THE PERCEPTIONS OF MOTHERS WITH AN INFANT RECEIVING NEONATAL INTENSIVE CARE- A DESCRIPTIVE STUDY: PHASE ONE

by

Marion I. Saydak, R.N., B.N.

A thesis submitted to the
Faculty of Graduate Studies of
University of Manitoba
in partial fulfillment of the
requirements for the degree of
Master of Nursing
School of Nursing
University of Manitoba

Winnipeg, Manitoba
(c) Marion Saydak, 1991

National Library of Canada

Bibliothèque nationale du Canada

Canadian Theses Service

Service des thèses canadiennes

Ottawa, Canada
K1A 0N4

The author has granted an irrevocable non-exclusive licence allowing the National Library of Canada to reproduce, loan, distribute or sell copies of his/her thesis by any means and in any form or format, making this thesis available to interested persons.

The author retains ownership of the copyright in his/her thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without his/her permission.

L'auteur a accordé une licence irrévocable et non exclusive permettant à la Bibliothèque nationale du Canada de reproduire, prêter, distribuer ou vendre des copies de sa thèse de quelque manière et sous quelque forme que ce soit pour mettre des exemplaires de cette thèse à la disposition des personnes intéressées.

L'auteur conserve la propriété du droit d'auteur qui protège sa thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.

ISBN 0-315-77030-9

Canadä

THE PERCEPTIONS OF MOTHERS WITH AN INFANT RECEIVING NEONATAL INTENSIVE CARE- A DESCRIPTIVE STUDY: PHASE ONE

BY

MARION I. SAYDAK

A thesis submitted to the Faculty of Graduate Studies of the University of Manitoba in partial fulfillment of the requirements of the degree of

MASTER OF NURSING

© 1991

Permission has been granted to the LIBRARY OF THE UNIVERSITY OF MANITOBA to lend or sell copies of this thesis. to the NATIONAL LIBRARY OF CANADA to microfilm this thesis and to lend or sell copies of the film, and UNIVERSITY MICROFILMS to publish an abstract of this thesis.

The author reserves other publication rights, and neither the thesis nor extensive extracts from it may be printed or otherwise reproduced without the author's written permission.

This thesis is dedicated to my husband Alan and my children Patrick and Megan. I feel their loving arms around me, always.

I wish to thank several people who were instrumental in providing support and guidance throughout the thesis process

A special THANK YOU to my thesis chairperson Dr. Ina Bramadat who provided guidance, mentorship, support, and direction. THANK YOU to Dr. Janet Beaton for her support, advice and suggestions. THANK YOU to Dr. Nigel MacDonald for his recommendations, support and patience.

THANK YOU TO:

The mothers that participated in this study.

Dr. Karen Luker

Angela McLoughlin

Mrs. Edith Parker

Naomi Granke and the nursing staff of NICU, St. Boniface Hospital

Melba Rous and the nursing staff of 8AW, St. Boniface Hospital

Joyce Olyniuk and the nursing staff of IMCN, St. Boniface Hospital

The nursing staff of NICU, Children's Hospital, Health Science Center

The nursing staff of IMCN, Women's Center, Health Science Center

My sister in law Maria J. Saydak for the support and humor she provided when I needed it most

My fellow graduate students, especially Debra Vanance, Laurie Thompson, Dianna Pallen, and Linda Turner, who are my "University Family." The laughter and the friendship will stay with me forever

Sylvia Yee and Lorraine Grenier, who have always supported me in my endeavors and were always there with helping hands and friendship

The "Birthday Breakfast Club", Claudette Mitchell, Jeannette Dick, Sharon Skulimowski, and Gail Franklin. The breakfasts and friendship were very much appreciated

Jeff Sloan, for his statistical advice

Margaret Struch for her assistance and encouragement

The Canadian Nurses Foundation for the Nursing Fellowship

Mr. Peter Janzen, a teacher who encouraged students to excel

For my mother Bea Bourree

A rose for my mother who was always there when I needed her. She has always supported me in whatever I did or wanted to accomplish.

ABSTRACT

The event of a child requiring neonatal intensive care (NIC) can have long lasting effects and repercussions (Affleck, Tennen, Rowe & Higgins, 1990). In this descriptive study, the perceptions of mothers with an infant receiving neonatal intensive care were investigated. A convenience sample of fifty-four mothers were asked their perception of the event, the support they perceived as beneficial or non-beneficial while their child was in NIC, and the support they perceived as beneficial or non-beneficial in preparing them for their baby's discharge home from NIC.

This study represented the the first phase of a collaborative intersite research project. British nursing researchers Luker and McLoughlin (1988) designed the study in a two phase format and developed the original interview questionnaires. The population for this study were mothers who had infants who had been admitted to a NIC unit or special care for at least 10 days. Mothers were interviewed at the time when their infants were being prepared for discharge.

Subjects verbalized strong and powerful feelings regarding the event. Mothers were specific and definite about what support was beneficial and non-beneficial during infant hospitalization and preparation for discharge. Nurses, during mothers' and infants' hospital stay, play a fundamental role in providing maternal support and supporting significant others (Perehudoff, 1990; Thorton, Berry & Dal Santo, 1984). Findings from this study substantiate this nursing role. Data from this research will aid in continuing to educate nurses about mothers who have infants requiring special care and their role in supporting these parents. Additionally, this study will provide the basis for continued research into maternal perceptions of support mothers receive in the community following discharge of the infant from neonatal intensive care.

TABLE OF CONTENTS

PAGE

ACKNOWLEDGEMENTS iii

ABSTRACT v

CHAPTER ONE: 1

STATEMENT OF THE PROBLEM 1

Purpose Of The Study 6

CHAPTER TWO: 8

CONCEPTUAL FRAMEWORK 8

Maternal Emotional Health 9

Maternal Abilities to Communicate and Caregive 11

Maternal Support System 13

CHAPTER THREE: 16

REVIEW OF THE LITERATURE 16

The Importance of and Consequences of Neonatal Intensive Care To Newborn Infants and Their Mothers 16

The Experience of Parents When Their Child Requires Neonatal Intensive Care 25

Relationships With Others 34

The Influence of Support On Parents When Their Child Requires Neonatal Intensive Care 36

Support During An Infant's Hospitalization 39

Support During Discharge 43

Support From Significant Others 47

CHAPTER FOUR: 50

METHODOLOGY 50

Glossary of Terms 51

Setting 52

Population and Sample 52

Procedure For Data Collection 54

Questionnaire 55

Implications of the Research Procedure
to the Human Subjects 57

Data Analysis 57

CHAPTER FIVE: 58

RESULTS OF STUDY 58

Demographic Data 58

Perceptions of Mothers Of Their Infant's Stay In An
Neonatal Intensive Care Setting 66

Previous Experience With Neonatal Intensive Care Units 66

Maternal Perceptions Regarding Their Infant's Admission 66

Initial Maternal Perceptions Of Neonatal Intensive Care Units 68

Mothers' Perceptions Of Support That Was Beneficial
And Non-Beneficial To Them While Their Child Was In
Neonatal Intensive Care 73

Maternal Involvement In Infant Care 74

Support From Nurses 77

Maternal Perceptions Of Support From NIC and IMC Nurses 77

Maternal Perceptions Of Support Received From
Post Partum Nurses 83

Maternal Perceptions Of Communication With
Special Care Nurses 84

Maternal Perceptions Of Communication With Physicians 85

Maternal Perceptions Of Support Received By And Extended
To Family Members By Nurses 86

Mothers' Perceptions Of Support That Was Beneficial
Or Non-beneficial In Preparing Them From Their
Baby's Discharge Home 88

Maternal Perceptions Regarding Their Infant's Impending
Discharge Home 88

Preparation And Support For Infant Discharge 90

Preparation For Infant Discharge 90

Confidence In Infant Care After Infant Discharge 92

Recommendations To Mothers With Infants Admitted To
Special Care Units 94

Suggestions To Improve Services In Neonatal Intensive Care
For Infants and Their Families 96

CHAPTER SIX: 100

DISCUSSION 100

Perceptions of Mothers of Their Infants' Stay In An
Neonatal Intensive Care Setting 100

Mothers' Perceptions of Support That Was Beneficial Or
Non-beneficial To Them While Their Infant Was In
Neonatal Intensive Care 103

Mothers' Perceptions Of Support That Was Beneficial Or
Non-beneficial In Preparing Them For Their Baby's
Discharge Home From Neonatal Intensive Care 110

Implications For Nursing 112

Study Limitations 115

Future Research 116

REFERENCES 120

TABLES: 60

Table A 60

Table B 61

Table C 63

Table D 64

Table E 76

Table F 78

Table G 91

APPENDICES: 135

APPENDIX A: 135

APPENDIX B: 139

APPENDIX C: 147

APPENDIX D: 152

APPENDIX E: 153

APPENDIX F: 154

APPENDIX G: 155

CHAPTER ONE

STATEMENT OF THE PROBLEM

Many mothers have difficulty coping and adapting to the change childbirth brings, even if the birth and subsequent care of the child after the birth is problem free (Affleck, Tennen, Allen & Gershman, 1986; Brooten, Gennaro, Brown, Butts, Gibbons, Bakewell-Sachs & Kumar, 1988; Hampson, 1988). The change is greatly intensified, however, if the newborn infant after birth requires special or intensive care (Booten et al., 1988; Goodman & Sauve, 1985; Miles, 1989). Having an infant in neonatal intensive care has the potential to affect every aspect of the mother's life. How the mother perceives this event, and the support she receives during this time can have implications for attachment to, and long term relationships with, her infant (Turner, 1988).

The concept of special care or neonatal intensive care for sick and premature newborns originated at the beginning of the 20th century, but did not gain momentum until recent times (Avard, 1986; Harrison, 1984; Secco, 1988). Because of the growing need for improvement in care delivery to premature and ill newborns, present neonatal intensive care (NIC) and neonatal intensive care units (NICU) were developed (Beaton, 1984; Goodman & Sauve, 1985). Approximately 25 percent of all newborns require special care after delivery (Babson, Benson, Pernoll & Benda cited in Blumberg, 1980). Furthermore, five percent of these newborn infants will require intensive care after birth (Blumberg, 1980) and will require longterm followup. With an estimated 17,500 infants born in Manitoba in recent years (Statistics Canada, 1990), neonatal intensive care has become an extremely important aspect of the health care of infants (Chapman, 1984;

Secco, 1988). NIC has facilitated the survival of infants who suffer from low birth weight, prematurity and a variety of disabilities and disease processes (Turner, 1988; Als, Lester & Brazelton, 1979; Brooten, Gennaro, Knapp, Brown & York, 1989; Brooten, Kumar, Brown, Butts, Finkler, Bakewell-Sachs, Gibbons & Delivoria-Papadopoulos, 1986; Gardner & Karmel, 1983; Yoos, 1989). Neonatal intensive care is especially important to newborns who are premature and of low birth weight as these infants comprise a significant percentage of live births (Beaton, 1984; Chapman, 1978; Chapman, 1980; Secco, 1988; Statistics Canada, 1990). The survival rate for premature, low birth weight babies has shown notable improvement with the introduction of neonatal intensive care (Chapman, 1984). Reports now indicate that the survival rate of very low birth weight babies have risen as high as approximately 80 percent in some institutions (Bauchner, Brown & Peskin, 1988; Hack, Fanaroff & Merkatz, 1979).

Initially, studies to determine the outcome of infants requiring neonatal intensive care focused solely on the infant (Schraeder, 1986; Yoos, 1989). In premature infants, growth and cognitive factors were deemed to be the important indicators of the child's subsequent development (Yoos, 1989, p. 31). It has only been recently that researchers have broadened their investigation of infants requiring intensive care to include other factors such as parental involvement, environmental impact and maternal perceptions (Nurcombe, Howell, Raugh, Teti, Ruoff & Brennan, 1984; Scraeder, 1986; Yoos, 1989).

Treatment of newborns in a neonatal intensive care involves high level technology, many invasive procedures, and intensive nursing and medical care (Als et al., 1979; Secco, 1988). The event is a stressful one, initiating a crisis in the lives of parents and

families (Beaton, 1984; Shosenberg, 1980; Steele, 1987). In addition, the infant is separated from the mother with limited occasion for maternal caregiving and contact (Bennett & Slade, 199l; Luker & McLouglin, 1988; Mercer, 1977; Ross, 1980; Zeskind & Iacino, 1984). Consequences of limited maternal caregiving and contact may be manifested in maternal stress and feelings of incompetence (Seashore, Leifer, Barnett & Leiderman, 1973). The mother may withdraw, become overly anxious, or be unable to cope with the crisis (Beaton, 1984; Yoos, 1989). This may have an impact on the maternal attachment process with interruptions of maternal child affiliations (Jeffcoate, Humphrey & Lloyd, 1979). Parents who have had a child in NIC report negative feelings regarding the experience (Yoos, 1989). Mothers may feel disengagement towards the baby, perceiving the infant is not their own (Davies, 1987; Goodman & Sauve, 1985; Jeffcoate et al., 1979; Pederson, Bento, Chance, Evans & Fox, 1987; Ross, 1980; Sammons & Lewis, 1985; Secco, 1988). Some parents have reported feeling that their child was "on display" (Fleischman, 1986, p.1), and a reluctance or fear of touching the infant (Harrison & Woods, 1991; Minde, Trehub, Corter, Boukydis, Celhoffer & Marton, 1978). Feelings of guilt, self blame, lack of confidence, anxiety, and fear may persist (Gennaro, 1985; Jeffcoate et al., 1979; Shosenberg, 1980; Yoos, 1989). As a result of these feelings, unsatisfactory parenting skills may be exhibited by the parent, placing the infant at risk for mistreatment, negligence, and lack of a nurturing environment (Ross, 1980). Research indicates that these infants are at greater risk for child abuse, neglect, rehospitalization, physical and developmental problems (Brooten et al., 1986; McCarton, 1986; Turner, 1988).

Mercer (1983) has identified that mothers with infants receiving intensive care may perceive a lack of support from loved ones and partners. Weingarten, Baker, Manning and Kutzner (1990) found that mothers that had negative perceptions of their infants also had higher incidences of troublesome marriages.

Other authors suggest that mothers with infants receiving neonatal intensive care require different and unique support (Shosenberg, 1980; Minde, Shosenberg, Marton, Thompson, Ripley & Burns, 1980) from others who are knowledgeable about or who have experienced a similar situation. Nurses have a major responsibility to support mothers in the hospital and at home (Brooten et al., 1988; Hampson, 1989; Minde et al., 1980; Secco, 1988; Shosenberg, 1980).

The expenditure for neonatal specialized care is coslty both in monetary and emotional terms (Brown, Brooten, Kumar, Butts, Finkler, Bakewell-Sacks, Gibbons & Delivoria-Papadapoulos, 1989; Brooten et al., 1986; Casiro, Becker & McFayden, 1988; Grassi, 1988; Gennaro, 1991; Hernadez, Offutt & Butterfield, 1986; McCormick, Stemmler, Bernbaum & Farran, 1986). Average costs of 1000 dollars per day have been reported for an ill infant receiving neonatal intensive care (Hernadez et al., 1986). The largest contribution to this cost is the provision of highly skilled and technical nursing services to ill and immature infants twenty-four hours a day (Hernadez et al., 1986). Personnel in neonatal intensive care units strive to give optimal technical and emotional care to infants and their families (Secco, 1988). To give excellent care that warrants the expense, places a considerable obligation on NIC health care providers (Grassi, 1988). They must continually determine if the care they are providing is compatible with the

NIC client and families' requirements, and whether it expedits a positive mother-child relationship (Secco, 1988).

Taking a new baby home has been described as a "major hurdle", particularily if the baby has been ill and required intensive care (Brazelton, 1981, p. 135). Often parents are poorly prepared for their infant's discharge home (Censullo, 1986) and there is a lack of community resources for them to draw upon after the discharge (Censullo, 1986, Samson, 1989). Additionally, little research has been conducted to determine what support mothers perceive as beneficial in preparing them for their infants' discharge home (Luker & McLoughlin, 1988). Censullo (1986) reports that mothers whose infants are discharged from special care may experience feelings of desertion by health care professionals and have increased needs for support. Parents may be reluctant to take the baby home after discharge, feeling uncertain, inept and unable to seek out information (Brooten et al., 1989; DuHamel, Lin, Skelton & Hantke, 1974), and doubting their ability to maintain the level of care received in hospital (McCarton, 1986; Seashore et al., 1973). Health problems the infant experienced in hospital may continue at home after discharge, placing a strain on the baby's caregiver (Turner, 1988). Parents may experience exhaustion in caring for the baby (Affleck, Tennen, Allen & Gershman, 1986) and disappointment in the child's growth and development (Turner, 1988). These feelings may overwhelm the parent, causing an alteration in mother-child attachment, subsequent relationships between mother-infant, and care giving to the infant (Turner, 1988). Recent literature suggests that caretaker stress of children who required special care at birth may continue for several years (Tobey & Schrader, 1990).

Purpose of the Study

Limited research has been conducted to investigate the actual perceptions of parents with newborns admitted to an intensive care setting and the support they receive while in the hospital and at home (Luker & McLouglin, 1988; Turner, 1988). This may be due to the relatively recent introduction of newborn intensive care. In the author's own professional experience, mothers with newborns admitted to an intensive care setting have stated that this event had a profound impact on their lives, their ability to relate to their infant, and their relationship with others. Mothers often anticipated difficulty in caring for and relating to their infant when the child was ready to go home. The purpose of this descriptive study was to investigate the perceptions of mothers who had an infant receiving neonatal intensive care. Data were collected to answer the following research questions:

1. What are mothers' perceptions of their infants stay in a neonatal intensive care setting?
2. What support do mothers perceive beneficial to them while their child is in NIC?
3. What support do mothers perceive beneficial in preparing them for their baby's discharge home from NIC?

(Adapted from Luker & McLoughlin, 1988, p. 6).

Nurses are intimately involved in providing care and giving support to both newborns and parents in the intensive care setting and community (Blackburn, 1983; Blackburn & Lowen, 1986; Couriel & Davis, 1988; Hampson, 1989; Noga, 1982; Turner, 1988). To give relevant nursing care, and to facilitate positive attachment between mothers and their

infants (Mercer, 1977), nurses must first determine how mothers actually perceive the event of having their infant in intensive care and what support is beneficial or non-beneficial to them during that time. Once mothers' perceptions are determined, nursing care and support can then be delivered to meet the mothers' actual requirements (Mercer, 1977). Thus, research to examine maternal perceptions about the experience of having an infant in neonatal intensive care, and what support is beneficial is a beginning point in planning and implementing nursing care.

The conceptual framework for this study will be discussed in following chapter.

CHAPTER TWO

CONCEPTUAL FRAMEWORK

The conceptual framework that directed this study was developed from attachment theory. Attachment is defined as a human emotional bond or tie that persists and endures (Blowby, 1969; Blowby, 1988; Jenkins & Westhus, 1981; Klaus & Kennel, 1983; Swanwick, 1984). Maternal attachment is further defined as the affectionate tie a mother forms with her child which lasts over time (Mercer, 1977; Taubenheim, 1981; Toney, 1983). A mother's attachment to her infant is important for the neonate to survive (Klaus & Kennel, 1983; Gaffney, 1986), thus maternal attachment with the infant is one of the most momentous relationship the infant will experience (Blowby, 1988; Brodish, 1982; Gaffney, 1986; Kemp, 1987; Kemp & Page, 1987).

In past, the concept of attachment was thought to begin after birth with a sensitive or critical period (Klaus & Kennel, 1983; Nelson, 1985; Secco, 1988). Unfortunately, the sensitive period was poorly researched, being developed from observations of animals and from unreplicable studies involving human mother and child dyads (Elliot, 1983; Richards, 1983). The concept of a sensitive period essentially has been refuted, while other dimensions of attachment theory have expanded (Elliot, 1983, Mercer, 1983). One expansion of attachment theory has developed through Mercer's (1977; 1981; 1983) research on parent-infant attachment. Mercer's work has provided a framework in which attachment of the mother to the infant can be better understood. She argues that the

quality of mother-infant attachment depends on certain preconditions (Mercer, 1983). The aspects she regards as crucial to maternal-infant attachment process can be summarized as follows:

1. maternal emotional health
2. maternal support system
3. maternal abilities to communicate and caregive

(Adapted from Mercer, 1983).

