factors which affect the maternal–infant relationship such as maternal anxiety, maternal emotional

availability, support system or infant related factors such as health status and infant emotional availability. These factors are relevant when considering the development of the maternal–infant relationship within the context of infant hospitalisation.

Maternal-foetal representations

Qualitative descriptions of maternal attitudes and adaptation to pregnancy indicate maternal-foetal attachment being facilitated by the maternal representation of the foetus/infant. At conception, a mother does not have access to information about her infant other than perhaps physical condition. She is not aware of her infant's temperament, personality traits or physical appearance. She therefore brings fantasised representations and projects them onto the infant. Benedek (1959), Bion (1967), and Winnicott (1957, 1965, 1971), were the first to comment on the fantasy life of the mother-her dreams, preoccupations, fantasies, and projective identifications as forms of representations (Stern, 1991). Bowlby's (1982) description of "internal working models," and Freiberg, Adelson, and Shapiro's (1975) "ghost in the nursery" discuss similar themes to Stern's (1991) "maternal representations". Maternal representations include imagined scenarios between mother and her infant, as well as a mother's attribution of physical and emotional characteristics to the foetus (Rubin, 1975). It becomes difficult for mothers whose infants are diagnosed antenatally with a congenital abnormality to successfully develop representations. Mothers in my study confirmed being unable to visualise what their infant would be like and what would happen after delivery.

During this time the mother also reflects on her sense of self. The representation of self-as-mother is thought to be based on the representations of self-as-woman and own mother-as-mother. The representation prepares her for the changes she will experience within her various roles – wife, daughter, her professional role and herself in the mothering role. The ideal image reflects the qualities, traits, attitudes, and achievements the woman finds desirable for motherhood (Mercer, 2004). The image she has of those close to her will also change – her partner as father, her parents as grandparents. This process does not begin with the pregnancy. The mother began the psychological process of building a representation of the family she would eventually have during her own childhood,

in her games, experiences, and by the examples of maternal behaviour seen in her own family environment.

As the foetus develops and grows in the mother's uterus, the representations of the infant change. These changes have been described by numerous authors (Ammaniti,1991; Bruschweiler-Stern, 1989; Stern, 1995). The researchers confirmed the emergence of a complex representational framework during pregnancy. During the first months of pregnancy the richness and specificity of the maternal representation increases. Stern (1995) alluded to this representation being assisted by ultrasound and foetal movements which confirm the pregnancy and occur around this time. At approximately seven months this specificity declines and positive representations give way to more negative representations. Stern (1995) suggests the alteration of the representation may occur to protect the mother from potential discordance with reality. The mother works through the representation of her future infant, swinging between two alternative representations. The first is the ideal infant, her preferred infant - healthy, strong, beautiful, intelligent, good-natured. The second is the alternative she fears - the sick, malformed or troublesome infant. Towards the end of pregnancy, increasingly the mother sees herself as the major contributor to the infant's life (Stern & Bruschweiler-Stern, 1989).

Mothers whose infants were diagnosed with congenital anomaly requiring surgical repair antenatally were usually given the diagnosis between 16 and 20 weeks gestation. At this point in their pregnancy their expectations were that they would deliver and develop a long-term relationship with a healthy infant. However, the diagnosis they received altered their perception of the foetus they were carrying and the outcome of their pregnancy. Their positive representations of their infant rapidly changed to negative representations. Mothers reported initially having exhibited symptoms of anxiety and shock. However, several described how they attempted to plan for their upcoming delivery of a sick infant. A major difficulty for them was their inability to visualise what would happen at the delivery. Concern for their infant continued up to delivery. As time of delivery drew closer they reported becoming more apprehensive.

Representation versus reality: The birth

At the time of birth the mother is faced with the task of integrating her expectation of the infant in her mind (her maternal representation) with the reality of the infant she has delivered. The task may be an extremely difficult task in the case of infants born sick or with congenital anomaly. "When the infant's appearance and behaviour do not conform with maternal representation at a conscious or unconscious level, then bond formation may be delayed because the infant is not able to play his or her part in the establishment of attachment" (Bialoskurski, et. al., 1999, p. 70).

Many mothers experience a disruption in their sense of self at this time as their priorities change. Themes of the mother's life previously thought to be of primary importance are put to one side and her focus becomes making the infant her own. At the moment of the birth of the infant, mothers are faced with important tasks. They are responsible for the infant's life, health, satisfying the infant's needs, regulating the infant's states, and establishing a new relationship (Tarkka, 2002). Mothers in my study were additionally faced with transporting themselves to the adjoining maternity hospital or to the NICU; meeting with health professionals regarding their infant's care; relaying information to their partner and family; establishing their breast milk supply and looking after their own physical and emotional wellbeing.

The maternal representation influences the meaning of the maternal–infant relationship to the mother, and will affect her emotional state. The mother's overt behaviour during the mother–infant interaction is potentially meaningful to the infant and is relevant to the infant's development (Stern, 1995). The maternal-infant interaction consists of overt behaviours exhibited by mother and infant in response to and in synchrony with the other. The interaction is audible and visible to others. However, in situations where there are obstacles to this personal interaction, such as infant surgery and other causes of mother-infant separation, this interaction may be delayed or not occur. Stern (1995) describes a relationship as "the remembered history of previous interactions". He stipulates that it is determined by how the interaction is interpreted by each of the many "lenses" of the participants: "These are the lens of fantasies, hopes, fears family traditions and

myths, important personal experiences, current pressures and many other factors" (Stern,1995, p. 12).

The mother is not the sole participant constructing a representation of the interaction. The infant is also involved in developing their own representation of the interaction. In constructing their representation of the interaction, the infant utilises recurring events. The highest priority events for the newborn are initially feeding, sleeping and contact with caregivers. Each of these events involves contact with the caregiver: "The feature of repeated exposure to these experiences is very important, because it is from the repetition that the infant can gradually construct a representation that is a generalised happenings" (Stern, 1995, p.81).

Observational studies of infants carried out initially in utero via ultrasound appear to demonstrate both the existence of individuality from the end of the first trimester and continuities in behaviour between pre and postnatal life. They support the idea that infants do have the capacity to perceive and respond to their environment well before 40 weeks gestation (McFadyen, 1997). In this study, the poor physical condition of infants initially prevented them interacting with their caregivers and their environment. Infant's energy levels were used to maintain physiological stability, consequently early opportunities for contact with caregivers was restricted to necessary touch. Often these early experiences of touch were with caregivers other than their mother and were experienced as uncomfortable or painful. Therefore the representation of interactions of the infant undergoing the experience of neonatal intensive care is quite different to the representation of interactions of the healthy newborn and may obstruct the developing relationship.

Rogan, et al. (1997) described the process of change, first time mothers underwent, during the "becoming a mother" process. The process progressed from an initial phase of "this isn't my life anymore" to mothers being "in a certain tune". The entry point to the basic social problem encountered by first-time mothers was at their first realisation of the impact the birth of their child would have on their life. They reportedly were overwhelmed by this realisation. The entry point reported in Rogan, et al. (1997) is similar to the first phase in the

"diagnosis to discharge" continuum reported in my study. Rogan, et al (1997) went on to describe the difficulties undergone by mothers as they realised they were responsible for the new infant and learned how to care for them. Factors impacting positively and negatively on their transition to motherhood were described. Several mediating factors identified in my study were similar to those found by Rogan, et al. (1997). For example, the nature of the infant, the mother's reaction to her infant, her experience with other babies and the nature of social support are comparable to the mediating factors of "***interactions with others***" and ***"interactions with infant".***

Rogan, et al. (1997) also noted that the important aspect of "realising" was recognising the difference between their earlier perceptions of motherhood and reality. In my study mothers were similarly overwhelmed when they realised the impact of caring for an infant requiring surgery would have on their lives. Mothers discussed the difficulty of preparing for the birth of their infant when they could not visualise what would happen at the birth and then later after discharge.