Mercer suggests that parents do not progress through the attachment process to "claim and identify the infant as a partner" in a positive way unless the preconditions for attachment are favorably met (Mercer, 1983, p. 28). Attachment theory will be discussed utilizing the above summarized version of Mercer's framework.

Maternal Emotional Health

Maternal attachment to the infant is now considered an ongoing process, affected by several elements during pregnancy and after birth (Brady-Fryer, 1989; Brazelton, 1981; Croft, 1982; Elliot, 1983; Gaffney, 1986; Mercer, 1983; Secco, 1988, Stainton, 1986; Williams, Joy, Travis, Gotowiec, Blum-Steele, Aiken, Painter & Davidson, 1987). Cranley (1981) suggests that maternal attachment for the child "begins during pregnancy as a result of dynamic psychological and physiological events" (p.281). From a similar perspective, Rubin (1984) views attachment in terms of "binding-in to the child" before birth (p. 62). In this process, the child and its appearance before birth are in the mother's imagination (Rubin, 1984). Thus, an inventive image of what the child looks like and will

look like after birth plays an important part in the attachment process (Rubin, 1984).

Whalley and Wong (1985) indicate that the attachment process is affected by how closely the imagined child resembles the real child after birth. The attachment process is enhanced if the infant is similar to the imagined child (Whalley & Wong, 1985). However, most infants in neonatal intensive care are immature, small and do not meet parental expectations (Secco, 1988). Mothers may have difficulty in adjusting to the true neonate, and may have to resolve the incongruity they perceive (Ross, 1980). They may be distressed because the baby does not parallel the "fantasy child" (Rubin, 1984; Secco, 1988). Combined with separation from the infant, stress and anxiety over the child's wellbeing and lack of information, the attachment process may be altered or even severely disrupted (Avant, 1981; Jenkins & Tock, 1986; Egeland & Farber, 1984). Excessive and overwhelming stressful feelings including feelings, of guilt, blame, anger, or grief, may increase the risk of a "dysfunctional relationship" between mother and child (Yoos, 1989). Stressful feelings experienced by mothers during this time may potentiate painful memories that persist over time and may alter maternal attachment to infants (Affleck, Tennen, Rowe & Higgins, 1990).

Faulty attachment between mother and infant can result in child abuse, neglect of the infant, and maternal inability to interpret infant caretaking needs (Avant, 1981; Dormire et al., 1989; Klaus & Kennel, 1983; Secco, 1988). Consequences of faulty attachment can be particularly detrimental to an infant who has required neonatal intensive care. Often the infant, after discharge from hospital, has continued need for care such as medication, observation, or treatments and if mothers are neglectful or

fail to understand the child's needs, the infant is at an even greater risk for developing serious complications (Secco, 1988).

Maternal self-confidence, parenting confidence and maternal anticipation of the infant have an impact on how the attachment process progresses (Jeffcoate et al., 1979; Seashore et al., 1973; Williams et al., 1987). How the mother perceives her infant and the events associated with that infant is "an important index of the health and functioning of the maternal-relationship" (Weingarten et al., 1990, p. 64).

Research with mothers of premature infants requiring neonatal intensive care has demonstrated that this event had a negative impact on maternal self-confidence (Gennaro, 1985; Seashore et al., 1973; Secco, 1988). Maternal perceptions of abilities and competence to care for a newborn in turn has an impact on how the mother parents that child (Rutledge & Pridham, 1987). Additionally, mothers whose infants are premature, were considered high risk during pregnancy or required neonatal intensive care after birth often perceive the child as unusual, trying in disposition and perplexing to interact with (Priel & Kantor, 1988; Harrison & Twardosz, 1984). Infant temperament has the ability to seriously alter the attachment process and may in some instances restrict the caretaking response (Secco, 1988; Weitzman & Cook, 1986).

Maternal Abilities to Communicate and Caregive

The attachment process and attachment ties between infant and mother after birth are intensified by certain "attachment behaviors" (Bowlby, 1969), which are developed in an "acquaintance process" (Gay, 1981; Marecki, Wooldridge, Dow, Thompson &

Lechner-Hyman, 1985; Kennedy, 1973).

Utilizing attachment behaviors and a competent level of communicative ability (Mercer, 1983), a mother makes discoveries about her infant and initiates a caregiving relationship (Harrison & Twardosz, 1986; Kennedy, 1973). Tomlinson (1990) found that maternal nonverbal and verbal behaviors were indicators of a mother's attachment and relationship with her newborn.

The infant, in an attempt to keep the mother in close proximity during the acquaintance process, utilizes behaviors such as crying, touching, clinging, gazing, vocalizing, sucking and interacting (Bowlby, 1969; Klaus & Kennel, 1983; Secco, 1988). Mothers in return exhibit behaviors such as touching, feeding, gazing, vocalizing, maintaining proximity, nurturing and caretaking (Bowlby, 1969; Klaus & Kennel, 1983; Tomlinson, 1990). Physical activities with and caregiving to the infant by the mother help to establish positive parent-child interactions (Boger & Smith, 1986) facilitiating secure attachments (Blackburn, 1983; Blowby, 1988; Klaus & Kennel, 1983). A child with a secure attachment to its mother has increased potential to be an adult who is "secure, self-reliant, trusting, cooperative, and helpful toward others" (Dizon, 1984, p. 28).

Because infants in NIC are ill, require skilled care, and are often unable to initiate or respond to attachment behaviors (Sims-Jones, 1986), the acquaintance process may be hindered (Secco, 1988). Possibilities for acquaintance between mother and baby are limited until the child is discharged from the hospital (Zeskind & Iacino, 1984; Secco, 1988). Often opportunities to hold and touch the child are restricted until the baby's condition is stable (Harrison & Woods, 1991; Secco, 1988). Additionally, mothers of

infants who require NIC often are discharged from hospital a few days following the birth. This further decreases the proximity of the mother to the infant, hampering time and occasions for "mothering" and maternal provision of infant care (Bennet & Slade, 1991; Gennaro, 1985; Mercer, 1977). Separation of the mother and baby, because the baby requires special care, potentiates feelings of maternal apprehension and anxiety (Jeffcoate et al., 1979; Klaus & Kennel, 1983; Mercer, 1981; Secco, 1988; Turner, 1988).

Delay and alterations in the attachment process can be exhibited in both maternal and infant conduct after discharge. The mother may be less responsive to the baby's needs, performing care for the infant in a routine and mechanical manner (Blehar, Lieberman & Ainsworth, 1977; Egeland & Farber, 1984; Mercer, 1977). Infant response to attachment disruptions may be displayed in anxious attachment behavior such as avoiding en face contact with their mother (Blehar et al., 1977), or exhibiting maladaptive behaviors displayed through sleeping, feeding and interactive problems (Mercer, 1983).

Maternal Support System

Attachment literature indicates that support systems have an impact on how maternal-infant attachment develops (Mercer, 1981; Klaus & Kennel, 1983). Affiliations with husbands, partners, significant others, and friends and the support received from these sources play a role in how the mother attaches to her infant (Dormire et al. 1989; Klaus & Kennel, 1983; Mercer, 1981; Mercer, 1983). Mercer (1981) argues that how mothers perceive the need for support from others and their reaction to her influence how she feels and acts (p. 76). Subsequent maternal parenting of the infant may relate to how

mothers perceive the support given by partners (Curry, 1983). Weingarten, Baker, Manning and Kutzner, (1990) found that mothers who perceived their premature infants in a negative way also had higher incidence of troublesome marriages (p. 64). Several authors strongly suggest that it is of vital importance to obtain mothers' perceptions of supportive others' involvement in the situation to determine what impact this will have on how the mother attaches to and develops a relationship with her infant (Weingarten et al., 1990; Spinner, 1978; Mercer, 1981).

Nurses have a central role to play in facilitating the attachment process in the NIC unit and after discharge of the neonate from NIC (Boxall & Whitby, 1983; Stainton, 1986). Stainton (1986) believes a "supportive environment" must be initiated in the hospital by health care givers and maintained in the community (p. 20). By giving "supportive nursing care" Stainton (1986) found that mothers experiencing alterations in the attachment process both at home and in the hospital were able to make positive adjustments (p. 20). It is significant to note, however, that mothers verbalized discontentment if nurses instituted interventions without consulting them (Stainton, 1986).

Assessment of, and intervention in the attachment process is primarily done by nurses (Harrison & Twardosz, 1986). Knowledge about maternal attachment, adjustment and development of positive relationships (Harrison, & Twardosz, 1986; Mercer, 1983) assist nurses to support parents, to diagnose, plan and deliver nursing care (Blackburn & Lowen, 1986). Eliciting maternal perceptions about the support they receive helps nurses to contribute to and foster effective support of mothers when their infants are in neonatal intensive care settings (Blackburn & Lowen, 1986; Weingarten et al., 1990) and when

these infants are discharged into the community (Turner, 1988).

Summary

The conceptual framework for this study gives nurses a foundation for comprehending the impact upon families of having an infant in neonatal intensive care, preconditions for maternal-infant attachment and subsequent mother-child relationships (Mercer, 1983). This is particularly important, as mothers who have infants requiring neonatal intensive care may have intensified or altered perceptions about the event and the support given to them during this time.

In the next chapter, a review of selected literature relevant to this study will be presented.

CHAPTER THREE

REVIEW OF THE LITERATURE

Parenting a child in a neonatal intensive care setting has been described as stressful and anxiety producing (Beaton, 1984). Research literature indicates this experience and the support received may influence mother-infant attachment, parenting, infant and family health and caregiving to the infant. In the following chapter a review of pertinent literature will be presented. The review will include selected literature from seven areas: 1) the importance and consequences of neonatal intensive care to newborn infants and their mothers, 2) the experience of parents when their child requires neonatal intensive care, 3) the impact of relationships with others, 4) the influence of support on parents when their child requires neonatal intensive care, 5) support during an infant's hospitalization, 6) support during discharge, and 7) support from significant others.

The Importance of and Consequences of Neonatal Intensive Care To Newborn Infants and Their Mothers

Concern for newborn infants has commanded societal attention for centuries (Brimblecombe, 1983; Honig, Caldwell & Richmond, 1986). The concept of special care or neonatal intensive care for sick and premature newborns originated at the beginning of the 19th century (Avard, 1986; Brimblecombe, 1983; Harrison, 1984, Secco, 1988). Medical consideration for small infants prompted the invention of incubators and special

guidelines and practices regarding their care (Avard, 1986; Brimblecombe, 1983; Harrison, 1984; Secco, 1988). Nursing interest in special neonate care is documented in Canadian literature as early as 1907.

Aikens (1907) describes problems nurses encountered when premature babies were born during cold weather. She outlines nursing care of small infants and argues that "a high degree of nursing skill" in this care was essential (p. 593). Other essential elements for the sick, small infant included mother's milk, massages of the infant with benzoinated lard, measures for additional warmth, instructions for making a homemade incubator and handling the baby as little as possible (Aikens, 1907, p. 593). Nursing care was provided for the mother and baby together, and it is implied that this occurred in the home environment (Aikens, 1907).

By 1922, nursing care for premature babies as described in Canadian nursing literature, took on more clinical features. Most of the care occurred in hospital settings, usually in a specially designated area called a "premature room" where "absolutely no visitors were allowed" (Tait, 1922, p.397). Feedings for infants weighing about three to four pounds consisted of mothers milk mixed with brandy, and warmth for the baby came from clothing and radiators (Tait, 1922). Mothers were sent home from the hospital after fourteen days with strict instructions about sterilizing articles used for pumping and transporting milk to the hospital (Tait, 1922).

Murray (1929) advocated scientific methods in premature infant care, including warmth and humidity of the nursery environment, strict schedules, minimal handling of the infant, and the use of oxygen in event of infant cyanosis (Murray, 1929). Nursing

care was exact and prescribed, with no one allowed in the hospital premature room except those who took direct care of the infant (Murray, 1929). Maternal involvement and care was not mentioned.

Unfortunately, the outlook for small infants was bleak until 1960 (Stewart, Reynolds & Lipscomb, 1981). Until this time mortality and handicap rates for these neonates were high (Stewart et al., 1981). Modern neonatal intensive care (NIC) and neonatal intensive care units (NICU) were developed to improve care delivery to premature and ill newborns (Beaton, 1984; Goodman & Sauve, 1985). As a result many of these infants do not die after birth, but live to return home with their parents (Gennaro, Brooten & Bakewell-Sachs, 1991).

Stewart et al. (1981) reviewed twenty-two reports from developed world countries to determine mortality and handicap rates of very low birth weight (VLBW) infants. They contend that VLBW infants comprise the primary workload for neonatal intensive care units and contribute to a significant portion of neonatal deaths (Stewart et al., 1981). Data from their review demonstrate that "chances of healthy survival" for these children are three times as high as they were in 1960, and that handicap rates for survivors are low and stable at six to eight percent (Stewart et al., 1981, p. 1038).

Survival rates for immature infants continue to increase, even if the neonate is of very low birth weight (Hack et al., 1979). Review of specified neonatal intensive care unit outcomes for very low birth weight infants have demonstrated that survival outcomes have dramatically improved for infants weighing less than 1000 grams (Hack et al., 1979). Since 1976, 50 percent of the infants born weighing between 750 and 1000 grams have

lived (Hack et al., 1979). Survival rates increased to 80 percent if the newborn weighed more than 1000 grams (Hack et al., 1979). By 1979, these investigators reported that the numbers of "fetal infants" weighing under 750 grams and between 23 to 26 weeks gestation admitted to NIC units were on the rise, and constituted a significant portion of low birth weight infants (Hack et al., 1979).

Ten years after their earlier (1979) study, Hack and Fanaroff (1989) discussed the outcomes for extremely low birth weight infants for the 1980 decade. They reviewed outcomes for 98 infants born between 1982 and 1988 and compared the with outcomes of 129 infants born between 1985 to 1988 (Hack & Fanaroff, 1989). All of the infants weighed less than 750 grams and were less than 28 weeks gestation. Results indicated the survival rate of the two groups did not differ significantly (Hack & Fanaroff, 1989). Eight percent of the infants born at 23 weeks gestation survived, however the chance of survival dramatically increased to 72 percent if the infant was over 25 weeks gestation (Hack & Fanaroff, 1989). Hack and Faranoff (1989) did find however, that the mean time from birth to death had increased from four hours for the first group to 880 hours for the second group. They attributed the extended time to increased intubation and mechanical ventilation of these "fetal infants" (Hack & Faranoff, 1989).

These researchers debate the ethical implications of the growing trend toward aggressive medical treatment and provision of intensive care for extremely low birth weight infants, particularly those under 600 grams (Hack & Faranoff, 1989). They point out that these infants have protracted stays in NIC units, have diminished long term outcomes at a tremendous expense and have become predominant consumers of health

care resources (Hack & Faranoff, 1989, p. 1648).

Ferrara, Hoekstra, Gaziano, Knox, Couser and Fangman (1989) examined the survival rates for a six year period of 175 acutely ill infants who received neonatal intensive care after birth. All infants were 26 weeks gestation or less and weighed less than or equal to 750 grams (Ferrara et al., 1989). All of the infants were ventilated and had aggressive medical treatment (Ferrara et al., 1989). Results of the study showed a survival rate of 21 percent for these neonates at the beginning of the study period to a survival rate of greater than 50 percent by the end of 1987 (Ferrara et al, 1989). Post-discharge follow up of the children in this study showed a severe impairment rate of 25 percent (Ferrara et al., 1989). Severe impairment was classified as any condition such as blindness, spasticity, deafness, hydrocephalus, or severe developmental delay (Ferrara et al., p. 1116). Because of a large proportion of "normal" infants in the follow up portion of the study, the researchers believe physicians and families must utilize current information in the decision whether to treat or not to treat small infants (Ferrara et al., 1989).

The confidence in neonatal intensive care to enhance survival opportunities for ill neonates is increased by the current report released from the Office of Technology Assessment in the United States, discussed by McCormick (1989). A review of published research demonstrates twenty years of neonatal intensive care has increased neonate survival rates and decreased moderate to severe handicap rates (McCormick, 1989). This is particularly important for infants of very low birth weight, as their survival rate has increased from 27 percent to 72 percent (McCormick, 1989).

Similar survival rates have been found from data gathered in Canadian settings. Data from studies show mortality rates for infants requiring neonatal intensive care in Canadian hospitals have decreased by approximately fifty percent (Lee, Gartner, Paneth & Tyler, 1982; Saigal, Rosenbaum, Stoskopf & Sinclair, 1984; Watt, 1985).

Although NIC facilitates the survival of compromised infants (Turner, 1988; Als, Lester & Brazelton, 1979; Brooton et al., 1988; Brooten et al., 1986; Gardner & Karmel, 1983; Yoos, 1989), long term consequences for children requiring NIC and their families continue to be a health care challenge (Lipsett & Field, 1981; Watts, 1985).

Long term health problems and rehospitalization are persistent problems for infants that required NIC (Barnard, Hammond, Sumner, Kang, Johnson-Crowley, Snyder, Speitz, Blackburn, Brandt, & Magyary, 1987; Gennaro et al., 1991; Mitchell & Najak, 1989; Termini, Brooten, Brown, Gennaro & York, 1990). Goldberger (1990) estimates 50 percent of all pediatric admissions to hospitals are under the age of two years. Additionally, neonates of low birth weight and premature are at a higher risk for sudden infant death syndrome (Bauchner et al., 1988; Goyco & Beckerman, 1990; McLoughlin, 1988).

Long term follow-up of children requiring neonatal intensive care indicates health problems may be displayed in various body systems (Levene & Dubowitz, 1982). Levene and Dubowitz (1982) summarized the findings of nine follow-up studies of outcomes for low birth weight (LBW) infants. They found LBW children experienced significant long term health problems including neurological damage, visual handicaps, hearing loss, respiratory function complications, growth alterations, and gastrointestinal difficulties

(Levene & Dubowitz, 1982). These children also were at an increased risk for rehospitalization and sudden infant death syndrome (Levene & Dubowitz, 1982).

Bauchner et al. (1988) describe the medical complications that infants who require neonatal intensive care experience. Risk for readmission to hospital for infants who are of low birth weight at birth and require intensive care, is twice the risk for normal weight infants (Bauchner et al, 1988). The risk quadruples if the neonate is below 1000 grams at birth (Bauchner et al., 1988). Other complications experienced by low birth weight infants requiring NIC include bronchopulmonary dysplasia (BPD), intraventricular hemmorrhage (IVH), retinopathy of prematurity (ROP), hearing impairment, and apnea (Bauchner et al., 1988).

Frequent respiratory infections and corrective surgery were found to be the most prevalent reason for readmission in a study conducted by Mitchell and Najak (1989). Out of a sample of 157 infants requiring neonatal intensive care at birth, 39 percent of the infants had to be readmitted to hospital within the first two years of life (Mitchell & Najak, 1989, p.28). Surprisingly, Mitchell and Najak (1989) did not find an increased rate of rehospitalization for respiratory illness for those infants suffering from BPD or for those who required artifical ventilation at birth, compared to other premature infants (p.29).

Ungerer and Sigman (1983) studied 20 premature and 20 full term infants at specified ages. The childrens' ability in the areas of play, sensorimotor, language, and general developmental skills were tested (Ungerer & Sigman, 1983). Results indicated toddlers born prematurly and tested at thirteen and a half months (corrected age) exhibited

more lags in sensorimoter, personal-social, and gross motor skills than full term infants (Ungerer & Sigman, 1983). They also had delays in language capacities when they were at twenty-two months of age (Ungerer & Sigman, 1983). Although the delays were not as apparent between the two groups of subjects when they reached the age of three years, the premature infants still experienced some degree of visual information-processing difficulty (Ungerer & Sigman, 1983).

Eilers, Deai, Wilson and Cunningham (1986) conducted follow-up assessments of 33 very low birth weight children when they reached the ages of five and eight years. Study data were collected utilizing questionnaires completed by teachers, physicians, audiologists and various psychometric tests (Eilers et al, 1986). Similar data were collected for siblings and classmates (Eilers et al, 1986). The researchers found that the children born with very low birth weight required additional specialized instruction in comparison to their peers (Eilers et al, 1986). However, those subjects who had older mothers and who came from a higher socioeconomic background experienced less difficulties than children with younger mothers and lower socioeconomic status (Eilers et al., 1986, p.206).

Aylward, Pfeiffer, Wright and Verhuist (1989) conducted a meta-analysis of eighty outcome studies of infants requiring neonatal intensive care published from the nineteen seventies to the mid nineteen eighties. The samples utilized in the outcome studies were obtained from various parts of the world, including North America, Europe, and countries in the Southern hemisphere (Aylward et al, 1989). Analysis of the data demonstrated that infant subjects who were of low birth weight at birth had lower intelligence/

developmental quotients than control subjects, although the difference was within one standard deviation for each mean (Aylward et al., 1989, p.519). Also, environmental factors appeared to have a greater impact on the infants intelligence/developmental progress than prenatal or perinatal factors (Alyward et al., 1989, p.515).

Subsequent problems and outcomes for children requiring neonatal intensive care at birth are not only displayed when the child is at a young age. Recent research has found that children who were low birth weight and required neonatal intensive care at birth may experience related sequelae when they are older and at a preadolescence age (Hunt, Cooper & Tooley, 1988). In a longitudinal study, Hunt et al., (1988) followed 108 children who required neonatal intensive care at birth. The researchers tested the children at four to six years of age and found a portion of the children displayed moderate intellectual and educational difficulties (Hunt et al., 1988, p. 596). The children again were psychologically tested at age 8 and 11 years of age (Hunt et al, 1988). Eighty percent of the children had normal IQ's, however, the sample did display a greater incidence of problems and disabilities (Hunt et al., 1988). Twelve percent of the children had language and performance disabilities and 24 percent had visual-motor disabilities (Hunt et al., 1988, p. 596). Interestingly, the researchers found that while severity of neonatal illness influenced the potential for normal outcomes, parent's education levels influenced how disabled the child would be in life (Hunt et al., 1988). The researchers state that health care professionals must consider that both neonatal illness and family environment factors effect outcomes for infants requiring intensive care at birth (Hunt et al., 1988).

The Experience of Parents When Their Child Requires Neonatal Intensive Care

Cohen (1982) vividly captures the experience of a mother giving birth to an infant requiring neonatal intensive care and leaving the hospital without her child. She states "to leave the hospital in a car filled with flowers but without the baby is like being alive in one's own casket. Certainly a part of any mother in this situation is close to death. The depression is overwhelming" (Cohen, 1982, p.5).

The birth of a sick infant evokes severe emotional upheavals for mothers (Steele, 1987). Many mothers feel this period in their life is fraught with stress and anxiety, often at crisis proportions (Beaton, 1984; Pederson et al., 1987; Shosenberg, 1980).

Steele (1987) believes the birth of a sick neonate initiates grief and crisis, forcing parents to deal with certain issues. These issues are: 1) coping with loss, 2) overcoming barriers to bonding, and 3) obtaining adequate information about the infants present and future needs (Steele, 1987, p. 13).

Steele (1987) describes the process in which parents progress through crisis and how they can be assisted and supported during this time. Attachment behaviors by parents should be encouraged and facilitated throughout the infant's stay in hospital, as Steele (1987) feels parents who have positive attachments to their infants are in a stronger position to solve problems and cope after discharge home of the infant (p. 16).

Pederson et al. (1987) found the experience of having an infant in neonatal intensive care had an impact on mothers' emotional response in several ways. The researchers interviewed 144 mothers with infants in neonatal intensive care to determine their concerns (Pederson et al., 1987). Ninety-five percent of the sample indicated they

felt emotionally distraught and experienced sadness, guilt, shock, anxiety,and/or insomnia (Pedersen et al., 1987). In addition, a majority of mothers reported that they cried continuously, experienced psychosomatic physical symptoms, and felt alienated from and disappointed in their infants (Pederson et al., 1987). Mothers also voiced worries about their infant's survival, their long term prognosis and whether the infant would require more care than usual in the home environment (Pederson et al., 1987).

Choi (1973), in a study that compared psychological reactions of mothers towards premature and normal newborns, found that mothers with premature infants experienced a significantly increased rate of depression and anxiety. Mothers of premature infants in the sample experienced feelings of worry, guilt, and a lack of self confidence (Choi, 1973, p.9).

More recently, Gennaro (1985) studied 35 mothers to determine their anxiety levels and problem solving ability. Shortly after giving birth to a premature infant, mothers were given the State-Trait Anxiety Inventory and the Means Ends Problem Solving Procedure (Gennaro, 1985). When the infant was discharged from NICU, mothers were tested utilizing the Postpartum Self-Evaluation Questionnaire (Gennaro, 1985). Findings demonstrated that mothers of premature infants were more anxious than certain segments of the general population (Gennaro, 1985). They did not, however, have differences in problem-solving abilities (Gennaro, 1985).

In a similar study with forty mothers of premature infants, Gennaro (1986) found that the experience of having a child in neonatal intensive care, regardless of the type or severity of illness, may potentiate increased levels of maternal anxiety. She also found

that mothers of premature infants with higher problem-solving abilities seemed to have higher levels of anxiety than those mothers with lower problem-solving abilities (Gennaro, 1986).

Forty-one mothers with preterm infants at one week of age and six weeks of age were studied and compared with a matched sample of mothers with full term infants (Gennaro, 1988). Out of the initial sample, sixteen mothers with preterm infants and ten mothers with full term infants were tested for seven weeks. Gennaro (1988) discovered that mothers with premature infants had higher levels of anxiety and depression than mothers with full term infants. A significant increase in anxiety and depression levels was only apparent during the first week of the infant's life (Gennaro, 1988). By the second week maternal anxiety and depression scores were relatively equal between the two groups (Gennaro, 1988).

Brooten et al. (1988) found mothers of high risk preterm infants were less depressed and anxious when their child reached nine months of age. The same mothers had higher levels of anxiety, depression and hostility at the time of infant discharge home from hospital (Brooten et al, 1988). First time mothers and mothers who had infants that stayed in hospital for longer periods of time, suffered less depression at the time of discharge than those mothers whose infants had a shorter hospitalization (Brooten et al., 1988, p. 213).

McCarton (1986) describes the parental experience of having a baby in a neonatal intensive care as riding "an emotional roller-coaster" (p. 6). Feelings of inadequacy motivate the mother to overcompensate in care of the infant (McCarton, 1986). The

mother may have unrealistic expectations of the baby, anticipating that the child will act in a manner similar to a normal newborn after discharge home from the hospital (McCarton, 1986, p. 7).

Mercer (1981), through a review of the literature, concluded that the birth of an sick baby interfered with mothers' attainment of their maternal role. She argues that the separation of the mother and baby, because the baby requires special care, potentiates feelings of apprehension and anxiety (Mercer, 1981). Mothers may exhibit avoidance behavior or detachment toward their infant (Mercer, 1981). They anticipate the death of the infant, and attempt to isolate themselves from the child (Mercer, 1981, p. 76).

Relationships between mother and newborn are altered when the infant is born with a condition that necessitates a neonatal intensive care environment (Jeffcoate et al., 1979). When parent-infant attachment is disrupted, feelings of depression, grief, denial and guilt may replace normal feelings of exhilaration and jubilation (Tarbert, 1985).

McCain (1990) investigated concerns of parents who had a premature infant in hospital receiving special care. Fifty-eight percent of the sample indicated they were concerned about their infant's health and development (McCain, 1990). Parents worried about learning disabilities, speech delays, and growth patterns (McCain, 1990). Other themes of parental concern included family functioning, finances, and parenting (McCain, 1990). Parents felt their infants were difficult to parent, irritable, inconsolable, and had irregular physical and emotional patterns (McCain, 1990).

The increased maternal concern about infant health during hospitalization and after discharge has been documented in recent research (Gennaro, Zukowsky, Brooten, Lowell

& Visco, 1990). Mothers of premature infants requiring intensive care at birth have been found to continually worry and question if their "child was normal yet?" (Perrin, West & Culley, 1989, p. 355). Mothers of these infants fear the child is unduly prone to health or developmental problems (Duhamel et al., 1974; Jeffcoate et al., 1979; Perrin et al., 1989). The belief that the child continues to be at risk, even after discharge home, motivates the mother at times to use excessive stimulation in order to promote "normal" infant responses or interaction (Field, 1982). Mothers may attempt to promote their baby's achievement of growth and size comparable to full term infant by overfeeding their infants, potentiating the risk for future health problems (Gennaro, 1991; Gennaro et al., 1990; Brooten, 1989). Brazelton (1981) labels these parents' actions as "encasing the infant in the cotton wool of anxiously caring parents" (p. 170).

Brady-Fryer (1989) investigated mothers' perceptions of their experience of developing a relationship with their preterm infant who required neonatal intensive care. Interestingly, mothers in the study described an alteration in their adaptation to the mothering role and their attachment to the baby (Brady-Fryer, 1989, p. 16). These mothers felt compelled to concentrate on the actual subsistence of the newborn rather than their need to develop a relationship with their baby (Brady-Fryer, 1989, p. 16). They described their inability to succeed in the attachment process because they lacked occasions to physically interact with the infant (Brady-Fryer, 1989, p.17). Subsequently, some mothers felt regret and expressed feelings of guilt, frustration and helplessness (Brady-Fryer, 1989, p.17).

Parents with infants requiring neonatal intensive care face several sources of stress

(Miles, 1989). Miles (1989) interviewed 53 parents of infants cared for in an intensive care setting. Data collection took place shortly before the infant's discharge from the unit (Miles, 1989). The appearance of the critically ill infant and altered parent-child relationships contributed the most to parent stress levels (Miles, 1989, p. 71). Parents felt they were under extreme stress when they perceived their infant was in pain, experienced apneic periods, and were fragile in appearance (Miles, 1989). They also experienced high levels of stress when they were separated from their infant, unable to help the infant, and received inadequate information (Miles, 1989). Other sources of stress included the parent's perception that NICU staff had an uncaring manner and had poor communication patterns with them (Miles, 1989).

Maternal feelings of guilt and incompetence are identified throughout the literature (Jeffcoate et al., 1979; Shosenberg, 1980; Whetsell & Larabee, 1988; Yoos, 1989). Guilt has been identified as the primary and "most intense" feeling experienced by parents with infants who are born prematurly and require intensive care (Whetsell & Larrabee, 1989, p. 21). The emotional reaction of guilt to a sick and ill infant can be destructive, with the potential to interfere with parent-child attachments and caregiving to the infant (Jeffcoate et al., 1979; Shosenberg, 1980; Whetsell & Larabee; 1988 Yoos, 1989).

Separation of mother and infant has an enormous impact on how the mother feels and acts (Seashore et al., 1973). Seashore et al. (1973), examined maternal self-confidence of two groups of mothers after birth of a premature infant. One group did not physically care for the infant in the first week of life, while the second group participated in care (Seashore et al., 1973). Analysis of study data demonstrated that denial of

maternal-newborn interaction directly affected the mothers self-confidence (Seashore et al., 1973, p. 376). Primiparous mothers who did not have interaction with, and did not participate in, care of their infant had lower self-confidence scores (Seashore et al., 1973). Interestingly, these self-confidence scores were predictive of maternal caretaking skill after the infant was discharged home one week (Seashore et al, 1973). The authors concluded that inclusion of the mother in providing care to a premature, hospitalized infant may positively effect maternal self-esteem and increase self-confidence (Seashore et al., 1973).

Gross, Rocissano and Roncoli (1989) found that mothers of toddlers who were premature at birth did not experience any deviance in self-confidence in comparison to mothers whose infants were full term at birth. They did find, however, that mothers were less self-confident if the child, who was premature at birth, had cerebral palsy (Gross et al., 1989). The researchers established that maternal self-confidence was related to previous child care experience before the birth of the present child (Gross et al, 1989). Thus, if the child had cerebral palsy, the mother would not have had previous experience with this condition, and would display decreased self- confidence (Gross et al., 1989).

Jeffcoate, Humphrey and Lloyd (1979), in a retrospective study with 59 parents, found that families may have disturbed relationships with premature infants. Two groups of parents, with premature and full-term infants, were asked to indicate their perceptions of their infants (Jeffcoate et al., 1979). Mothers with premature infants perceived their babies much more negatively than those mothers with full term infants (Jeffcoate et al, 1979). Mothers with infants who required neonatal intensive care were very anxious and

had notable difficulty in attaching to the child (Jeffcoate et al., 1979). The researchers believe it is the mother who experiences the most alteration in expectations, who experiences loss of self-esteem, and decreased self-confidence (Jeffcoate et al., 1979). This is because she was unsuccessful in delivering a "healthy full term infant" and is not able to assume care giving responsibilities for her child after birth as expected (Jeffcoate et al., 1979, p. 349). Interestingly, paternal perceptions and self-esteem were not as affected as the mothers (Jeffcoate et al., 1979).

The "medicalization" of parenting an infant in intensive care has an impact on parental-infant attachment, decision-making about the child, and communication between involved parties (Pinch & Spielman, 1989, p. 1017). Because of the intense stress experienced by parents in this situation, they often are passive in making decisions about the infant's care, leaving this accountability to health care professionals (Pinch & Spielman, 1989; Steele, 1987). The prime need of parents with infants in intensive care is for support and a caring attitude by health professionals in order to assist them through this difficult time (Pinch & Speilman, 1989).

The effect of frequent, regular parental contact with an infant receiving neonatal intensive care was examined by Harper, Sia, Sokal and Sokal (1976). Ninety-one parents in the study sample answered a questionnaire dealing with such factors as parent-infant contact and parental anxiety (Harper et al., 1976, p. 442). Results of the study demonstrated that a large percentage of the parents were highly anxious and experienced emotional distress (Harper et al., 1976, p. 443). Data demonstrated that the more contact the parent had with the infant, the higher their anxiety level rose (Harper et al., 1976, p.

443). Although the parents felt more anxious when in contact with their infant, they strongly perceived their contact made an important difference to their infant and the care the baby received (Harper et al., 1976, p. 444).

Research conducted by Brown, Gennaro, York, Swinkles and Brooten (1991) supported the findings of Harper et al. (1976). Brown et al. (1991) did not find a relationship between maternal anxiety and maternal visiting and telephoning (p.44). Additionally, the researchers were unable to demonstrate a relationship between maternal visiting, telephone inquiries and infant weight, rehospitalization, or acute care visits after discharge home (Brown et al., 1991, p. 43). They did uncover, however, a relationship between parental visits and perceptions of the infant (Brown et al., 1991). The more contact the mother had with the infant in hospital, the more optimistic maternal perceptions were of the infant at discharge (Brown et al., 1991). In addition, maternal perceptions were augmented if both parents visited together (Brown et al., 1991, p.44).

Results from a study conducted by Zeskind and Iacino (1984) indicated maternal contact with their infant in a neonatal intensive care unit had implications for maternal-child relationships. The researchers discovered that mothers who visited their child in NIC on a regular basis had more reasonable perceptions of their infant (Zeskind & Iacino, 1984). Thirty-two mothers with infants requiring intensive care were divided into a control and study group (Zeskind & Iacino, 1984). The study group received support in the form of information, explanation of procedures, discharge teaching, and encouragement to visit their infant in the NIC units (Zeskind & Iacino, 1984). After discharge of the infant home, visits were made every week for six weeks by a "project

interventionist" (Zeskind & Iacino, 1984). In comparison to the control group, mothers in the study group visited their infants more in NIC, had realistic observations of the infant's behavior and had more positive expectations regarding their infant's future prognosis (Zeskind & Iacino, 1984, p. 1887). Zeskind and Iacino (1984) hypothesize that because the study mothers had greater contact with their infants in a neonatal intensive care setting, infant recovery was expedited and thus the period of hospitalization was much shorter than those infants in the control group.

Relationships With Others

Families who have high risk infants requiring neonatal intensive care are said to be in "chronic crisis" (Tarbert, 1985). Families may experience several problems after the birth of a child requiring NIC, including altered relationships between members and changed martial relationships (Mercer, 1983).

McHaffie (1990) found the birth of a sick and ill infant interfered with maternal responsibilities and communication with others. Another study established that mothers felt they alone bore the major burden of child care when their infant was discharged home and that they were unhappy in their marital relationship (McCain, 1990).

Mercer (1983) states that mothers with infants receiving intensive care may perceive a lack of support from loved ones and partners. She attributes this negative perception to a discrepancy between the parents as to what the actual need for maternal support really is (Mercer, 1983).

Weingarten et al. (1990) were unable to demonstrate a relationship between

mothers' perceptions of their infants and the quality of their relationship with their partners. Mothers with altered perceptions about their infants, however, had a higher incidence of troublesome marriages (Weingarten et al., 1990).

Minde, Marton, Manning and Hines (1980) found a link between maternal response to an infant's behavioral cues, maternal caretaking behaviors and familial relationships. The researchers discovered that mothers with continually low activity towards their infant had difficult relationships with family members such as their mothers and husbands (Minde et al., 1980, p. 11).

Blackburn and Lowen (1986) studied 50 parents and 83 grandparents whose infants and grandchildren required neonatal intensive care. Not surprisingly, both mothers and grandparents felt strong emotional reactions to the event, though in varying degrees (Blackburn & Lowen, 1986). Although parents and grandparents identified their spouses as their "main source" of support, during this trying time, only fathers and grandparents perceived that they received adequate or needed emotional support (Blackburn & Lowen, 1986, p. 176). Mothers, on the other hand, perceived they received less than desired emotional support (Blackburn & Lowen, 1986). The researchers also noted that grandparents were a source of support for the distressed parents, however, they too required their needs for support to be met (Blackburn & Lowen, 1986). Provision of support by family members to each other appeared to be restricted by hospital visiting policies (Blackburn & Lowen, 1986, p. 177). These findings are contrary to the study results of Pederson et al. (1987), who established that mothers of sick infants perceived they received more support than mothers whose infants were not ill.

<u>The Influence of Support On Parents When Their Child Requires Neonatal Intensive Care</u>

Support has been described as a strategy utilized by (Beaton, 1984), or reaction of (Mercer, 1981), maternal significant others (including husbands, partners, relatives, friends or community members) and health care professionals towards mothers who have infants requiring neonatal intensive care (Luker & McLoughlin, 1988).

Support includes teaching, giving guidance and information, caregiving activities, providing emotional maintenance or backing (Zarling, Hirsch, & Landry, 1988; Cochran & Brassard, 1979; Parke & Tinely, 1982; Tracy, 1990), and affirming relationships (Dormire et al. 1989). Dunst and Trivette (1986) propose that support is a "multidimensional construct that includes physical and instrumental assistance, attitude transmission, resource and information sharing, and emotional and psychological sharing" (p. 403). Support, with qualities of emotional empathy and understanding, may benefit parenting and infant development (Crnic, Greenberg, Ragozin, Robinson & Basham, 1983). Satisfaction with family functioning by family members with a developmentally disabled child, have been positively associated with network and functional support (Failla & Jones, 1991). Mercer and Ferketich (1988) found that perceived support was a salient dimension.

Several authors subdivide the concept of support into two categories, informal and formal (Luker & McLoughlin, 1988; Parke & Tinsley, 1982). Informal support is provided by relatives and friends (Luker & McLoughlin, 1988; Parke & Tinsley, 1982), while formal support comes from health care professionals such as nurses, physicians and social workers (Luker & McLoughlin, 1988, p. 6). Bryce, Stanley and Enkin (1988)

propose that support is "the comfort, assistance, and information one receives through formal and informal contacts with individuals or groups" (p. 20). The client's satisfaction with sources of support and the number of support sources available (Dunst & Trivette, 1986) helps nurses to determine what care, strategies and resources are beneficial or not beneficial to mothers and families. The concept of support assists nurses in appreciating the influence of emotional, informational and tangible support (Affleck et al., 1986; Mercer, May, Ferketich & Dejoseph, 1986; Roberts, 1984) on individual and family behavior and on outcomes of the intensive care experience (Roberts, 1984).

Support has been shown to have both benefical and adverse effects (Bryce et al., 1988). Benefical support has been associated with attachment (Mercer, 1983), individual well being, parental-child perceptions and relationships, child behavior and development (Dunst, Trivette & Cross, 1986), attitudes, maternal competence (Dormire et al., 1989), and subsequent parenting (Belsky, 1984; Crnic et al., 1983). Further, support acts as a cushion or shield for individuals experiencing stress (Crnic et al., 1983; Heaman, 1988). Thus, it eases stressful situations and tensions in a family with an infant requiring intensive care and after discharge of the infant home (Ross, 1980), and reduces residual effects or harm to individuals' health (Heaman, 1988). The "beneficial effects of support" have been shown to increase clients' utilization of health care resources, and shorten recovery periods (Bryce et al., 1988, p. 20).