Rogan, et al. (1997) also identified a category named "working it out" which referred to strategies used by mothers as they progressed towards becoming "in tune" with their baby. These strategies included active problem solving and self appraisal. Reference was made to the mothers' use of trial and error in terms of developing mothercraft skills. Reference is also made to the increase in maternal confidence and experience, and the maturation of the infant occurring over time which results in a more satisfying relationship. What is not described is the ways in which the women managed their difficulties. Insufficient information was provided to ascertain whether a similarity exists between these strategies and those used by mothers during the "***maintaining equilibrium***" process.

My data supports an increase in maternal confidence and experience over time. However, maternal confidence and experience does not suffice as an explanation for women's ability to overcome the challenges of motherhood. These factors are related to the mother's ability to develop coping strategies which enable her to negotiate the challenges of motherhood. It is the meaning of her relationship with

her infant which is her primary focus and influences her ability to develop coping strategies.

CONCLUSION

It can be seen that there is agreement with the emergent theory of ***"maintaining equilibrium"*** and the existing theories of mother-infant relationships. Several themes identified by other researchers were evident in the emergent theory which not only adds to the credibility of the theory, but also, given that "***maintaining equilibrium***" is grounded in the experiences of mothers, emphasizes the importance of using mothers as a primary source of data.

This theory is unique as it illuminates the importance of the maternal perception of her relationship with her infant to explain the behaviour of mothers, when faced with a situation which they perceive as threatening. The theory investigates the ways in which mothers endeavour to sustain the developing relationship with their infant.

CHAPTER EIGHT: IMPLICATIONS FOR PRACTICE

INTRODUCTION

The current study highlights mothers' perceptions of the birth of a sick infant and the ensuing hospitalisation as crises which threaten their dream of an immediate and ongoing relationship with their infant. The need to overcome the emotional and physical distress of the event triggered them to respond initially by distancing themselves from the cause of their distress. In order to realise their dream of preserving a relationship with their infant, mothers regained emotional equilibrium by altering their perception from one of crises to challenge. This enabled them to use strategies which allowed them to sustain the developing relationship.

Three major themes were reported by mothers that contributed to their perception of the birth and postnatal care of their sick infants, and the subsequent distress surrounding the experience. These themes included "***interaction with others***", "***interaction with the health system***" and "***mother and infant interaction***" as discussed in Chapter Six. Their experiences in this situation indicate that the emotional and physical needs of mothers and their infants are underestimated and are often not addressed by healthcare staff.

Despite the large body of literature available concerning the implementation of family-centred care into NICUs in other countries, there is little evidence of its implementation within Australian neonatal units. As the literature reveals, if positive change is to occur, health professionals working within the neonatal care area must genuinely accept that having families involved more with the care of their infants produces better patient outcomes. Indeed, positive outcomes have been reported in neonatal transitional care units with reduced length of hospital stay and rehospitalization rates, and reduced parental anxiety (Forsythe, 1998). The chapter discusses the implications for clinical practice identified in this study and outlines several recommendations for improved practice.

ALTERNATIVE MODELS OF PRACTICE

Research shows that social interaction is important for infant development and the developing mother–infant relationship (Aita & Snider, 2003; Browne & Talmi, 2005; Glass, 2002). In this study the mother's primary preoccupation with the ongoing relationship with their newborn facilitated use of strategies to overcome the distress associated with the infant's need for surgery post-birth. The findings also reveal the extreme level of distress and anxiety mothers endure in response to their infant's illness. Neonatal nursing staff, therefore, have a responsibility to enhance the quality and appropriateness of mother-infant interactions over the course of the newborn's hospitalization, so that this distress is alleviated as much as possible.

There is an increasing expectation by neonatal service providers that parents are able to take their infants home earlier than has previously been expected. This is an unrealistic expectation, given that parents are not always welcome in the neonatal nursery until just before discharge. The mothers in this study generally longed to help care for their infants, yet were cautioned not to do so until the infant was stable, and this situation was only reversed a short time before discharge. Thus health staff paid little regard for the desperate need mothers had to hold, care for and get to know their sick infant while in the safe environment of the neonatal care unit. The mothers felt they were not seen by staff as being able to contribute to the decision-making process regarding the care of their newborn. Mothers rarely expect to be able to make "medical" decisions for their infants; they defer these decisions to the experts. However, decisions about when and how their infants are handled, for example, are well suited to negotiation between mothers and nursing staff. If the aim of care is to discharge infants to the care of their families as soon as they are able to go then it is essential that we learn to work with families.