Although support has many positive benefits, it can be perceived as threatening and associated with tension and friction (Crittenden, 1985; Tracy, 1990). Tracy (1990), through research with 45 at-risk families, found that supportive networks that were

"critical" of the individual caused strain and conflict. In the study, "critical" networks were negatively correlated to emotional support (Tracy, 1990, p. 255).

Maternal support systems have an influence on how maternal-infant attachment develops (Mercer, 1981; Mercer, 1983; Klaus & Kennel, 1983) and on the security of the attachment of the child to the mother (Crittenden, 1985). Maternal feelings and actions are related to mothers' perceptions of how others react to her need for support (Mercer, 1981). Parenting of the infant may relate to how mothers' perceive the support given by partners (Belsky, 1984; Curry, 1983), social networks and the attitudes toward, and conditions of, work (Belsky, 1984). Schraeder and Tobey (1990) have related subsequent longterm caretaker daily disturbances to resource and support difficulties, such as financial problems and lack of social support (p. 88). Obtaining maternal perceptions of supportive others involvement in the situation helps to determine what effect this will have on how the mother attaches to and develops a relationship with her infant (Weingarten et al., 1990; Spinner, 1978; Mercer, 1981). Affleck et al. (1986) investigated social support and mothers' adaptation during the period of discharge from the hospital to home. Three areas of support were investigated: emotional, informational and tangible support (Affleck et al., 1986). Interestingly, mothers had increased satisfaction with the three types of support, if the infant experienced developmental or health problems after discharge. The researchers found that mothers' satisfaction with support was not related to the amount of "perceived support" (Affleck et al., 1986). They hypothesize that mothers with more realistic perceptions of supportive others have more realistic perceptions of their infants (Affleck et al., 1986 p.14). Similar results were found in a

study conducted by Affleck, Tennen, Rowe, Roscher and Walker (1989).

Weissbourd and Kagan (1989) discuss the benefits of support and of family support programs. They assert that support empowers families and fosters their strengths and abilities (Weissbourd & Kagan, 1989). By contact with friends and groups, gaining from advice and information, families can be in a better position to cope, manage their lives, and provide positive parenting (Weissbourd & Kagan, 1989).

Dunst et al. (1986) investigated the mediating influences of social support on personal, family and child outcomes on families with mentally, physically disabled, and developmentally at risk children. They discovered that the more helpful and supportive sources in the network were, the more positive certain variables were (Dunst et al., 1986). These included personal wellbeing, attitudes, parent-child interaction, and child behavior and development (Dunst et al., 1986, p. 403). Similar results were found in a study by Crnic, Greenberg Ragozin, Robinson and Basham (1983). These investigators also found a positive relationship between support and maternal attitudes (Crnic et al, 1983). Effective support, provided to mothers in this study by partners and community members, appeared to increase maternal satisfaction with life, decrease stress levels and promote more positive attitudes in parenting roles (Crnic et al., 1983).

Support During An Infant's Hospitalization

Interest in mothers and their newborns in a NIC setting is expressed throughout the literature by health professionals. This interest is portrayed through written opinion of health professionals regarding the support they perceive the infant and mother require

both in the hospital and at home (Luker & McLoughlin, 1988). Gennaro et al. (1991) argue that nurses are responsible for evaluating "which components of care are most beneficial and cost effective" (p. 34). Because nurses in the hospital have the most interaction with the family and may be the primary support for the family (Thorton, Berry & Dal Santo, 1984), it is appropriate to ask mothers what nursing support is helpful or not helpful (Luker & McLoughlin, 1988). Research investigating mothers' perceptions of the support they need both in the hospital and at home is a recent occurrence (Luker & McLoughlin, 1988).

Nurses' roles and methods in providing support have been identified. The major ways and means of rendering support to mothers and families are by providing teaching, information (Brooten et al., 1989; Gennaro, 1991; Kennedy, 1973; Mercer, 1977; Mercer, 1983; Ross, 1980; Steele, 1987; Thornton et al., 1984;), emotional care, opportunities for caregiving and contact (Blackburn, 1983; Jenkins & Tock, 1986; Thornton et al., 1984), by promoting attachment and bonding between mother and infant (Mercer, 1977; Mercer, 1983; Steele, 1987; Tarbert, 1985), and facilitating communication between health care professionals and parents (Mercer, 1977; Mercer, 1983; Miles, 1989; Thorton et al., 1984).

Steele (1987) stresses the need to support parents during the bonding and attachment processes. By "personalizing" the infant with a name card or pictures, encouraging physical or verbal contact, or identifying an infant's positive response to parental contact, a nurse can effectively support mothers in coming to terms with this situation (Steele, 1987).

Jenkins and Tock (1986) state that nurses must be supportive to parents who are separated from premature infants requiring special care. Nursing support of parents, claim the authors, should include encouragement of the parents to touch the infant and to maintain regular contact with the infant (Jenkin & Tock, 1986, p. 33-34).

Including parents in caregiving and encouraging contact with their infant in NIC can help mothers develop confidence and promote assumption of their maternal role (Kelting, 1986). Offering parents choices in caregiving and negotiating times for caretaking has been productive in generating parental feelings of control (Whetsell & Larrabee, 1988). Thorton et al. (1984) advise nurses that effective support begins when nurses teach parents how to care for their infants. Parental inclusion in caregiving activities can progress gradually, from touching the infant to total caregiving and rooming-in with the infant (Thorton et al., 1984).

Blackburn (1983) believes parents with preterm infants in a neonatal intensive care setting need to be taught how to stimulate their infant in an appropriate, knowledgeable manner. Nurses in a NIC setting, states Blackburn (1983), have two primary objectives: 1) to provide a supportive environment for infants to develop, and 2) to "foster positive parent-infant interaction" (p. 85). The nurse acts as an intermediary for the infant in the intensive neonatal care setting and helps to create an environment that supports infant-parent dyads to achieve optimal development and attachment (Blackburn, 1983). Nursing support includes teaching parents about their infants and teaching appropriate infant caregiving skills (Blackburn, 1983). Nurses must first assess infant capabilities before encouraging parents to stimulate their infants (Blackburn, 1983).

Although several health care authors promote the use of teaching to improve maternal perceptions of, and interactions with, their infants (Harrison & Twardosz, 1986), some research has demonstrated that teaching does not necessarily achieve the expected end. Harrison and Twardosz (1986) studied the effects of an intervention program that included specific teaching with three groups of mothers. They found no difference in maternal perceptions or interaction behaviors among the groups that received usual care and support, a short term teaching program or special attention (Harrison & Twardosz, 1986). The researchers encourage further study into what constitutes effective or noneffective interventions (Harrison & Twardosz, 1986).

Cohen (1982) describes the nurse's role in caring for parents of a sick and ill infant as one of giving information and emotional support. Cohen (1982) states the nurse has high credibility levels and often displays a caring attitude by establishing contact, being sympathetic, patient, effective and nurturing with the parents. She warns nurses against becoming "surrogate parents" for the infant, explaining this type of support may not be beneficial as the parents involved may become resentful and threatened (Cohen, 1982, p.24).

The provision of adequate information to mothers consistently, is stressed throughout the literature as a means of support (Kennedy, 1973; Mercer, 1977; Mercer, 1983; Ross, 1980; Steele, 1987; Thorton et al., 1984). Steele (1987) states that providing parents with basic, consistent, repetitive information should occur throughout the infant's hospital stay (p.19). Nurses who provide information to parents should be sensitive to the parents' level of understanding, their need for privacy, and their level of anxiety

(Steele, 1987).

Miles (1989) indicates an important part of reducing parental stress is facilitating communication with NIC staff members. In a study of 53 parents, findings demonstrated that parents found certain aspects of NIC health professional communication stress provoking (Miles, 1989). When parents were not adequately informed about care for their infant, they felt their stress level increased and were affected by both verbal and nonverbal communication exhibited by staff (Miles, 1989). NIC staff nonverbal communication that parents perceived as stressful included acting cold, distant, uncaring, and appearing worried (Miles, 1989). Parents also felt increased stress when they perceived staff were not telling them what was wrong, informing them how ill their baby was, and not communicating to them enough information about tests or treatments performed on the infant (Miles, 1989. p.72). Miles (1989) recommends parents be provided with constant communication about their infant from all health professionals involved in the infant's care.

Support During Discharge

Discharge home of an infant who has required neonatal intensive care may initiate a maternal and family crisis (Affleck et al., 1988; Sammons & Lewis, 1985; Siegel, Gardner & Merenstein, 1989; Tarbert, 1985). Mothers may experience conflicting emotions about the homecoming of their infants, feeling relief, strain (Brooten et al., 1988; Steele, 1987), excitement, pride and anxiety (McHaffie, 1990). Mothers may have many doubts and be uncertain (Duhamel et al., 1974), perceiving the hospital staff knows

the baby better than they do (Seashore et al., 1973, p.370; Steele, 1987; Mercer, 1977). In addition, professional supervision, support and care may stop at the door of the hospital (Schrader, 1986), leaving parents to feel abandoned, frustrated, deserted and alone (Censullo, 1986). The parental feelings of desertion by professionals may coincide with a time when the parents need increased support (Censullo, 1986). Parents may have misgivings about their ability to care for their infant (McCarton, 1986; Seashore et al., 1973), and feel inadequate and unable to seek out information (Brooten et al., 1986; DuHamel, Lin, Skelton & Hantke, 1974). The infant may require additional care due to health problems, causing caregiver strain (Turner, 1988), and exhaustion (Affleck et al., 1986). Subsequently, alterations in mother-child attachment, relationships, and care giving to the infant may be experienced (Turner, 1988).

Several authors propose that discharge planning and follow-up begins with identifying maternal and family resources before the actual discharge (Arenson, 1988; Hampson, 1989; Sammons & Lewis, 1985; Siegel et al., 1989; Sterling, 1990). From this assessment, teaching and information can be tailored to meet maternal needs (Siegel et al., 1989).

Brooten et al. (1989) conducted a content analysis of predischarge teaching given to families with infants requiring special care. They found predischarge teaching centered around infant caretaking such as feeding, infant health, and growth and development (Brooten et al., 1989). Additionally, mothers were taught how to function within the health care system and how to utilize available community resources (Brooten et al., 1989).

Arenson (1988) describes the components of adequate discharge planning and teaching. She proposes the goals of discharge teaching should be to: 1) maintain the infant's health, 2) maximize parent's confidence and competence, 3) decrease the stress of hospital to home transition, 4) minimize illness risk and potential for rehospitalization, and 5) reestablish the family unit (Arenson, 1988, p.48).

Discharge teaching and information should be standardized and involve important members of the care team, including primary nurses, community health nurses, physicians, support groups and specialists (Arenson, 1988). Discharge preparation should begin well before the infant is discharged, not hours or a day ahead (Cohen, 1982). Families should be given instructions, followup information, and support that makes them feel as though they have some direction and they are not being abandoned (Ross, 1980).

Rooming-in (Klaus & Kennel, 1983, 1982; Thornton et al., 1984) or "nesting" with the infant (Salitros, 1986) is recommended by experts in maternal-infant care as one way to provide support to mothers with recovered infants ready for discharge. Parental anxiety has been shown to be greatly reduced if mothers are afforded the opportunity to take responsibility for 24 hour care of their infant before discharge home (Consolvo, 1986).

Parents of "high risk" infants requiring neonatal intensive care have many concerns regarding the infant's discharge from the hospital (Goodman & Sauve, 1985, p. 235). Mothers of high risk infants and normal newborns were interviewed in a study by Goodman and Sauve (1985) to determine the "concerns" of each group two weeks and six weeks after discharge of the infant home. Mothers with normal newborns had less concerns than those mothers with high risk infants (Goodman & Sauve, 1985, p. 239).

Mothers of high risk infants were anxious about several problems such as attachment difficulties, infant interaction behaviors, infant feeding, sleeping schedules and maternal difficulties with significant others (Goodman & Sauve, 1985, p. 239-241).

Gennaro, Brooten and Bakewell-Sacks (1991) argue that "postdischarge follow-up services" for premature and low birth weight infants play a significant role in reducing postdischarge problems (p.29). Community health nurses have a major responsibility for providing support and follow-up care (Arenson, 1988; Casiro, Becker & McFadyen, 1989; Censullo, 1986; Couriel & Davies, 1988; Gennaro et al., 1991; Hampson, 1988; Mercer, 1977; Noga, 1982; Roberts, 1984; Secco, 1988; Shosenberg, 1980). Baker, Kuhlmann and Magliaro (1989) propose that the community health nurse will be "one of the most critical and utilized support services" (p. 657). Brooten et al. (1991) outlines various postdischarge services for low-birth-weight infants. Some authors argue that postdischarge follow-up of mothers should be conducted by specialists (Brooten et al., 1991; Brooten, 1989; Brooten, 1986) and community special care baby services (Brooten et al., 1991; Couriel & Davies, 1988), while others indicate the pediatrician is the focal person in providing support in the community (Brooten et al., 1991; Bauchner et al., 1988). Unfortunately, there is only modest professional follow-up available for mothers and infants who required NIC following discharge (Affleck et al., 1986; Brooten et al., 1986; Casiro, Becker & McFadyen, 1989; Crnic, Greenberg & Slough, 1986; Ross, 1980; Schraeder, 1986). The follow-up services provided for infants who required NIC after birth and are discharged into the community may not meet parental needs and concerns (Gennaro et al., 1991; Samson, 1989). Health care professionals may be less cognizant

of the stress and strain placed on mothers and families after the infant is discharged, because the provision of follow-up care in the community may be diffuse (McCormick et al., 1986).

Parents with high risk infants who are discharged from the hospital have unique needs (Censullo, 1986). Censullo (1986) indicates parents need the support of the community health nurse to facilitate their coping abilities. After parent and infant needs are identified by the nurse, interventions can be instituted, depending upon the family's requirements (Censullo, 1986, p.146). The interventions may include family counselling, education, and emotional support (Censullo, 1986, p.150-152). Parent support groups are identified as one resource that community health nurses can utilize to promote parental coping abilities (Censullo, 1986).

Turner (1988) contends that, although support extended by community health nurses facilitates earlier discharge of infants requiring NIC, more research is needed to determine the effects and benefits of this support.

Support from Significant Others

Support for mothers with infants who required neonatal intensive care and are discharged home can come from of variety of significant others, including family and community members. Close relatives, friends, church members and clergy have all been identified as important sources for providing support to mothers while the infant is in hospital and at home (Baker et al., 1989). Mercer et al. (1986) found that mothers often perceive their "mates" a primary source of support (p.341).

Gennaro (1991) encourages nurses to assist parents in "mobilizing support" from extended family members (p.58). Encouraging family members to attend information sessions for parents helps the family to participate in care for the infant upon discharge (Gennaro, 1991).

Zarling, Hirsch and Landry (1988) indicate maternal family and friends may be uncertain of how to react to the birth of an ill premature infant. Thus, their support towards the mother may be less than ideal (Zarling et al., 1988). Often relatives and friends are denied customary events and rituals that commemorate the birth and provide an avenue to show support for parents (Zarling et al., 1988).

Support groups with parent members experiencing similar circumstances may provide an opportunity for mothers to share common problems, verbalize feelings and fears, and learn from parents who have been "through the same situation" (Boukydis, 1982; Hampson, 1989; Mercer, 1977; Kelting, 1986; Sammons & Lewis, 1985; Siegel et al., 1989; Shosenberg, 1980). Support groups can help participants to build confidence in caregiving (Toseland, Rossiter, Peak & Smith, 1990). Participation in support groups aids mothers to deal with feelings of failure and lack of traditional and family support (Shosenberg, 1980).

Minde, Shosenberg, Marton, Thompson, Ripley and Burns (1980) observed that mothers with infants requiring NIC, demonstrated more positive interactive behavior when they participated in a support self-help group. Group members consisted of other parents experiencing similar circumstances, nurses and "veteran mothers" (Minde et al., 1980). Not only was the parent's behavior positive during the infant's hospital stay, but it also

continued after discharge of the infant home for an extended period of time (Minde et al., 1980).

Summary

Review of the literature has demonstrated that there is a tremendous challenge for parents in coping and adapting to a newborn child requiring special or intensive care (Brooten et al., 1989; Goodman & Sauve, 1985). Maternal perceptions of the experience and the support received during this time may have implications for infant and family functioning, health and long term relationships (Turner, 1988; Weingarten et al., 1990). This study determined what perceptions mothers have of the NIC experience and what support they perceive as beneficial during infant hospitalization and preparation for discharge.

CHAPTER FOUR

METHODOLOGY

This study represented the the first phase of a collaborative intersite research project. British nursing researchers Luker and McLoughlin (1988) designed the study in a two phase format and developed the original interview questionnaires. Luker and McLoughlin are presently utilizing the questionnaire in their research project "A Descriptive Study Of The Formal and Informal Support Received By Parents Who Have Had An Infant In A Neonatal Intensive Care Unit." After all studies are individually concluded, intersite results will be compared.

In the first phase of this exploratory, descriptive study, mothers' perception of their newborn infants' stay in a neonatal intensive care setting was investigated. Information was collected regarding maternal perceptions of the event, and their perceptions of what support was beneficial and what support was not beneficial to them while their infant was in the setting and when their infant discharge was planned.

In the second phase of the study, the same mothers were interviewed by another graduate student six weeks after discharge home of their infants, to determine their perception of community support they received and problems they experienced (Hamelin, 1991).

Design

The study was descriptive in design. A descriptive design was appropriate to this study because the data collected provided information pertaining to certain descriptions about the defined population (Wilson, 1985). This study is important as in the past mothers have been infrequently consulted or asked about their perceptions of their newborn infants' stay in a neonatal intensive care setting and the support they receive (Luker & McLoughlin, 1988; Polit & Hungler, 1987).

Glossary of Terms

The following is a glossary of terms utilized for this study.

Maternal Perceptions: This term refers to the mother's "conscious awareness of the situation and her infant's and others' response to her..." (Mercer, 1981, p.76). Maternal perceptions in this study were "measured as feelings or thoughts, verbally expressed by the mother and quantified during the interview" (Mercer, 1981, p.76).

Neonatal intensive care: This is the care neonates receive after birth which is delivered by highly skilled nurses in conjunction with other personnel and includes special care, constant observation, immediate intervention, and sophisticated technology (Avard, 1986, p.22). Neonatal intensive care occurs in a clinical setting and may be given in Neonatal Intensive Care Units, Intermediate Care Units, or designated nurseries which act as Special Baby Care Units or deliver special baby care (Avard, 1986).

Support: Support is a strategy (Beaton, 1984) utilized by, or a reaction of (Mercer, 1981) maternal significant others (this includes husbands, partners, relatives or friends) and

nurses towards mothers' who have infants requiring neonatal intensive care (Luker & McLoughlin, 1988). Support includes teaching, giving guidance and information, caregiving activities, providing emotional maintenance or backing (Zarling et al., 1988; Cochran & Brassard, 1979; Parke & Tinely, 1982; Tracy, 1990), and affirming relationships (Dormire et al., 1989).

Neonate: Neonate is a term used to describe an infant from the moment of birth to 28 days of life (Moore, 1983, p.1093). The term in this study is used synonymously with infant, newborn or baby.

Setting

Two large urban hospitals, which are the neonatal intensive care centers for a midwestern province, were the settings for this descriptive study. The settings included a total of five units which provided neonatal intensive care and special care to infants.

Populations and Sample

The population for this study were those mothers who had infants requiring NIC, and who had been admitted to a NIC unit or special care for at least 10 days. Mothers at the time of the interview had infants who were being prepared for discharge. A convenience sample of 54 mothers was selected from a possible sample of 59 mothers. Five potential subjects were eliminated from the sample because they expressed a lack of interest in the study, or expressed feelings that indicated they were under too much stress at that particular time to participate.

The sample obtained from the two settings met certain selection criteria. Mothers who took part in the study:

1. Had reached an age of 18 years or more
2. Spoke and read English,
3. Had a baby in Neonatal Intensive Care or Intermediate Care Nursery admitted after birth, and remaining for a minimum of 10 days,
4. Lived in the City of Winnipeg or within a 160 kilometer radius of the city, and
5. Were not involved in the research study "Shortened Hospital Stay for Low Birth Weight Infants" (Casiro, Becker & McFadden, 1988). These mothers were not included as they received special preparation and follow-up as a component of this particular study.

Mothers' with infants with lethal conditions and anomalies were not included in the sample because of their unique needs and the anticipated outcome of the infants' demise.

Convenience sampling was used to obtain a study sample that was both applicable and attainable (Wilson, 1985). A limitation of this approach is that the sample obtained by convenience sampling has a potential for exhibiting certain biases not exemplary of the population (Wilson, 1985). Potential biases anticipated in this study were that all mothers' with infants receiving neonatal intensive spoke and read English, and lived within a reasonable proximity of the city of Winnipeg. Mothers who could not speak English or did not live within a 160 kilometer radius of Winnipeg were not asked to take part in the study.

Procedure for Data Collection

Permission for access to study subjects and to access hospital charts for the purpose of collecting demographic data was obtained from two teaching hospitals in a major midwestern Canadian city (See Appendix A).

In consultation with the researcher, potential subjects were assessed regarding the applicability of study criteria and were approached initially by another party. The initial contact person was an assistant head nurse in each NIC and IMCN unit, designated by each institution. The designated nurse utilized a protocol (see Appendix D) to inform potential subjects of the study. The protocol allowed for a consistent introduction to potential subjects of the purpose of the study, and the researcher, and included an invitation to have one of the researchers contact them by telephone to further explain the study. If the potential subject was in agreement, the designated nurse obtained their telephone number. The potential subject then was contacted via telephone, by the investigator following the protocol outlined in Appendix E. Again, if the potential subject granted permission and met the study criteria, a time was established for the first interview.

At the beginning of the first interview, both graduate student researchers, for phase one and two of the study, were present to introduce themselves and answer any questions. The student colleague researcher then departed, leaving the researcher to conduct phase one of the interview with the subject. Throughout the process several opportunities were given to the subject to ask any questions or discuss any concerns. Both graduate student researchers had access to the demographic data. Demographic data were collected in

Phase 1 from the subjects and their infant's hospital chart utilizing the demographic guideline outlined in Appendix C (Adapted from Luker & McLoughlin, 1988).

Limited risk to study subjects was anticipated, however the researcher was prepared to conclude the interview immediately if the subject was unable to tolerate the interview. A description of the study (see Appendix F) was given to the potential subjects. Before the actual interview began, all subjects gave a written consent (see Appendix G).

To expedite data collection and insure the quality of the data, personal interviews were carried out with each subject (Polit & Hungler, 1987). All interviews were conducted in a suitable location, acceptable to the subjects. Most of the interviews were conducted in the hospital setting, however, three of the interviews were conducted in the subjects' home at their request. Utilizing a interview questionnaire, the researcher delivered the questions orally to the subject. For each close ended question, the subject's response was coded on the answer sheet according to the choices corresponding to each question. The subject's answers to open ended questions were transcribed by hand by the researcher. Care was taken to ensure the response given by the subject was transcribed "as closely as possible" (Polit & Hungler, 1987, p.232).

Questionnaire

An interview questionnaire developed by Luker and McLoughlin (1988) was utilized (see Appendix B) to gather information from subjects who chose to participate in the study. The interview questionnaire included a mix of close ended and open ended questions (Luker & McLoughlin, 1988; Polit & Hungler, 1987). Use of a questionnaire

which includes both types of questions allows the researcher to gather information proficiently, while providing opportunities for the subject to express their viewpoints (Polit & Hungler, 1987).

Luker and McLoughlin (1988) constructed the questionnaire, with attention to specific aspects about the problem identified in the literature. The questionnaire was constructed with particular regard to ensuring the question were clear, unbiased and comprehensive (Luker & McLouglin, 1988, p.10).

Revisions to the interview questionnaire were made by the researcher to make the tool applicable to Canadian neonatal intensive care settings. Revisions included wording changes and an expansion of study sample criteria. These changes were approved by Luker (1989) and did not alter the intent of the study.

Before the actual study began, piloting of the interview questionnaire was done. Piloting or a "trial run" of the questionnaire helps the researcher to determine if the questions asked are appropriate and comprehensive (Luker & McLoughlin, 1988; Polit & Hungler, 1987). Three pilot subjects comprised "a panel of experts" obtained from the community and known to the researchers (Polit & Hungler, 1987). Women who piloted the questionnaire had infants who required Neonatal Intensive Care. The data collected through this procedure were not included in the actual study sample data. Rather, the information was used to determine if the interview questionnaire needed any revisions (Polit & Hungler, 1987). Pilot subjects were able to answer interview questions without difficulty and did not suggest any necessary revisions.

Implications Of The Research Procedures To The Human Subjects

A proposal for the study was approved by the Ethical Review Committee at the University of Manitoba School of Nursing (See Appendix A). Each subject was required to sign a consent for their participation in the study. The consent form outlined who would be included in the study, the time committment of approximately 40 minutes for the interview, a guarantee that all information would be held in the strictest of confidence, and an offer of a summary of the thesis study results. Study subjects were informed they could decline to answer any question they found unacceptable, and might end their commitment in the study at any time.

The consent assured the subject that they would not be identified on any of their answers to the questionnaire. All interview questionnaires were coded with a number. The researchers were solely responsible for assigning code numbers to study subjects, therefore maintaining subject anonymity. Because the thesis study was a part of a two phased collaboration project, the researchers, thesis committee members, and a statistician had access to the demographic data. The data on the computer is being kept for further utilization in the collaborative research project. The researcher had exclusive access to the questionnaires, which were stored in a secure, locked cupboard. Questionnaires were shredded after the study was completed.

Data Analysis

After gathering information from study subjects, data were prepared for analysis (Polit & Hungler, 1987). Quantitative data from close ended questions were coded and

entered into the computer (Polit & Hungler, 1987). Statistical analysis was performed in consultation with a statistician. Descriptive statistical analysis, utilizing the Statistical Package for Social Sciences (SPSS-X) software, included frequency distributions, measures of central tendency and variation (Polit & Hungler, 1987; Luker & McLoughlin, 1988; Sloan, 1990).

Because the interview questionnaire included questions which were open-ended, qualitative analysis of subject responses also was performed. Responses to these questions were examined, analyzed, and coded into categories that emerged from the data (Wilson, 1985).

Data were obtained that described mothers' perceptions of their infants' stay in an neonatal intensive care setting; what support was beneficial and non-beneficial to them while their child was in NIC; and what support they perceived as beneficial or non-beneficial in preparing them for their baby's discharge home.

Study findings are summarized in the following chapter.

CHAPTER FIVE

RESULTS OF STUDY

In this chapter the results of the study will be presented. Both qualitative and quantitative data were obtained through interview questions. Results from the study and analysis of the data will be discussed as follows:

1. Demographic data of study subjects,
2. The experience of having an infant in neonatal intensive care,
3. Support that was beneficial or non-beneficial during hospitalization, and
4. Support that was beneficial or non-beneficial in preparation for discharge.

Demographic Data

The sample for this study consisted of 54 mothers. The mean age of the women was 29 years of age. Mean number of years of education was 13 years. The majority (65%) of sample resided in Winnipeg. The most frequent family income was more than $43,000.000. Almost all (98%) of the sample were caucasian. Forty-six percent of the women had worked before the birth of the baby. All of the mothers lived with their spouse or partner, and over half (54%) of the mothers had previous children.

The mean age of gestational age for infants was 32.7 weeks. The mean weight for the infant was 2012 grams. Fifty-seven percent of the neonates were of low birth weight. Most of the infants (83%) were admitted to special care because of prematurity at birth. The average length of stay for infants in NIC units was 17.2 days, and 29.3 days

in IMC units. Almost one-half (46%) of the infants experienced multiple complications while hospitalized, however most (78%) of the infants required no immmediate treatment at time of discharge. Further demographic data are presented in Tables A and B. Demographic data pertaining to infants are presented in Tables C and D.

TABLE A

DEMOGRAPHIC DATA - MOTHERS

AGE AND EDUCATION

VARIABLE	MEAN (STANDARD DEVIATION)	RANGE
AGE (YEARS)	29 (3.787)	21-37
EDUCATION (YEARS)	13 (2.679)	07-22

TABLE B

DEMOGRAPHIC DATA - MOTHERS

VARIABLE		N(%)
RESIDENCE	URBAN	35(65%)
	RURAL	19(35%)
ETHNIC ORIGIN	CAUCASIAN	53(98%)
	NATIVE NORTH AMERICAN	01(02%)
FAMILY INCOME	<$23,000	09(17%)
	$23,OOO-43,000	21(40%)
	>$43,000	23(43%)
	NOT REPORTED	01
OCCUPATION (Blishen & McRoberts, 1976)	70+	02(04%)
	60-69	07(13%)
	50-59	14(26%)
	40-49	07(13%)
	30-39	04(08%)
	BELOW 30	05(09%)
	OCCUPATION NOT LISTED	06(11%)
	UNEMPLOYED/HOMEMAKER	09(16%)
WORK BEFORE BIRTH OF BABY	YES	40(74%)
	NO	14(26%)
PLAN TO WORK AFTER MATERNITY LEAVE	YES	25(46%)
	NO	18(33%)
	UNSURE	11(21%)
PREVIOUS CHILDREN	YES	29(54%)
	NO	25(46%)
LIVING WITH SPOUSE/ PARTNER	YES	54(100%)
	NO	00(0%)

TABLE B-Continued

DEMOGRAPHIC DATA - MOTHERS

VARIABLE		N(%)
PLANNED PREGNANCY	YES	45(92%)
	NO	04(08%)
	5 NOT REPORTED	
PREGNANCY	SINGLE GESTATION	51(94%)
	TWIN GESTATION	03(06%)

TABLE C

DEMOGRAPHIC DATA-INFANT

VARIABLE		
GESTATIONAL AGE AT DELIVERY	MEAN IN WEEKS	32.7
	(STANDARD DEVIATION)	3.699
	RANGE	24-42
BIRTHWEIGHT	MEAN IN GRAMS	2012
	(STANDARD DEVIATION)	772.753
	RANGE	600-3880
	>2500	10(18%)
	<2500	44(82%)
	EXTREMELY LOW BIRTH WEIGHT (ELB)<1000	05(09%)
	VERY LOW BIRTH WEIGHT (VBL)<1500>1000	08(15%)
	LOW BIRTH WEIGHT (LBW) <2500>1500	31(57%)
DISCHARGE WEIGHT	MEAN IN GRAMS	2667
	(STANDARD DEVIATION)	645.335
	RANGE	1928-4235
	>2500	28(52%)
	<2500	26(48%)
LENGTH OF STAY IN NICU (DAYS)	MEAN IN DAYS	17.3
	(STANDARD DEVIATION)	21.302
	RANGE	0-87
LENGTH OF STAY IN IMCN (DAYS)	MEAN IN DAYS	29.3
	(STANDARD DEVIATION)	21.481
	RANGE	0-118

TABLE D

DEMOGRAPHIC DATA - INFANT

VARIABLE		N(%)
HOSPITAL	SITE A	33(61%)
	SITE B	21(39%)
UNIT	NICU ONLY	01(02%)
	IMCN ONLY	08(16%)
	NICU, IMC	19(35%)
	NICU, SPECIAL CARE UNIT	05(09%)
	NICU, IMC, SPECIAL CARE UNIT	18(33%)
	IMC, SPECIAL CARE UNIT	03(05%)
TRANSFER FROM OUTSIDE OF HOSPITAL	YES	06(11%)
	NO	48(89%)
REASON FOR ADMISSION TO SPECIAL CARE	PREMATURITY	45(83%)
	APNEA	01(02%)
	SEIZURES	02(03%)
	RESPIRATORY DISTRESS	03(06%)
	CARDIAC ANOMALY	01(02%)
	SEPSIS	01(02%)
	ASPHYXIA	01(02%)
COMPLICATIONS DURING HOSPITALIZATION	NONE	13(24%)
	BPD	01(02%)
	INTRAVENTRICULAR HEMORRHAGE (IVH)	10(18%)
	MULTIPLE COMPLICATIONS	26(48%)
	NECROTIZING ENTEROCOLITIS	01(02%)
	RENAL FAILURE	01(02%)
	HYALINE MEMBRANE DISEASE	02(04%)

TABLE D-Continued

DEMOGRAPHIC DATA - INFANT

VARIABLE		N(%)
CONDITION AT DISCHARGE	NO IMMEDIATE TREATMENT REQUIRED	42(78%)
	APNEA MONITOR	01(02%)
	HOME OXYGEN	01(02%)
	REQUIRES MEDICATION	05(09%)
	REQUIRES FURTHER SURGERY	03(05%)
	RETINOPATHY OF PREMATURITY	01(02%)
	CONGENITAL ANOMALIES REQUIRING TREATMENT	01(02%)

Perceptions of Mothers of Their Infants Stay in an Neonatal Intensive Care Setting

Previous Experience With Neonatal Intensive Care Units

Mothers were asked if they had visited a Neonatal Intensive Care Unit or an Intermediate Care Unit previous to their baby's admission. Thirty-two percent of the subjects (n=17) indicated they had visited a special care unit previously to their baby's admission, however, more than two-thirds (68%) of the mothers (n=37) had not had previous experience with a neonatal intensive care unit. Eighteen percent of the sample (n=10) stated they had had a previous child in special care, four percent (n=2) stated they had visited these units through family members, two percent (n=1) had experience through their work, and nine percent (n=5) indicated they had visited through a hospital arranged tour.

Maternal Perceptions Regarding Their Infant's Admission

The experience of having an infant admitted to special care aroused strong emotions and feelings for most of the mothers in the study. When asked how they felt about their baby being admitted, almost two thirds of the sample (n=35; 65%) replied they were frightened, worried, scared or overwhelmed.

> The having to be admitted was difficult. We were not happy about the baby being born earlier. We were worried--what was the repercussions of all this treatment. Was it better to have treatment or to "let die".

> I was scared stiff and not because of the care but because something must be quite wrong to have to come to an NICU. I had lots of mixed feelings.

> I was devastated. It was very traumatic.

Fifty percent of the mothers (n=27)indicated they had not expected the baby's admission to neonatal intensive care.

> I was told right after the baby was born. I was apprehensive.I was unsure of what was taking place. I was in shock. It was unexpected. The baby was five pounds four ounces-I didn't think she should be there. It was disappointing.

Another mother stated that:

> I felt anxious. It was very hard especially when it is your first. Prenatal classes don't prepare you for this sort of thing. It was a shock and very frightening.

Twenty-six percent (n=14) of the mothers expected their infants' admission to special care because the infant was premature, born under a crisis situation or they had been prepared by going on a tour previous to the birth:

> I was prepared for it by the tour we had before the baby was born.

> I knew the baby was going to be premature. I had been through it before so I wasn't too shocked.

The remaining twenty-four percent (n=13) did not comment on expectations they had of their child being admitted to NIC.

Some mothers (n=30) experienced positive feelings towards the infant's admission:

> I think I felt grateful-because of my history. I was grateful he was alive. I had a feeling of relief. I trusted the people in the unit. I trusted their expertise.

Although mothers were generally disappointed the baby was admitted to special care, twenty-two percent (n=12) indicated they were grateful there were neonatal intensive care facilities available to give care to ill newborns after birth:

> You are grateful that there are facilities like that to take care of babies. They are in good hands. In a rural community they aren't ready for that.

> It was really scary, but I was thankful it was around...at the home hospital they didn't have the care to give her...they didn't have the facilities.

Initial Maternal Perceptions Of Neonatal Intensive Care Units

Three major catagories emerged from data gathered about initial maternal perceptions of the neonatal intensive care unit. When asked what their first impressions were, sixty-eight percent (n=37) of the mothers indicated it was the physical environment of the unit that had greatest effect on their initial perceptions. They were at times overwhelmed by the activity in the unit, the technology, machinery, physical space and lighting of the unit. For one mother:

> It looked so modern. It was like a nuclear, safe, secure, place.

Another found that:

> It was busy. The alarms going off were quite scary. The background noise is OK, but when you are sitting with your child and the alarm goes off you think "My God what is going on." I wasn't aware of all the machinery involved. I had never seen so many machines and equipment. It was scary. I didn't know what was happening.

Another made the following comment about her baby:

> He was all stuck full of needles and in an airtent.

Eleven mothers gave their first impressions which pertained to the emotional atmosphere created in the unit and the feelings it aroused. For some, the atmosphere was positive:

> They were very kind. Once greeted, I felt comfortable and relaxed.

> They were very nice and personable. They let us stay and watch the ultrasound to see if the baby had kidneys. They were very good.

> It was just great. The nurses seem to like to take care of her.

Others found the emotional atmosphere impersonal.

Seven mothers expressed surprise at the type of babies that were being cared for in the unit. They seemed unaware there were so many small babies that required care.

> I was surprised to see so many babies. You don't hear about preemies talked about in the open.

> I was quite taken aback by how many small babies were in the nursery.

One mother stated her first impression were blurred and that she could not remember much about it. Another mother experienced feelings of devastation and numbness. She thought her baby was going to die.

Three open ended questions were asked of the mothers to determine their perceptions of the infant's admission to NIC and the first acquaintances with their infant. Mothers were asked to describe any particular worries they may have had when the infant was admitted to neonatal intensive care. Ninety-three percent (n=50) of the mothers expressed particular concerns, while seven percent (n=4) stated they didn't have any particular worries about their baby's admission.

The primary worry of mothers whose infants were admitted to neonatal intensive care was that the infant was going to die. Thirty-eight percent (n=21) of the sample expressed feelings that demonstrated they were concerned for the infant's survival.

> I thought she was going to die. I had been through Lamaze classes and I thought I would have a normal labor and delivery. I felt guilty.

> They call my baby the miracle baby. The baby came as close to death as possible.

Whether or not he would make it because he was so ill. The greatest day in my life was when the nurse said one day "Well I think we will be sending this one home." Then I knew he would make it.

Forty-four percent (n=24) of the subjects had particular worries related to the infant's condition and present health. They were concerned with the infant's size, lungs, and tests performed on the infant.

His size and his breathing. He was small for 36 weeks. Was the Demerol effecting his breathing?

Basically the lungs. Previous test when I pregnant showed the baby's lungs were not mature. I was concerned he would have breathing problems.

The fact that he was only 31 weeks gestation. When we came in he was hooked up to the ventilator and monitors.

The fact she would have to undergo sleep studies....blood tests-is this painful to the baby.

Nine mothers had particular concerns about their baby's future development and health.

We were concerned she would catch up to other kids.

His future health problems because he was so early. His susceptibility to brain damage or ear or eye problems.

...if there was going to be any permanent damage.

The fourth particular worries mothers expressed were those which indicated a concern for the quality of care delivered in the unit, including their involvement in that care. Fourteen percent (n=8) made statements referring to this concern.

Nobody told me until I started asking question. If they tell you, then they don't tell you how and what for.

I was worried about me being a part of her care. The staff seemed so complete

in her care, that maybe they didn't need me. It felt like they had completely taken over.

Not knowing everything that was going on with the baby. We didn't know what the drugs were that they were giving him. There was no consent. You relied on them to know what they were doing. There was no control.

...that they would be able to take care of him so that he would be better.

The opportunity to touch their infant initiated pleasurable feelings in most of the women. When asked how they felt about touching their baby, fifty-nine percent (n= 32) of the subjects indicated they welcomed the opportunity, enjoyed the experienced and expressed a strong desire to touch the infant.

I wanted to do it. I spent 6 hours a day talking and touching him.

I touched him right away. I couldn't wait. I was happy. I know they weren't unbreakable. I had been through this experience before.

I was happy. I checked him right out. I felt so relieved he was bigger than we thought.

I wasn't afraid. I needed to touch him.

Nine mothers were initially apprehensive, but after touching the infant once, they enjoyed the experience.

I was scared at first. Once I did touch her I wanted to have her all the time.

Twenty-four percent (n=13) of the subjects were wary of touching their infants and communicated it as a negative experience.

I wanted to touch her but they can feel the tenseness and the alarms went off. I felt "oh no" what have I done.

I was really, really leery. She looked thin and fragile.

> I didn't want to touch her at first. I thought "how red she is."
>
> With the baby being on the respirator it was hard. When you touched him his heart rate would go down.

Five women, when touching their babies, appeared to take their cues from the nursing staff. The nurses provided direction, support and permission.