Nursing staff's failure to recognize that mothers ultimately have the full responsibility for their infants, and as such are the best people to provide many aspects of care, may obstruct the developing relationships between the mother and infant. Promoting the mother's involvement in care is facilitated by providing her

with the opportunity to review personal experiences and encouraging her to express needs for support from the nurses. The mother's involvement can be facilitated when health professionals work alongside the mother to help her recognise and understand the infant's cues for recognition and need. Establishing a good caregiver-mother relationship will in turn facilitate the development of the mother's confidence and sense of relatedness to her infant. These strategies will be more likely to enable the mother's presence in the nursery and their willingness to be involved in their infant's care.

Although family-centred care is being increasingly viewed as best practice in child healthcare settings (MacKean, et al., 2005), my study reveals that, in practice, commitment is lacking. Most acute care nurseries run parent support groups and provide written information for mothers. Others have developed philosophies of care committed to the provision of family centred care; however, in routine clinical practice, the philosophy of care seems to have remained unchanged. The central theme of care remains focused on medical management in the belief that this is the sole contributing factor to the physical wellbeing of the infant. The emotional wellbeing of the infant and family is often neglected.

After discharge mothers who have experienced the trauma of a very sick infant requiring surgery immediately following birth may be faced with providing care which goes beyond that which would have been required had their infant been born healthy. Assisting mothers to manoeuvre through the healthcare system when facing this experience will support them in their next challenge along the continuum once the infant is discharged. A positive experience is essential as there is strong evidence that some NICU experiences shape mothers' interactions with professionals for many years into the future (Coyne, 1995).

The mother's ability to read the baby's cues and respond in a reliable and sensitive manner determines the quality of the mother-infant attachment. The process and timeframe around which women become mothers is individual. Rubin (1975) found that this occurs at the end of the first month after delivery, while Mercer (2004) confirms it may take the first twelve months to achieve. In the case of the sick infant where the normal process has been obstructed by medical

intervention it may take much longer. It is, therefore, of the utmost importance that health professionals understand the crucial role they play in supporting the maternal-infant relationship as a way of ensuring the mother is able to meet the infant's total needs. Further research in this area is required.

This important requirement is strongly influenced by the present reality of today's healthcare system, which is distinguished by increasing patient acuity and a decreasing neonatal nursing workforce (NSW Health Workforce Planning Unit, 1998; Spence, 2001a; Spence, 2001b). Hurst (2001) reported that the increased nursing staff to patient ratios in the NICU impeded the mother's ability to secure meaningful moments with their infant. Similarly, mothers in my study described how the nursing staff to patient ratios were often such that nurses could barely keep up with the infant's basic care needs, much less provide information, guide mothers in developing the skills necessary to care for their infants, and assist in the appraisal of the mother's interactions with their infants.

The mothers acknowledged that their priority was to watch over their infants to keep them from danger. The need to safeguard their infant has ramifications for the facilitation of the maternal-infant relationship. Mothers need to feel safe to interact with their infant. If they are feeling unsupported they are less likely to hold and interact with their infant. Mothers are devastated if their infant becomes unstable while they are interacting with them. The nurse must be available to prepare for and support mothers during these periods. Consistency in staffing, the provision of experienced staff to all areas of the intensive care nursery and the recognition that the needs of parents in step down units are as important as those of families in acute areas, are all essential aspects of family-centred service provision. Although difficult to achieve, it requires an acknowledgement from health administrators that families of infants convalescing after discharge from intensive care continue to experience stress and require far more support than is currently provided.

As this study reveals, the needs and coping strategies of mothers change over time and are dependent on the situation. Therefore, it is most appropriate to develop strategies that facilitate an understanding of the support required by mothers and

their families that is individualised to their needs. The model with which most neonatal nurses would currently be familiar is the Newborn Individualised Developmental Care Assessment Program (NIDCAP) advocated by Als (1979). Als and Gilkerson (1995, p. 178) defined the philosophy of the NIDCAP as "a professional alliance that supports the parents engrossment with their child and the infants neurobiologically-based expectations for nurturance from the parents and other family members, an alliance that listens to the language or the behaviour and uses the dialogue between the infant, family and professional caregiver to guide care".

It is clear in this study that the NIDCAP model was not operating adequately to support the mothers and infants. Although all staff in the study unit had received some information on aspects of developmental care, allocation of trained NIDCAP staff to infants in the study was inconsistent. Consequentially mothers in the study were exposed to varying levels of family-centred developmentally appropriate care.

The introduction of a family-centred, individualised developmental care program requires a considerable commitment from the health organisation in terms of both human and physical resources relating to the educational preparation of nurses. Most nurseries in Australia have moved to introduce aspects of developmental care, for example, the introduction of mandatory quiet times, light and noise reduction, kangaroo care and the nesting of infants. However, the introduction of these aspects of care represent only the physical changes within the care nursery, which are important but the also the easiest aspects to improve.

The practical application of the philosophy of individualised family-centred developmental care is more difficult to achieve. Working towards this care philosophy impacts on every area of service provision. It requires planned care including strategies for maintenance and accountability within the model of practice. The philosophy of individualised family-centred care should be reflected in all documentation – patient records, policies, clinical guidelines, competency assessments. Implementing an individualised family-centred care model also impacts on staff training, recruitment and retention, clinical practice and the

newborn care environment. It requires the provision of facilities for parents to be resident with the infant which include adequate space around cots, parent rooms, expressing rooms for breastfeeding mothers and flexible visiting hours for parental support persons (Byers, 2003; Kuschel, & Roy, 2005; McGrath, 2001). The essence of individualised family-centred care is the delivery of individualised care centred on the needs of the infant, within the context of their family and community.

The NIDCAP model is clearly a most effective way of improving the focus of care towards the total needs of the infant and parents, however, the model was developed for practice within the North American context. When evaluating this model, and similar models of care for the purpose of implementation into Australian NICUs consideration should be given to the differing needs and resources of neonatal nurseries to those of the North American health-care system. It is, therefore, recommended that the health-care sector initiate development of an individualised family-centred care model of practice that is suited to the Australian setting.

An integrated approach to the physical, technological and mental health of infants is long overdue in clinical practice within Australian neonatal units. The belief that a family-centred developmental model of care would benefit both families and health professionals has resulted in the implementation of different aspects of such a model being introduced in many NICUs within Australia (Kuschel, & Roy, 2005). The ideal solution would be a co-ordinated approach across all units to the development and implementation of an individualised family-centred developmental care intervention suited to the Australian context.

EDUCATIONAL PREPARATION OF NEONATAL NURSES

Nursing has an obligation to parents, families and to neonatal nurses in terms of the academic preparation of neonatal nurses. In the past, preparation of neonatal nurses has focused on the physical and technological needs of the sick newborn set within the dominant medical management model. Little consideration has been

given to nursing concerns, including the emotional needs of the newborn and family, and the particular needs of nurses who provide this high intensity care.

It is important to think about the newborn's experience in this situation, in order to best support their emotional and psychological, as well as their physical, development. Very little has been provided in neonatal nurse educational curriculum regarding the relationship between mothers' psychological needs and the long-term effects on infant development. There is a presumption that, once the infant's physical status is stable, the mothers' needs are satisfied. However, this study and many other studies show that mothers continue to demonstrate difficulties approaching discharge from the NICU and long after. An educational approach to nursing curricula which integrates the physical, technological and mental health needs of infants and families requires consideration.