> Once the nurses explained I knew when to touch fairly confidently.
>
> I needed to be told by the nurses that I could touch him.

Forty-three percent (n=23) of the mothers indicated there wasn't anything that particularly bothered them when touching their baby. However, an infant's fragile appearance and a fear the mother might break or harm the infant was a particular concern that bothered thirty-seven percent (n=20) of the subjects.

> I was scared because he is so tiny. His head is so soft. I felt the baby is made of glass-he might break.
>
> I was very afraid of harming him when I touched him. He was so fragile.

Intravenous tubing, machinery and equipment proved to be a deterrent to mothers in touching their infant. Twenty-four percent (n=13) expressed feelings they might disturb the equipment connected to the baby, or that it was difficult with the machinery.

> Because she had so much stuff hooked up to her, we were scared we would touch something we weren't supposed to.
>
> The respirator bothered me when touching my baby. I didn't want photographs until he was extubated.
>
> I was worried about touching the wires and things.

Six mothers made statements which referred to alteration in attachment and bonding with the infant. One mother indicated she touched her baby as much as she could in order to actively bond with the infant. Three mothers did not want to become too attached to their infant because they thought the child might not live, while two mothers thought restrictions on touching their infant inhibited the attachment process and they didn't feel "connected" to their infants until much later in the hospital stay.

One mother was extremely distressed about touching her infant. The condition of her baby, his appearance and the technology employed to save the baby inhibited her from touching him. Her account is particularly poignant.

> He was so very sick and skinny. He didn't look like a baby. His face was "destroyed" from being on the ventilator. There nothing you can do about it because they are trying to save him. At one time I said why don't you just unplug the machine and let him go. I counted 50 wires connected to machines. His skin was bleeding from tape being pulled off. They told me he couldn't feel it.

Mothers' Perceptions of Support That Was Beneficial and Non- Beneficial to Them While Their Child Was in Neonatal Intensive Care

Both qualitative and quantitative questions asked during the interview generated data ascertaining maternal perceptions of support given to them while their child was in NIC. These data helped to determine maternal perceptions of the support which was beneficial or non-beneficial. Provision of support came from nurses, doctors, husbands/partners and family.

Maternal Involvement In Infant Care

Visits to the neonatal intensive care unit to see the baby were an important event in order to maintain contact with the infant (See Table E). Eighty-three percent (n=45) of the subjects visited at least once a day, thirteen percent (n=7) visited every other day, two percent (n=1) visited every third day, and two percent (n=1) visited twice a week. The average length for each visit was 139 minutes. Eighty-seven percent (n=47) travelled by private car to visit the baby, at an average expense of eight dollars per trip. Average length of time it took mothers to travel to the hospital was thirty-two minutes. Three mothers walked to the hospital, three took buses, and one took a taxi. Two mothers received help towards their travel expenses, one from the social worker from the IMC unit social worker, the other from hospital social services.

When mothers were unable to visit their infant, they expressed feelings of guilt (n=3), anxiety (n=2), and disappointment (n=6). Five mothers were unable to visit frequently because they lived out of town and it was too far to travel. One mother was unable to visit due to exhaustion.

Two of the mothers considered their visits short in length. One mother kept her visit short at the request of the nurses, and the other mother stated she had other things to do. Only one mother out of the sample of fifty-four did not initiate telephone contact with the neonatal intensive care unit when she was unable to visit.

Maternal involvement in the care of their infant was important to the mothers in this sample. Many mothers expressed feelings of pleasure and appreciation when given the opportunity to perform some of their infant's care. Fifty-seven percent (n=31) wanted to

become involved all of the time in the care of their baby on admission. Nineteen percent (n=10) wanted to be involved most of the time, and thirteen percent (n=7) some of the time. Six mothers did not want to be involved in care. Most of the mothers (n=30, 56%) desired involvement in infant care immediately, while forty-four percent (n=24) took an average of two days to want to be involved in the care of their baby.

TABLE E

MATERNAL VISITS TO NIC UNIT

VARIABLE	VISITS	N(%)
	AT LEAST ONCE A DAY	45(83%)
	EVERY OTHER DAY	07(13%)
	EVERY THIRD DAY	01(02%)
	TWICE A WEEK	01(02%)

Support From Nurses

Support received from nursing staff during the mothers' hospitalization and the subsequent infant's stay in hospital had a profound and far-reaching effect on mothers. Support came from nurses in several ways including encouragement, emotional support, communication, and inclusion of the mother in caregiving to the infant. Support from special care unit nurses and postpartum nurses were also assessed through maternal perceptions.

Maternal Perceptions Of Support From NIC and IMC Nurses

Generally, mothers received encouragement from nursery nursing staff to take part in their infants' care (See Table F).

TABLE F

MATERNAL PERCEPTIONS OF ENCOURAGEMENT TO TAKE PART IN INFANT CARE

VARIABLE		N(%)
MATERNAL PERCEPTION	ENCOURAGED ALL OF THE TIME	20(37%)
	ENCOURAGED MOST OF THE TIME	14(26%)
	SOME OF THE TIME	17(31%)
	RARELY ENCOURAGED	01(02%)
	NEVER ENCOURAGED	02(04%)

Maternal reaction to nurses' encouragement or lack of encouragement to become involved in the care of their baby ranged from feelings of appreciation to feelings of incompetence and rejection. The most prevalent category arising from analysis of the open ended question was maternal appreciation and feelings of having received beneficial support. Sixty-eight percent (n=37) felt encouraged from receiving beneficial support such as nursery nurses answering mothers' questions, explaining policies and procedures, making mothers feel welcome, giving encouragement and guidance, and allowing the mothers to perform infant care.

> I felt quite welcome.
>
> The staff at the NICU were very encouraging and supportive. They let me stay when they were giving report about the baby at change of shift.
>
> The reaction was positive with questions. I wanted supervision and they gave me support and encouragement. They gave me lots of support and encouragement as I was a new mother.
>
> I was glad they were willing to be patient with me in holding him and handling him. He was so small and you are not used to it.
>
> The nurses were very sensitive to our needs. They seemed to perceive our feelings and seemed to be willing to talk to us.

Thirty-two percent (n=17) of mothers felt the nurses manner and lack of support effected them negatively. Support that was not beneficial to the mothers were nurses' lack of encouragement, rejection, inability to address maternal concerns and inattention to mothers' emotional needs.

> In the IMCN I got some really negative feelings, like they didn't want me to be there. I got the feeling that the IMCN staff didn't want me and that I was an intruder and I was in the way.

> There was one nurse that rubbed us the wrong way. It was shift change and she wanted to go home. She told us it was 10 minutes to report time when we wanted to hold the baby.
>
> Some were very clinical about it all. I found this threatening, a lot of this is personality. Overall I stayed away from IMCN, I felt like a bump on a log and I seemed out of place. I felt like I should get out--there was no place to sit. It seemed like the nurses were glad when you left. It seemed there was nothing I could do--I said to myself, why am I doing this...I didn't get support from the nurses until I cried, then a nurse came and hugged me and I felt better. Some of them seemed distant.
>
> The staff encouraged me to go home but I wanted to stay in the hospital and be with her all the time. It was traumatic for me to leave the hospital without her. I was very upset and cried when I had to leave her.

Some nurses actions added to the mother's stress:

> The nurses were quite protective of the baby. How the nurses reacted sometimes put additional stress on us.
>
> It was hard--we were having a hard time with the nurses. We weren't content with their answers. Some nurses became defensive...although questions were invited by nurse, but they couldn't answer them. This was very hard and the situation became tense.

Forty percent (n=21) of the sample stated how they perceived the encouragement received depended directly on the nurse.

> Certain nurses encouraged you and some didn't. Some nurses reacted to you differently. Some were more positive. How I felt when I went home depended on which nurse was on.
>
> It depends on who the nurse was. Some of them I didn't trust. They were cold, yet then there were some that were really nice and wanted you to.

Thirty-eight (70%) mothers were satisfied with the care they received from nurses on the NICU or IMC units, while twelve (22%) were fairly satisfied. Four mothers were dissatisfied with the care they received from NICU or IMC nurses.

Dissatisfaction with nursing care for the mother seemed to relate to the emotional atmosphere of the unit, lack of communication, and the differences between NIC and IMC unit practices.

> In IMCN we were not told very much. It was difficult to get information from one nurse to the next it was a different viewpoint. Everybody had a different opinion.

> There was a difference between NICU and IMN. There is different rules in each unit. When you are still following NICU rules and then get "snapped at" by the IMCN staff...You get the feeling that the baby is in IMCN and in our care so please leave the nurses alone and we will give the baby back to you when he is better.

> There seems to be inconsistency between nurses and how they want parents to participate in the care. Sometimes the IMC nurses make you feel unorganized. There was a contrast between the NIC unit and the IMC units.

> In NICU you are very involved with your baby but in IMCN they make you feel like you should be outside the unit looking through a window.

> The nurses shouldn't alienate the mother. They should have the nurses take care of your baby for a longer time. Every day there is a different nurse taking care of the baby. You don't feel comfortable until you get to know the nurses. This is for the mother as well as the baby.

Mothers gave specific suggestions regarding special care nurses communication and care. They indicated what nurses should not say:

> Nurses should never say to you "God wouldn't have let this happen to you if he didn't think you could handle it."

> Don't tell mothers to get their rest. Mothers may think this is asking them to leave. I didn't want to hear that.

Mothers also suggested information that would be helpful:

> Parents need to know the little things like good gases are progressive signs.

> Tell the nurses to give the mother permission to cry and to give support.

Five mothers made specific reference to support and care received from nurses and their ability to bond with their babies. One mother felt the nurses' encouragement for maternal caregiving facilitated bonding, while four mothers felt lack of nurses' encouragement, understanding and care inhibited bonding with their children.

> The IMCN nurses don't let you bond with your child. I had to actually negotiate times to see my baby. They forget you are the mother. They make you feel that if you ask questions that you have no right to ask them. They would kick me out when they thought it wasn't the right time to visit.

Maternal satisfaction with nurses care and caregiving to their infant was high. Seventy-eight percent (n=42) of the mothers were very satisfied with the way the nurses in NICU or IMCN cared for their infant. Nine mothers (17%) were fairly satisfied, and three mothers (5%) were dissatisfied. Fair satisfaction or dissatisfaction appeared to relate to inconsistency between nurses and in nursing care between nursery units.

> I was sometimes satisfied and sometimes dissatisfied. The nurses often contradicted each other on several matters. One nurse says one thing and then another nurse says another.
>
> In IMCN they couldn't respond to your baby's need as well as NICU. The IMCN nurses always seemed busy.
>
> There is a difference between what nurses do between NICU and IMC.
>
> I was more satisfied with the staff's care in the NIC unit. In the IMC unit they have more babies and less staff.
>
> There should be more continuity of care with the nurses. The baby gets 3 new nurses a day. The baby has so many new nurses, its frustrating. Because he is doing so well, I wonder if the nurses are paying attention to him. If something would happen to him would anybody be watching.

Maternal Perceptions of Support Received From Postpartum Nurses

Mothers were asked to respond to close-ended questions that explored their perceptions of the support received from post partum nurses when their infant was in NIC. The care and understanding provided by post partum nurses promoted a high degree of satisfaction in forty eight-percent (n=26) of the mothers. Thirty-two percent (n=17) were only fairly satisfied, and twenty percent (n=11) were dissatisfied with the support received. Responses from open-ended questions helped to clarify why the subjects felt less than complete satisfaction or dissatisfaction.

> They didn't acknowledge that I had a baby because the baby was in NICU. They didn't ask about the baby or give me postpartum care. It was hard to listen to them give teaching to your roommate who had a baby. I was pumping my breasts with a machine,"my mechanical baby", while the nurse was teaching my roommate how to breastfeed her baby.
>
> They are short staffed. I was transferred here and when I arrived the nurses made it very clear they were very short staffed and told me so. My doctor insisted I stay. You could really feel the tension from the nurses. It makes you really want to get out in a hurry. I didn't want to be an unwanted guest in the hospital.
>
> I wasn't satisfied because they showed me little caring. Mothers with babies in NICU should be given the option to go to an antepartum ward. It was hard to be in the same room with a mother who had the baby and I didn't.
>
> I was not asked about my baby by the post partum staff for 5 days. It was like I didn't have a baby. I didn't get any teaching. They seemed to ignore me because I didn't have a baby in the room. I got satisfactory "physical care" but no emotional care. I think the nurses were concerned but didn't know how to treat me as a client.
>
> I think it is hard for the staff to reach to moms with babies in NICU. I didn't get any teaching information this time.

Mothers made specific suggestion regarding care from postpartum nurses:

> They shouldn't put mothers who have babies in IMCN with mothers who have their babies with them. Your sleep is interrupted by the babies who are with their mothers. You are under an emotional strain. It hurts, it just reminds you that you don't have your baby.

> The postpartum nurses need to know the status of the baby. Perhaps both the postpartum and nursery nurse could see the mom together.

Maternal Perceptions of Communication With Special Care Nurses

The opportunity to communicate and gain information about their infant was important to most mothers.

Eighty-percent (n=43) felt free to ask questions about their baby at any time, seven percent (n=4) felt they could ask questions most times, eleven percent (n=6) some of the time, while one mother never felt as though she could ask questions.

Eighty-two percent (n=44) of mothers thought they were told enough about their baby by the nurses on the unit. Eighty-nine percent (n=48) understood the information given to them by nursing staff and ninety three percent (n=50) felt they could go back if they required additional details. One mother commented that if she needed more information she just read the chart.

Several mothers suggested that nurses should improve their consistency in communicating about infant conditions and unit practices.

> There needs to be better communication between the nurse at change of shift.

> More consistency is needed in what mothers are told about their baby. Often I would be told one thing and the next day I would be told another thing.

Maternal Perceptions of Communication With Physicians

Maternal perceptions of communication with physicians were less positive than their perceptions of communication with special care nurses.

Thirty-three percent (n=18) of the subjects felt they were not told enough about their baby by the physicians in NICU or IMCN. Sixty-seven percent (n=36) felt they received enough information.

Sixty-five percent (n=35) of the sample understood the information communicated to them by physicians, however thirteen mothers stated they had difficulty comprehending and asked the nurses to explain. Forty-seven (n=87%) mothers felt they could go back to the physician for more information.

Mothers gave additional comments regarding physicians and recommendations to improve their physician communication.

> The doctors when they thought the baby was going to die asked me to think about an autopsy. He wasn't even dead yet.
>
> The doctor in NICU, when asked a question, just gave us a short answer and walked away from us. I was not impressed.
>
> The doctors also could consult us more about what decisions they are going to make. Parents should be a part in making the decisions with the doctors. It seems like the parents have no choice in what they do.
>
> It's helpful if the doctors... didn't use so many medical terms. It would be helpful if they used layman's terms.

Forty-three out of fifty-four mothers had contact with their infant's physician since the baby's birth, and twenty-eight mothers had visited their family physician since delivery.

Maternal Perceptions of Support Received By and Extended to Family Members By Nurses

Maternal perception of support received by family members during their child's hospital stay was determined by their partner's involvement in infant caregiving during the infant's hospitalization. Questions were also asked about the care and support extended by nursing staff to mothers' partners and family.

Sixty-one percent (n=33) of mothers felt their partner wanted to become immediately involved in infant care after admission to special care. Six fathers (11%) wanted to become involved most of the time, while twenty-two percent (n=12) only wanted to be involved some of the time. Three mothers (6%) felt their partner did not want to be involved at anytime.

Fifty-nine percent (n=32) of the fathers wanted to immediately become involved in his infant's care, while thirty- two percent (n=12) of the fathers wanted to become involved within an average of seven days. Five fathers (9%) took an average of fifty-two days to become involved in their baby's care.

Mothers perceived that nursing staff encouraged the baby's father to become involved in infant care thirty-seven percent (n=20) all of the time, twenty-four percent (n=13) most of the time, and twenty-two percent (n=12) sometimes. Four percent (n=2) of the fathers were rarely encouraged to participate in infant care and seven fathers (13%) were never encouraged to participate.

Mothers perceived paternal enjoyment when the fathers were involved in infant care and considered this as a positive event. When fathers were involved in infant care

mothers perceived that the fathers were happy and pleased to be encouraged to help with infant care, and wanted to actively participate in caregiving activities:

> He wanted to be involved in everything. He wanted to read the chart. He wanted to know exactly what was going on. He wanted to know what PH levels meant.
>
> He was quite happy. He holds the baby and feeds the baby.

When fathers were not included, mothers appeared to view this as having a negative effect, as expressed in their comments.

> He said "What's wrong with me?" The nurses seemed to talk to the mother but not the father.
>
> He didn't get to hold him. I had to give him all the information.
>
> The same way I did. You didn't trust them. You always wondered how the baby was when you weren't there. You were afraid they wouldn't call you if something happened.

Generally mothers were satisfied with the way the staff cared for their partners or other family member. Sixty-nine percent (n=37) of mothers were very satisfied with the care extended to their family members. One woman commented that fathers seem to get pampered more in IMC nursery and that the nurses seemed to make an effort for the fathers. However, twenty percent (n=11) were only fairly satisfied, and eleven percent (n=6) dissatisfied with the care. Less than complete maternal satisfaction came from mothers' perceptions of the nurses' lack of communication with their partners, and the failure to demonstrate a caring manner:

> They never said anything to him at all.
>
> He didn't get much contact.

> My husband felt they didn't care for him as much. There was one instance when my husband was told to leave the IMC nursery because the nurse were having report. We were told we could visit any time in the IMC nursery.

Special care nursery visiting policies also had an effect on maternal satisfaction. Mothers, at times, felt family members were isolated from her infant. The need to introduce the baby to family or friends was a strong maternal desire.

> Immediate family members that lived in Winnipeg were not allowed to see the baby. It is hard because he is in so long. I would like to introduce my mother to the baby.

> At times in IMC, the grandparents were not made to feel welcome. They felt like intruders.

> Our children were not allowed one time to see the baby. In IMC nursery my mother couldn't visit. Special permission was given, but it wasn't communicated to the other nurses. When this happened it was handled very unprofessional.

Mothers' Perceptions of Support That Was Beneficial or Non-beneficial in Preparing Them For Their Baby's Discharge Home From NIC

Maternal Perceptions Regarding Their Infant's Impending Discharge Home

The event of the infant's discharge in the near future caused additional maternal emotional upheaval and initiated anticipation. Many mothers in the sample experienced renewed, powerful feelings of anxiety, excitement, and fear.

When asked their feelings about taking their baby home in a few days time, mothers indicated they experienced both positive and negative feelings about the impending discharge of the baby, often at the same time. Although they had longed for this to

occur, they were apprehensive and anticipative towards the event. Sixty-one percent (n=33) of the mothers stated they were excited, thrilled and couldn't wait for the infant's discharge from hospital:

> I can't wait. I am really excited.
>
> I am "itching" to take her home. I didn't want to leave her behind in the first place
>
> I want her to be home right now. It's all I can think about.

Eight (15%) mothers stated they were apprehensive about taking their baby home. These mothers indicated they were scared, worried, and nervous:

> I am scared...my other baby stopped breathing when we took him home.
>
> Nervous. I think I read too much about premature babies.

Twenty-four percent (n=13) of the subjects had mixed feelings regarding this event. Mothers were excited and apprehensive, often at the same time:

> A part of me is apprehensive. I am not sure what the monitor is going to be like. The other part of me is ecstatic. I am looking forward to the CPR course tomorrow. Another part of me will be glad I don't have to come to the hospital and worry about the other children and be away from my family.
>
> I am happy and scared at the same time. I hope the seizures don't reoccur.
>
> I am excited but scared. I have mixed feelings. You don't know if she is going to have a brady or apnea at home. You just don't know, is there going to be something you can't help her with.

Preparation and Support for Infant Discharge

Mothers were asked about the preparation and support they received to prepare them for their child's discharge home. Subjects were also questioned about the support they anticipated they would receive at home and the problems they might encounter.

Preparation for Infant Discharge

In anticipation of their infant's discharge, mothers were asked how they felt the nurses had contributed to preparing them to take their infant home. Surprisingly, only forty-one percent (n=22) of the subjects stated they had been very well prepared (See Table G). Four mothers (7%) perceived that they had received no preparation. None of the mothers indicated they did not need much preparation.

TABLE G

MATERNAL PREPARATION FOR INFANT DISCHARGE

VARIABLE		N(%)
MATERNAL PERCEPTIONS	VERY WELL PREPARED	22(41%)
	ADEQUATELY PREPARED	09(17%)
	SOME PREPARATION	10(18%)
	VERY LITTLE PREPARATION	09(17%)
	RECEIVED NO PREPARATION	04(07%)

Confidence in Infant Care After Infant Discharge

Several of the mothers stated they felt confident about caring for their baby after discharge. Forty-eight percent (n=26) of the sample felt very confident, forty-eight percent (n=26) felt fairly confident, and four percent (n=2) felt nervous with some doubts about how they would cope.

Although the majority of the mothers felt confident or fairly confident they could cope at home in caring for their infant, several women stated they would have worries after the baby was discharged from the hospital. Seventy-four percent (n=40) said they would have worries, thirteen percent of the sample (n=7) indicated they would have no worries, and seven women stated they had mixed feelings about whether they would have worries or not. When asked what they would worry about, many concerns were communicated to the researcher. Many mothers in the sample (n=29, 53%) indicated they would worry about infant apnea and bradycardia at home:

> The breathing. If he has any irregularities breathing. He is going home on Theophylline.
>
> Its the bradys that I am going to worry about.
>
> ...also about will he have another apnea or brady?

Thirty percent of the subjects (n=16) stated they would have concerns about the infants condition and health.

> That the baby is gaining weight. That he is healthy.
>
> If he will gain weight. Also if he gets sick or has any setbacks.

I am concerned about her eyes and because she is so small.
...her back, she has to have an operation when she is about 2 months old.

...whether her hemoglobin is low...whether she has enough oxygen.

Eighteen percent (n=10) said they would worry about infant feeding.

The breastfeeding...how is she feeding?

About whether he will be able to feed and if he will get too tired when feeding.

...about feeding...is she getting enough.

Nine mothers worried about their ability to observe the infant closely enough at home.

...if I might miss something like if she has a temperature or if something might happen.

Scared and worried that I won't know what to do...I really don't know my baby's personality yet.

I will worry about missing any seizures she would have.

Five mothers worried sudden infant death syndrome (SIDS) would occur when the infant was at home.

The only worry I may have is with his apneas he may be at risk for crib death at home. He may have an apnea at home and I might not be there.

I will also worry about SIDS.

Two mothers expressed concern about monitors in the home for the infant. One mother worried about the monitor being in the home and the other mother worried that she didn't have a monitor at home. Only one mother indicated she would have worries

that related to her infant's circumcision, umbilical cord, and color when he cried.

Many of the mothers (n=35, 65%), when asked if problems arose at home with whom would they first discuss them, chose their spouse or partner. Twenty percent of the sample (n=11) chose their baby's pediatrician, four women stated they would first discuss problems after the baby's discharge with a close relative, and two mothers indicated they would contact the NICU or IMCN units. Only two women indicated they would contact the community health/public health nurse. Interestingly, sixty-eight percent (n=37) of the sample had met or had been contacted by the community health/public health nurse after the birth of their infant. Thirty-two percent (n=17) had not met or been contacted by the community health/public health nurse.

Basis of support for the mother after the baby was discharged home were explored with the subjects. The majority of the sample, (n=46; 85%), indicated they thought their spouse/partner would give them the most support. Thirteen percent (n=7) indicated a close relative, and one mother indicated the baby's pediatrician. No mother chose the community health/public health nurse as giving the most support to them when they took their baby home.

Recommendations To Mothers With Infants Admitted To Special Care Units

When asked what were the most important things mothers with infants just admitted to neonatal intensive care units needed to know, thirty percent (n=16) of study subjects responded that mothers required up to date, ongoing, continuous communication regarding their infants condition. They urged mothers to continually ask questions about their baby.

> I would tell her to ask lots of questions because they won't tell you unless you ask.
>
> Try to be kept up to date about "everything" that is going on with her baby.
>
> She needs to know what is happening with the baby.
>
> Don't settle for answers you don't understand. Don't be afraid to ask questions. I there is anything you want to know ask. Don't just walk away.

Fifty-four percent (n=29) of mothers wanted to reassure other mothers that their infants were receiving good care and the staff were competent to care for the baby.

> That everything will be OK and that the baby is in excellent care. The nurses are there every time the baby cries.
>
> To be assured that the doctors and nurses know what they are doing.
>
> Don't worry because the baby is in good hands. The nurses are fantastic with the babies. They treat the babies like their own.
>
> That the people who are taking care of her baby are extremely skilled. That the staff are used to taking care of the babies.
>
> One of the most important things is how well trained and supportive the staff in NICU is.

Nine mothers (17%) in the sample wanted to reassure new mothers with infants requiring special care that the equipment in NIC units was initially overwhelming, but not to be afraid.

> Don't be scared of the machines, they are there to help not to hinder.
>
> All the monitors mean something, they should ask questions about them so you can feel confident about the monitors instead of feeling fearful about them.

Seven subjects (13%) encouraged other mothers to love and care for her child and

to know the baby belongs to her.

> Don't be afraid to take responsibility for your baby as well as the nurses and doctors. You have a right to say what you think is good for your baby.
>
> That babies do know who their parents are.
>
> She needs to touch and love her baby. Its OK to love her baby.
>
> She should always remember that it is her baby. She is important and not to forget that this baby belongs to you despite how some of the nurses make you feel.

They also felt mothers needed reassurance that she was not alone, the ordeal would not last forever and there was always hope.

> That she is not alone and that it will work out and it will be OK.
>
> The baby is not going to be in for ever. It is going to get better.
>
> There is always hope.
>
> To have faith in the nurses and the doctors and God. They have answered our prayers.

<u>Suggestions to Improve Services in Neonatal Intensive Care For Infants and Their Families</u>

Forty-eight mothers (89%) responded with suggestions to improve the service for babies in special care units and their families. Only six mothers (11%) stated they could not think of any improvements that could be made.

Seventeen percent of the mothers (n=9) commented about lack of available parking spaces and the difficulty it posed in visiting their infant. They suggested special parking services be made available:

> The parking...its quite a hassle to park when you come here.
>
> You need improved parking--could there not be a sign to identify cars of parents with babies in NICU--sometimes you can't just visit your baby for 1 or 2 hours especially if they are very sick.

Improvements in parent orientation to neonatal intensive care units were a basic concern for most of the mothers. Mothers also felt parents should have up to date communication from the staff, similar to nurses reports.

> The charge nurse should meet parents at the door and greet us. She should say to parents "What name do you prefer to be called by?" Parents should be orientated to the unit and shown were to wash their hands--show them where the baby's nurse is. They need to know the phone number and need to know the rules and regulations.
>
> A simple orientation of what monitors are on your child and what it means when the monitors go off.
>
> Parents need to have an orientation to the unit and a booklet to help them understand what is going on. They need some orientation to the setting.
>
> Sometimes things aren't explained to the families--rules and things like that. It would have helped if they had explained the rules at the beginning such as washing your hands. Then you don't feel like a stranger or intruder when you visit your baby.
>
> There should be a "Parent's Report"...a 24 hour summary of the baby's condition and what's been going on. There should be a chart for the parents--maybe they can take it home.

Many mothers felt a support group for mothers and families with infants requiring neonatal intensive care would have been advantageous to share feelings and to provide support to each other.

> Having a place for parents to go and talk together in the hospital about what's happening to us...so that we can be supportive.

> Perhaps meeting other parents in the same situation would be helpful.
>
> They need a parent group with babies in IMC nursery. Talking to other parents who have gone home with monitors-what are their feelings?
>
> What would be helpful would be a mothers' support group. Nurses are wonderful but they haven't seen the other side of it. It would help to prepare you for what you are going through.

Mothers in the sample stated improvements could be made to facilitate privacy for parents and to promote family unity.

> Putting screens up--screen between cubicles would give parents a bit more privacy when holding the baby. It would also cut down on some of the distractions.
>
> They need more room in the IMC nursery. They need a private place for families. A play area for children would help.
>
> It would be nice to have somewhere private. Parents need a private place to take a break.
>
> My 10 year old could only visit once a week in IMC nursery. This was hard--maybe they could come in more frequently.
>
> In the IMC nursery it would help if siblings and other family could come in to see the baby. My older son is very upset he can't go in and touch her. He has to look through the window. He doesn't want to come to visit.
>
> If you had more people to come in to visit. Having the family to visit is very important. It really helps to have family support for the parents. And more frequent times for extended family--not just once a week.
>
> It would be helpful if there was accommodation for all of the family to stay together if they are from out of town.
>
> If there is someplace you can bring your other kids when you come to visit, so you don't have to leave them at a babysitter all the time.

Mothers expressed satisfaction and pleasure when nurses drew or took pictures and

wrote notes about the infants, placing them on the incubators. Mothers stated this action helped to improve the environment and made them feel good. Three mothers "roomed in" with their infant in preparation for discharge. They found this experience helpful and strongly recommended the opportunity be offered to other mothers.

Conclusion

Data obtained through qualitative and quantitative interview questions helped to identify mothers perceptions of the experience, what support was beneficial to them during their infant's stay and the support beneficial to them in preparation for their infant's discharge. Findings from the study and analysis of the data indicated that the experience of having a child in neonatal intensive care was frightening and at times a terrifying ordeal. Support or lack of support from nurses and significant others had a profound and far reaching effect on mothers and how they perceived the experience.

In the following chapter, study results and selected relevant research will be discussed. Implications for nursing and recommendations for future research will be presented.

CHAPTER SIX

DISCUSSION

In this descriptive study, the perceptions of mothers with an infant receiving neonatal intensive care were investigated. Mothers were asked their perception of the event, the support they perceived as beneficial or non-beneficial while their child was in NIC, and the support they perceived as beneficial or non-beneficial in preparing them for their baby's discharge home from NIC. In the following chapter, study findings will be discussed. Implications for nursing, study limitations, plans and suggestions for future research will be presented.

Perceptions of Mothers of Their Infants' Stay In An Neonatal Intensive Care Setting

For most of the mothers in this study, the experience of having an infant admitted to special care aroused feelings of fright, worry, and shock. Many of the mothers did not anticipate their baby's admission to neonatal intensive care. Mothers indicated they were devastated, traumatized, and apprehensive. These findings substantiate those of earlier studies (Choi, 1973; Cohen, 1982; Pederson et al., 1987; Jeffcoate et al., 1979).

Mothers' initial perceptions of the NIC units their baby were admitted to after birth, developed into three major categories: Many mothers were effected by: 1) the physical environment, 2) the emotional atmosphere created in the special care unit and, 3) by the number of ill infants requiring special care. Similar findings are documented by

Sammons and Lewis (1985). These authors found that mothers were greatly effected by: 1) the physical environment, 2) the emotional environment of NIC and, 3) the impact NIC had on the infant (Sammons & Lewis, 1985, p. 92). Miles and Carter (1983) also propose that NIC emotional and physical environments impact on parent's stress levels. However, in more recent research, Perehudoff (1990) found that generally, NIC environments caused parents relatively low levels of stress (p. 42). She hypothesizes that one of reasons for this is that parents are reassured when their infant is in NIC (Perehudoff, 1990). Twenty-two percent of the subjects in this study indicated that they were grateful there were NIC facilities available to give care to ill newborns after birth.

The literature documents that mothers who have infants admitted to NIC after birth have many worries and high levels of concerns (Gennaro et al., 1990; McCain, 1990; Perehudoff, 1990; Sammons & Lewis, 1985). Mothers in this study followed similar patterns. Thirty-eight percent of the mothers in the study worried about their infant's potential demise, while 44 percent worried about their baby's present health and condition. Mothers were also concerned about how the infant's illness and treatment instituted would effect the child's future health and development.

Alterations in attachment between mother and infant were reported in the present study. Mothers commented they did not feel connected to their infant until much later after the birth. Interestingly, some mothers avoided becoming too attached to their infant, fearing the child's demise, while other mothers actively strove to become attached to their infant, fearing without their concerted effort attachment might not have occurred. Comparable findings and observations have been documented in the literature (Klaus &

Kennel, 1982; Mercer, 1981; Siegel et al., 1989). Gennaro (1986) substantiated that mothers who have a child in neonatal intensive care experience heightened anxiety, regardless of type or severity of infant illness. Fear for the infant's ability to survive may be one reason for this increased anxiety. The feeling of fear for the infant's survival has been identified in previous research (Blackburn & Lowen, 1985; Harper et al., 1976; Jeffcoate et al., 1979; Perehudoff, 1990; Pederson et al., 1987).

Touch has long been associated with forming an attachment between mother and child (Blowby, 1969; Harrison & Woods, 1991; Klaus & Kennel, 1983; Mercer, 1977; Tomlinson, 1990). Skin to skin contact is one way of acquainting partners and promoting the attachment process (Klaus & Kennel, 1983). Some parents have been found to avoid touching ill infants for fear of causing injury or harm or because of the infant's fragile appearance (Harrison & Woods, 1991; Mercer, 1977; Minde et al., 1978). Although thirty-seven percent of the mothers indicated they initially felt they might break or harm the infant, most of the women after touching their infant found it to be pleasurable and enjoyable experience. This finding is comparable to those found by Harrison and Woods (1991). Only 24 percent of the mothers were extremely apprehensive about touching their infant and found it was a negative experience. For these mothers the child's appearance and response to their touch proved inhibitive. Other deterrents for mothers in touching their babies were the machinery and equipment utilized to care for the infant. Similar findings and observations have been documented by Harrison & Woods (1991), Mercer (1977) and Pederson et al. (1987). Miles (1989), Miles and Carter (1983) and Perehudoff (1990) also found that the equipment utilized for infant care were a source of stress for

parents.

Maternal participation in infant caregiving has been deemed as an important avenue in promoting parent-infant attachment while the infant is receiving intensive care (Klaus & Kennel, 1983, 1982; Mercer, 1981). Several women reported nursing encouragement and actual participation in caregiving activities facilitated maternal bonding with their infant. Additionally, mothers in this sample advised new mothers in a similar situation to actively seek inclusion in child caregiving activities. They advised mothers that their love and care was unique, important and special to their child. They reasoned that their child belonged to them and that they had responsibility to participate in care and make decisions.

Mothers' Perceptions of Support That Was Beneficial Or Non-Beneficial To Them While Their Child Was In Neonatal Intensive Care

Maternal involvement in infant care was important and desired by most of the subjects of this study. The mothers endeavored to maintain contact with their infant despite obstacles such as limited resources, other children at home, and long distances to travel. Previous research has shown that parents, although anxious about their infant's condition, perceived their visits made a difference in the infant's care and outcome (Brown et al., 1991; Harper et al., 1976; Zeskind & Iacino, 1984). Eighty-three percent of the sample visited their infant at least once a day, on an average of 139 minutes per visit. During their visits, mothers related that they sat and talked to their infant, played soft recorded music, participated in care, or looked at their child. During the interview,

mothers often would proudly display small toys placed on or in incubators, outfits they had made or pictures they had taken of the baby. Several authors have recommended that nurses encourage mothers in these same activities and attempts of becoming involved in the infant's care (Jacques, Amick & Richards, 1983; Mercer, 1977; Steele, 1987; Siegel et al., 1989; Thorton et al., 1984).

Women in this sample were greatly affected by the provision of beneficial or non-beneficial support from nurses and other health care professionals during their infant's stay in NIC. Support from health care professionals, particularly nurses, was exhibited by giving encouragement, providing emotional support, communicating, and assisting the mother to perform caregiving for her infant.

Maternal feelings of lack of control in infant care and difficulties in forming attachments with newborns are potentiated if the child is ill at birth (Pederson et al., 1987). Encouraging mothers to take part in infant care has been identified as one way of promoting parental adaptation to the event of a newborn requiring NIC (Blackburn, 1983; Klaus & Kennel, 1983, 1982; Jaques et al., 1983; Sammons & Lewis, 1985; Siegel et al., 1989). Interestingly, however, only sixty-three percent of the mothers in the sample perceived they were encouraged all or most of the time to take part in their infant's care. Thirty-seven percent of the mothers perceived their involvement in infant care was encouraged some of the time, rarely, or never. Almost half of the sample perceived the encouragement they received depended directly on the attitude and manner of the nurse.

Jeffcoate et al. (1979), indicate that parents of premature infants found support such as information giving, direction in infant care, and reassurance helpful (p. 350).

Siegel et al. (1989) suggests that welcoming parents to the special care unit helps to reduce parental stress. Sixty-eight percent of the women in this study acknowledged they had received beneficial support from nursing staff through the nurses' ability to answer their questions, give explanations, to create an atmosphere that welcomed them to the unit, give direction and allow them to perform infant care.

Mothers felt they received non-beneficial or negative support when they perceived the nurse as rejecting, non-encouraging, and inattentive to maternal concerns and emotional needs. Thirty-two percent of the subjects related feelings of being treated as an intruder, of being threatened, and being intimidated. These feelings may be, in part, due to mother's perception of the nurse functioning in the mother's envisioned role (Kelting, 1986). The mother may experience a sense of loss of control and anger about her inability to sustain and protect her infant (Consolvo, 1984; Steele, 1987).

Mothers were asked to state their level of satisfaction with the care they received from special care units and the care given to their infants. Generally, mothers were satisfied with the care they received from nurses working in special care nurseries, while they were very satisfied with care extended to their infants. Dissatisfaction or partial satisfaction with support and care received from nurses seemed to arise from the differences in practices between special care nurseries. The literature indicates that changes in environment and levels of care may precipitate parental anxiety (Sammons & Lewis, 1985; Steele, 1987). Recently, Koyotylo, Parker and Chapman (1991) investigated mothers' perceptions of their newborn infant's transfer between special care units. The researchers found that although mothers were relieved the infant's condition was

improving, they were dependent on familiarity with units and health care professionals, and were negative in perceptions of their "preparation for transfer" and continuity of care (Kolotylo et al., 1991, p. 146). Cagan (1988) attributes parental feelings of fear and stress when their child is transferred to different hospital units, to iatrogenic dependence of parents. She advises that nurses at times encourage parental dependence and feel the infant is "her baby" (Cagan, 1988, p. 277). Mothers in this study noticed dissimilarities between units such as different rules, regulations and policies, inconsistencies between nurses' manners and abilities, and parental privileges. Subjects also commented on different special care nurseries nurses' ability to observe and provide care for their infants. They appeared afraid, because the infant was transferred from one unit to another, that they and the child would not receive the same quality of care. Mothers also perceived nurses from different units were possessive of the baby. These findings confirm those of Kolotylo et al. (1991), and viewpoints expressed by Cagan (1988), Mercer (1977), Sammons and Lewis (1985), Steele (1987) and Thorton (1984).

Forty-eight percent of subjects were highly satisfied with the care and support provided to them by postpartum nurses to them after the birth of their infant. Fifty-two percent of the mothers were less than completely satisfied or dissatisfied. At times mothers felt they were an unwanted guest in the hospital after the birth of their infant. They also expressed displeasure at being placed in the same room as a mother with a normal newborn, and not receiving teaching or information about the baby. Previous findings on this aspect have been inconsistent. Siegel et al. (1989) advises some mothers may find it "too painful" at being placed in a room with a "normal" mother, while

Pederson et al. (1987) did not find mothers of ill infants were any more resentful of being placed in a room with other mothers and infants than mothers of well infants. Mercer (1977) advises that a mother's decision about room choices should be honored (p. 120).

The need of parents to have consistent, adequate, up-to-date information is identified throughout the literature (Kennedy, 1973; Mercer, 1977; Mercer, 1983; Miles, 1989; Ross, 1980; Steele, 1987; Thorton, 1984). Women in this study perceived that it was important to communicate and gain information about their infant. Eighty percent of the women felt they could approach nursing staff with their questions and concerns at anytime. Eighty-two percent indicated they were not told enough about their infant by special care nursing staff. Almost all of the mothers understood the information received and felt comfortable in asking for clarification if they did not understand. They did however, urge nurses to be more consistent when communicating with other nurses.

Miles (1989) found through research that certain nursing non-verbal behaviour and communication such as acting cold, distant, and worried could be interpreted by parents as negative and uncaring. This study confirms this finding as 32 percent of the mothers perceived the nurses non-verbal behaviour negatively. Non-verbal behaviour which was disturbing to parents in this study included nurses acting distant, cold, and impersonally, being unreceptive to communication attempts by mothers, or not acknowledging them and being abrupt in manner. Non-verbal behavior which was perceived by mothers as positive was touch provided in a comforting way, hugging, a welcoming manner, and a pleasant demeanour.