This study has highlighted several immediate priorities for the preparation of clinically effective neonatal nurses

- the development of high level communication skills with mothers and other family members
- the need for relationship training
- the need for a better understanding of the parent-infant relationship

Mothers depend on the bedside nurse to provide explanations and accurate information in regard to the care of their infant. It is inappropriate for the nurse to fail mothers by passing this responsibility to other members of the team. Nurses, who either feel ill-prepared or uncomfortable in relaying information to mothers, often use this strategy. It has the effect of undermining the parent's confidence in the nurse's level of expertise in caring for their infant and may continue to influence their opinion of health professionals. In this highly technical and intensive care environment, minimum standards of nurse education should be established to ensure that neonatal nurses are able to support parents in their efforts to make sense of the information and experiences of Neonatal Intensive Care.

Minimal standards of educational preparation would include the ability to communicate effectively with mothers as previously mentioned. It is essential that nurses are able to relate effectively with people from a range of social and cultural backgrounds. The divergence between the perception of mothers and nurses regarding the meaning of the experience of the sick infant has been discussed. One way this divergence can be remedied is through effective communication, so that common meaning between all key parties can be established. The degree to which mothers believe they can control the situation has an important impact on the degree to which the situation causes them stress. The most harmful and distressing situations are those in which they feel entirely helpless, believing that nothing they can do will alter the outcome. Providing information to parents will empower them, thereby restoring, even partially, their sense of control over this difficult situation.

The literature suggests that the extent of parental involvement in their infant's care varies considerably (Coyne,1995). This study provides an explanation for this phenomenon. The level to which mothers are able to be involved at any particular time during the hospitalisation may change according to their perceptions of their current situation and their behavioural responses to it. In order to provide sensitive, high quality care, the neonatal nurse needs to be comfortable in their emotional involvement with mothers and understanding of the mother's variable response to the situation. Education on stress-coping response may be important in changing the current deficits in this area.

There is also an urgent need for relationship training, ideally addressed in educational preparation of midwives and neonatal nurses. There is a particular need in regard to the important role they play in the facilitation of the mother-infant relationship. Nurses are regularly required to build relationships with dysfunctional families. It is often the mothers from these families who are viewed as difficult, but who are often in most need of support. Nurses who accept different styles of family relationships will be better equipped to intervene appropriately at each event along the continuum of the NICU experience.

There are no uniform or standardized responses available for every circumstance: emotional involvement will vary considerably with the needs of each mother. In

order to support mothers, the expert neonatal nurse requires preparation to assess the extent to which mothers are physically and emotionally able to be involved in their infant's care. The expert neonatal nurse should be able to assess mothers' resourcefulness and their concerns at any particular point along the "**diagnosis to discharge**" continuum. Expert neonatal nurses are those who have been adequately prepared and have the experience to enable them to work with the health system to prevent unnecessary technological intrusions to the developing maternal-infant relationship.

Neonatal nurses are pressured to push infants and their parents along the "**diagnosis to discharge**" continuum as the bed situation demands. The ethical dilemma for nurses is that families and mothers, in particular, may not be psychologically ready to move smoothly along the continuum. While the condition for which the infant was initially admitted has usually resolved, many of these infants have ongoing neuro-behavioural problems, and issues associated with physical therapy and feeding, for which mothers require further support. One approach might be to improve the ability of parents to take their newborns home through the implementation of a model of care which supported both the physical and psychological wellbeing of the infant.

Unfortunately, neonatal nurses are less well prepared to support mothers and other family members in 2006 than they have been for many years. The numbers of neonatal nurses with specialty training working within NICUs in Australia are decreasing (NSW Health Workforce Planning Unit, 1998; Spence, 2001a). An increasing number of inexperienced nurses are being employed directly into the NICU owing to the general shortage of nurses to acute care areas. While most neonatal nurseries provide orientation programs and nurse transitional programs, the curriculum provided within these unit based programs omit topics essential for the development of an expert neonatal nurse. A review of these curricula reveals that none of them provide the level of knowledge on neuro-behavioural development, parent-infant relationship and communication skills required to care for families of sick or premature infants.

In addition to communication and relationship training being included in preparatory neonatal nurse curriculum, existing staff require the support of adequate staffing, group work and educational workshops. These strategies would go toward enabling staff to understand the psychological processes involved for parents, particularly mothers dealing with the birth of a sick infant and the ongoing uncertainty of their relationship with their infants. The technically expert nurse should be offered the challenge of providing quality family-centred care.

Recommendations to achieve these aims include developing the knowledge base of new and experienced neonatal nurses about the neurobehavioural capabilities of newborns and the principles of infant mental health. This knowledge base would support staff in communicating and building relationships with families in crisis.

CONCLUSION

The complexity of the NICU environment is confronting for many mothers and may interfere with the quality of the developing parent-infant relationship. Over the years I have witnessed mothers display a wide variety of responses toward their newborn infants and to the NICU environment. These varied responses become more obvious at different stages throughout hospitalization. The aim of this study was to examine the developing relationship between infant and mothers facing serious illness in the NICU.

A literature review of studies concerning the area of neonatal intensive care was undertaken. Themes identified within the literature included: newborn surgery; parental experiences of the NICU; the parent-infant relationship and interventions developed to facilitate parenting. Numerous studies confirm mothers whose infants have been admitted to NICU experience greater levels of psychological distress which consequentially places the parent-infant relationship at greater risk. However, the majority of studies were situated within the preterm population of the NICU. No studies were found concerning the effect of neonatal surgery on the parent-infant relationship. This paucity of information led me to undertake an investigation of mothers' perceptions of their relationships with their infants through a grounded theory analysis of in-depth interviews.

Symbolic interactionism was chosen as the theoretical perspective for the study since the basic premise of the perspective explains that behaviour is related to the meanings people attribute to situations and to other individuals. Therefore this perspective acknowledges the meaning a mother attributes to her relationship with her infant as unique to her, which will influence her perception of the relationship and, in turn, her behaviour within that relationship. The qualitative methodology of grounded theory was employed to examine the parent-infant interaction and the problems faced by these individuals.

The experience of carrying and then delivering an infant requiring surgery in the newborn period was viewed by the mothers in this study as a series of crises with which they had to overcome. It was found that mothers were being propelled along a continuum by forces which for the most part were out of their control. They moved through each event along the continuum irrespective of whether they coped well or not. Mothers were faced with an ambiguous future; they had anticipated the mother–infant relationship in a specific way. After the diagnosis, mothers were faced with a possibility that this relationship might be altered or, at worst, lost completely. Mothers perceived the uncertainty of the prognosis as a threat from the point of diagnosis of the congenital anomaly until the point of discharge. The level of distress mothers encountered was evident within each event along the diagnosis to discharge continuum. This distress was exacerbated by poor interactions with both the health system and health professionals which in turn impacted on the mothers' ability to interact with their infants. Mothers managed by dealing with one major event at a time. The level to which mothers are able to be involved in the care of their infant at any particular time during the hospitalisation may change according to their perceptions of their current situation and their behavioural responses to it.

In order to provide sensitive, high quality care, the neonatal nurse needs to be comfortable in their emotional involvement with mothers and understanding of the mother's variable response to the situation. While it is doubtful that the experience of the birth of a sick infant would ever be totally free of distress for mothers, implications for practice with the aim of decreasing this distress have been clearly identified from the themes discussed. Implications for practice

primarily concern the introduction of alternate models of practice which support families to care for and develop relationships with their sick newborns. Despite the move toward introduction of developmentally supportive, family centred care programs into NICUs throughout the world over the past fifteen years, this has not been the case within Australia. Neonatal nurses are in a prime position at the bedside to play an important role in the facilitation the mother-infant relationship through such interventions. Expert neonatal nurses are those who have been adequately prepared and have the experience to enable them to work with the health system to prevent unnecessary technological intrusions to the developing maternal-infant relationship. Therefore, adequate educational preparation and professional development of neonatal nurses is essential.

Finally. this theory is unique as it illuminates the importance of the maternal perception of her relationship with her infant to explain the behaviour of mothers, when faced with a situation which they perceive as threatening. The theory investigates the ways in which mothers endeavour to sustain their developing relationship with their infants. Neonatal nurses should be offered the challenge of providing quality, family-centred care which supports the developing mother-infant relationship.

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