Subjects had more difficulty with physician communication. Although 67 percent

of the women felt they received enough information about their infant from physicians, 33 percent felt they did not. Twenty-four percent of the subjects had difficulty comprehending the information given to them by physicians and required further explanation. Thorton (1984) suggest that parents with children in neonatal intensive care have difficulty comprehending information during this stressful time. They "listen selectively" and do not always "absorb" information (Thorton, 1984, p.130). Also, parents may be more sensitive than health care professionals realize (Miles, 1989). Communication to parents must be given in a careful and sensitive manner (Siegel et al., 1989; Thorton, 1984). Mothers in this study wanted basic, up to date information about their baby. They appreciated being consulted in decision-making and wanted information in "layman's terms".

Many authors indicate fathers assume several roles when their infant is ill and receiving neonatal intensive care (Consolvo, 1984). Maternal partners have been identified as a source of support, although there is debate whether this support is always helpful to the mother (Mercer, 1983; Minde et al., 1980; Zarling et al., 1988). Levy-Shiff, Hoffman, Mogilner, Leninger and Mogilner (1990) found that fathers who visited often and participated in caregiving had more positive perceptions of their infants. Indirectly this also may be a beneficial means of support between parental partners (Levy-Shiff et al., 1990). Sexton and Stephen (1991) found, through research with grieving post-partum women, that the majority of mothers perceived nursing support helpful to fathers. In fact, some mothers expressed the desire for more support to be directed towards their partners by nurses than was provided (Sexton & Stephen, 1991).

Levy-Shiff, Sharir and Mogilner (1989) found that, initially mothers engaged in caregiving more than fathers when their infant required special care, but by discharge they participated in caregiving activities equally (p. 96). Seventy-two percent of mothers perceived their partner desired participation in infant care immediately or most of the time after infant admission to intensive care. Paternal participation in infant care was immediate for 59 percent of the fathers, while 32 percent of the fathers took an average of seven days to become participants in their child's caregiving activities. Nine percent took an average of 52 days. Consolvo (1984) contends that some fathers of sick infants may feel inadequate in comparison to highly skilled personnel in NIC (p. 29). This may account for the initial reluctance of fathers to become immediately involved in infant care.

Women in the study were appreciative and appeared to enjoy their partner's inclusion in infant care. When nurses did not include fathers in care or exhibited untoward non-verbal behavior, mothers perceived this as negative support and felt it inhibited their partner's attempts to become involved.

Although 69 percent of mothers were very satisfied with nursing care for family members, they verbalized discontent about the isolation they felt from family members. Feelings of isolation were mainly due to hospital visiting policies. This finding supports the research of Blackburn and Lowen (1986). These researchers found that parents strongly desired extended family participation, particularly grandparent visiting and contact, but perceived these family members were restricted by hospital policy in doing so (Blackburn & Lowen, 1986, p. 177).

Mothers' Perceptions Of Support That Was Beneficial Or Non-beneficial In Preparing Them For Their Baby's Discharge Home From NIC

Mothers in the sample experienced conflicting, powerful feelings when notified of impending infant discharge. Maternal feelings ranged from excitement, apprehension, to a mixture of ecstacy and fear. Similar results have been found in previous research (Brooten et al., 1988; Steele, 1987; McHaffie, 1990).

Many mothers related that they felt very confident to fairly confident in their ability to care for their infant after discharge. This was an fascinating finding, as only 58 percent of the sample perceived they had been very well or adequately prepared by nurses for their infant's discharge. The remaining 32 percent had received partial, very little or no preparation. The confidence in their ability to care for their infant and that "everything would be alright" after they took the infant home may be an example of McCarton's (1986) description of parental unrealistic expectations of special care babies after their discharge home. These mothers may have expected the infant to respond and "act" like a normal newborn after discharge, despite the severity of infant illness and limited development during hospitalization (McCarton, 1986).

Although generally confident in their ability to care for their infant, mothers indicated they would continue to have worries and concerns after discharge. Fifty-three percent of the sample indicated they would worry about infant apnea and bradycardia at home. Thirty percent of the subjects related they would worry about their baby's condition and health, while 18 percent thought they would have concerns regarding infant feeding. Mothers also worried they would not be able to observe their infant closely

enough or that SIDS would occur. Gennaro et al. (1990) and Butts, Brooten, Brown, Bakewell-Sachs, Gibbons, Finkler, Kumar and Delivoria-Papadapoulos (1988) similarly found that infant health was the most common concern of mothers after infant discharge. Specifically, one study showed that mothers worried about infant breathing and medical treatment (Gennaro et al., 1990). Duhamel et al. (1974) and Goodman and Sauve (1985) document maternal concern over SIDS and infant feeding. McCain (1990) describes parental concern about infant health and development. Butts et al. (1988) found that mothers were concerned about respiratory, gastronintestinal, feeding, and medical problems.

Almost all of the mothers indicated their partners would be their major source of support after infant discharge. This supports earlier findings by Mercer et al. (1986). Although they were being prepared for infant discharge, only 68 percent of the women in this sample had been contacted or met the community health nurse. This finding was interesting, as community health nurses have a major responsibility in providing support and follow-up care (Arenson, 1988; Casiro, Becker & McFadyen, 1989; Censullo, 1986; Couriel & Davies, 1988; Gennaro et al., 1991; Hampson, 1989; Mercer, 1977; Noga, 1982; Roberts, 1984; Secco, 1988; Shosenberg, 1980). Baker et al. (1989) argue that community health nurses "likely will be one of the most critical and utilized support services" for parents (p. 657). None of the women chose the community health nurse as a major source of support or primary avenue for problem solution.

Implications For Nursing

The implications and recommendations for nursing arising out of this study are fundamental and basic. For decades, nursing has been intimately involved in the care of infants that are ill and require neonatal intensive care (Blackburn, 1983; Turner, 1986). Through provision of highly skilled care, nurses have contributed to positive outcomes of sick infants (Aikens, 1907; Brooten et al., 1989). However, the provision of physical care is only part of the comprehensive care that must be provided for mother and infant in neonatal intensive care (Symanski, 1991). One of the most striking findings of this study was the degree of effect nurses had on parental feelings towards and about their infants, their family, themselves, and the event of having a child in NIC. Mothers indicated that how they felt and to some extent how they perceived their relationship with their infant, depended directly on the nurse. Nurses must be aware of the impact their care and provision of, or lack of, support has on parental lives. Direction for nurses in neonatal intensive care units should not only include how to support parents during this time (Kelting, 1986), but also the reasons why support is beneficial or non-beneficial to parents. Mothers must be individually consulted about their perceptions (Perehudoff, 1990) of the event of their baby being admitted to special care and what support they perceive as beneficial. Too often parental and nursing perspectives are incongruent (Symanski, 1991). Research has demonstrated that mothers' memories of this trying and often painful time can effect them for months (Affleck et al., 1990). Mothers have related that, in addition to painful rememberances of their infant's near demise and the difficulty in coping with the NIC experience, they also had lasting memories of difficulties with

NIC staff (Affleck et al., 1990, p. 77).

Blackburn and Lowen (1986) propose that nurses' roles in caring for infant's requiring special care and their families include 1) assisting parents to identify and contend with their feelings, 2) providing emotional support, 3) facilitating attachment and interaction between parent and child, and 4) preparing parents for their infant's discharge home (p. 170). Others indicate that nurses must act in an advocacy role (Penticuff, 1989; Thorton et al., 1984). Certainly there are several instances where nurses can and do fulfill these roles, as exemplified throughout the study. However, there are several areas that require further consideration. Suggestions from study subjects to improve services in NIC for infants and their families included:

1. Attention should be directed towards promoting the mothers' physical and emotional comfort during her hospitalization after the birth and her infant's stay in special care. Parents should be made to feel welcome, and nurses should be attentive to maternal physical and emotional needs (Siegel et al., 1989). Extreme care must be taken to avoid communicating to mothers that they are an enigma to hospitals (Cohen, 1982). Nurses should be attentive to ensuring privacy for parents (Steele, 1987). Practical information should be provided to parents, such as where to wash their hands, telephone numbers of the unit, and policies of the unit (Steele, 1987; Siegel et al., 1989). Parents in this study were very distressed when they were not informed of hospital "official and unofficial" rules and regulations. They wanted a parent orientation so they would feel less of an intruder or a stranger to the NIC unit. Perehudoff (1990) hypothesizes that one

of the reasons parents in her study reported relatively low levels of stress from the NIC environment, might be due to the comprehensive orientation to the unit they received from NIC staff (p. 42).

2. Provisions should be made for the mother to room-in before infant discharge home (Steele, 1987). Research has demonstrated mothers derive many benefits from this experience (Consolvo, 1986; Klaus & Kennel, 1982; Salitros, 1986; Steele, 1987; Thorton et al., 1984). Subjects in this studywho were provided with this opportunity were very positive and grateful.

3. A support group should be established for parents that have infants in special care. Support groups that include other parents, others that have experienced similar situations, nurses and health care team members can provide important emotional support and an avenue for the parent to ventilate feelings they may be reluctant to verbalize (Boukydis, 1982; Kelting, 1986; Klaus & Kennel, 1982; Minde et al., 1980; Sammons & Lewis, 1985; Shosenberg, 1980; Siegel et al., 1989).

4. Attention should be given to the difficulties parents face when they have a child in neonatal intensive care. Parents may experience several inconveniences and difficulties in visiting their infant in intensive care (Pederson et al., 1987; Siegel et al., 1989). Measures to minimize problems can be as basic and practical as ensuring parents have adequate parking facilities when visiting their infant. Parents often related how difficult it was to visit their child or to leave their infant, sometimes at critical moments, because of inadequate parking.

5. Hospital visiting policies for special care units should be re-evalutated (Blackburn

& Lowen, 1986). Mothers require support from significant others, especially during their infant's stay in neonatal intensive care (Blackburn & Lowen, 1986). Visiting hours should be liberal, flexible and include all family members (Klaus & Kennel, 1982; Miles & Carter, 1983; Pederson et al., 1987; Thorton et al., 1984). As evidenced by data in this study, mothers perceived present visiting policies inhibitive and isolating, limiting the support they received from family members.

6. There should be clarification of the community health nurses' role after discharge of the infant from hospital. Turner (1986) contends that "it is not clear to what extent" community nursing support reduces problems or mothers' stress (p. 167). Presently, there is limited knowledge about parental perceptions of the community health nurses' role after infant discharge from special care (Luker & McLoughlin, 1988). As previously discussed, many mothers in this study had not been contacted or met the community health nurse, even though they were being prepared for infant discharge. The community health nurse was not anticipated by subjects to be a source of support or avenue for future problem solution.

Study Limitations

The limitations of this study are related to the type of sampling used to obtain subjects, sample size, and study subject selection criteria.

Wilson (1985) indicates that convenience sampling limits the generalizability of study findings and reduces the possibility of the sample exemplifying the actual

population. Convenience sampling was used in this study, therefore the study results are not generalizable. The subjects in this study were educated, caucasian women who lived with partners or husbands. Only one subject was not causcasian, and the sample did not include any single parents.

Another limitation arises from the relatively small sample size. Increasing sample size in studies increases the power of statistical measures applied to the data (Wilson, 1985). The sample size for this study was only 54 subjects.

All of the subjects lived within 160 kilometers of the city of Winnipeg, spoke English, and had a telephone in their residence. The study did not include subjects living in remote Manitoba regions, or rural areas more than 160 kilometers of Winnipeg. Also mothers who did not speak English and did not have telephones were not included. The deletion of these subjects may have potentiated the possibility of receiving incomplete information about the perceptions of mothers regarding their infant's stay in NIC. Data from this study could not answer questions such as: Do none caucasian, single, non-educated women who live more than 160 kilometers from the city of Winnipeg, or do not have a telephone have the same or different perceptions from the mothers of this sample?

Future Research

Plans are to continue the collaborative research study after thesis requirements are met. For those who participate, collaborative research can provide a variety of resources, a development of collegiality, an opportunity to conduct intersite (international and local) research, and direction for the novice researcher by more experienced

researchers (Beaton, 1990; Hagle, M., Barbour, L., Flynn, B., Kelley, C., Trippon, M., Braun, D., Beschorner, J., Boxler, J., Hange, P., McGuire, D., Bressler, L. & Kirchhoff, K., 1987; Sprague-McRae, J., 1988). Funding has been received from St. Boniface Hospital Foundation by a collaborative group to conduct Phase III of the project. This phase, designed by Luker and McLoughlin (1990), will examine the support received by the same mothers, when their child reaches one year of age (Bramadat, Saydak & Hamelin, 1991).

Attention has been given to continuing the longitudinal project with future phases of the study. Mothers in this study could be interviewed when their child reaches school age and middle childhood as there is documented evidence that children who required NIC at birth and their families continue to experience difficulty, even as the child grows older (Eilers et al., 1986; Hunt et al., 1988).

Other research that should be contemplated are studies that include the nurses' perspective during the infant's stay in NIC (Secco, 1988). At present the project concentrates on obtaining maternal perspectives, however it would be helpful to obtain perspectives of the supportive others involved (Blackburn & Lowen, 1986; Perehudoff, 1990; Secco, 1988), and compare them to the mother's. Nurses from special care units and postpartum units could be interviewed about the support mothers require while their infant is in NIC, and to see if they are aware of the mother's feelings about the event and the support they require at that time. Of particular importance is a research study to determine why there is less maternal satisfaction with postpartum nursing care while a infant is in NIC. Additionally, nurses in the community should be interviewed to

determine their level of understanding of maternal perspectives and requirements for support during preparation for discharge and after the infant is discharged home (Samson, 1989; Secco, 1988). Further research is needed to determine what contribution community health nurses make to the care of parents and infants that required special care (Turner, 1986, p. 167).

Research has indicated that maternal support systems influence maternal-infant attachment development (Crittenden, 1985; Mercer, 1981; Mercer, 1983; Klaus & Kennel, 1983; Klaus & Kennel, 1982). Blackburn and Lowen (1986) advise that extended family and significant others also had strong emotional reactions to the birth of a child that requires special care. They found that various family members may differ in their ability to support others and in the support they themselves require (Blackburn & Lowen, 1986). Perehudoff (1990) indicates that parents differ in their perception of some aspects of the NIC experience. Interviewing significant others at the same time as the mothers are interviewed would ascertain their feelings about the situation and provide information on how they could be supported and how they support the mother during their infant's stay in special care (Blackburn & Lowen, 1986; Perehudoff, 1990).

Conclusion

The event of a child requiring neonatal intensive care can have several long lasting effects and repercussions (Affleck et al., 1990). Mothers in this study verbalized strong and powerful feelings regarding the event. Subjects were specific and definite about what support was beneficial and non-beneficial during infant hospitalization and preparation for

discharge. Nurses, during mothers' and infants' hospital stay, play a fundamental role in providing maternal support and supporting significant others (Perehudoff, 1990; Thorton et al., 1984). Findings from this study substantiate this nursing role. Data from this research will aid in continuing to educate nurses about mothers who have infants requiring special care and their function in supporting these parents. Additionally, this study provides the basis for continued research into maternal perceptions of support mothers receive in the community following discharge of the infant from neonatal intensive care.

REFERENCES

Affleck, G., Tennen, H., Allen, D., & Gershman, K. (1986). Perceived social support and maternal adaptation during the transition from hospital to home care of high-risk infants. Infant Mental Health Journal, 7(1), 6-18.

Affleck, G., Tennen, H., Rowe, J., & Higgins, P. (1990). Mothers' remembrances of newborn intensive care: A predictive study. Journal of Pediatric Psychology, 15(1), 67-81.

Affleck, G., Tennen, H., Rowe, J., Roscher, B., & Walker, L. (1989). Effects of formal support on mothers' adaptation to the hospital-to-home transition of high-risk infants: The benefits and costs of helping. Child Development, 60, 488-501.

Als, H., Lester, B., & Brazelton, T. (1979). Dynamics of the behavioral organization of the premature infant: A theoretical perspective. In Field, T. (Ed.), Sostek, A., Goldberg, S., & Shumna, H. (Co-Eds.), Infants Born at Risk: Behavior and Development. New York: Spectrum Publications.

Aikens, C. (1907). The care of the premature baby. Canadian Nurse, 3(11), 593-595.

Arenson, J. (1988). Discharge teaching in the NICU: The changing needs of nicu graduates and their families. Neonatal Network, 6(4), 29-52.

Avant, K. (1981). Anxiety as a potential factor affecting maternal attachment. JOGNN, 10(6), 416-419.

Avard, D. (1986). Special care for neonates: No longer a sideshow. Dimensions, (April), 22-23.

Aylward, G., Pfeiffer, S., Wright, A., & Verhuist, S. (1989). Outcome studies of low birth weight infants published in the last decade: A metaanalysis. Journal of Pediatrics, 115(4), 515-520.

Baker, K., Kuhlmann, T., & Magliaro, B. (1989). Homeward Bound: Discharge teaching for parents of newborns with special needs. Nursing Clinics of North America, 24(3), 655-664.

Barnard, K., Hammond, M., Sumner, G., Kang, R., Johnson-Crowley, N., Snyder, C., Speitz, A., Blackburn, S., Brandt, P., & Magyary, D. (1987). Helping parents with preterm infants: Field test of a protocol. Early Child Development and Care, 27, 255-290.

Bauchner, H., Brown, E., & Peskin, J. (1988). Premature graduates of the newborn intensive care unit: A guide to followup. The Pediatric Clinics of North America, 35(6), 1207-1226.

Beaton, J. (1990). Crises in graduate nursing education. Canadian Nurse, 86(1), 29-32.

Beaton, J. (1984). A systems model of premature birth: Implications for neonatal care. JOGNN, 13(3), 173-177.

Bennett, D., & Slade, P. (1991). Infants born at risk; Consequences for maternal post-partum adjustment. British Journal Of Medical Psychology, 64, 159-172.

Belsky, J. (1984). The determinates of parenting: A process model. Child Development, 55, 83-96.

Blackburn, S. (1983). Fostering behavioral development of high-risk infants. JOGNN, 12(3),76s-86s.

Blackburn, S., & Lowen, L. (1986). Impact of an infant's premature birth on the grandparents and parents. JOGNN, 15(2), 173-179.

Blehar, M., Leiberman, A., & Ainsworth, M. (1977). Early face-to-face interaction and its relation to later infant-mother attachment. Child Development, 48, 182-194.

Blishen, B., & McRoberts, H. (1976). A revised socioeconomic index for occupations in Canada. Canadian Review of Sociology And Anthropology, 13(1), 71-79.

Blumberg, N. (1980). Effects of neonatal risk, maternal attitude, and cognitive style on early postpartum adjustment. Journal of Abnormal Psychology, 89(2), 139-150.

Boger, R., & Smith, A. (1986). Developing parental skills: An holistic, longitudinal process. Infant Mental Health Journal, 7(2), 103-111.

Boukydis, Z. (1982). Support groups for parents with premature infants in NICUs. In R. Marshall, C. Kasman, & L. Cape, (Eds.). Coping With Caring For Sick Newborns. Philadelphia: W. B. Saunders.

Bowlby, J. (1969). Attachment and loss: Volume 1: Attachment. New York: Basic Books.

Bowlby, J. (1988). A secure base: Parent-child attachment and healthy human development. New York: Basic Books.

Boxall, J., & Whitby, C. (1983). The role of the nurse in mother-baby interaction. In J. Davis, M. Richards, & N. Roberton, (Eds.). Parent-Baby Attachment In Premature Infants. New York: St. Martins Press.

Brady-Fryer, B. (1989). Mother-preterm infant relationships in the NICU. AARN, 45(1), 16-18.

Bramadat, I., Saydak, M., & Hamelin, K. (1991). Mothers perceptions of support following discharge of an infant from Neonatal Intensive Care. Proposal to St. Boniface Hospital Foundation.

Brazelton, T. B. (1981). On becoming a family: The growth of Attachment. New York: Delacorte Press.

Brimblecombe, F. (1983). Evolution of special care baby units. In J. Davis, M. Richards, & N. Roberton, (Eds.). Parent-Baby Attachment In Premature Infants. New York: St. Martins Press.

Brodish, M. (1982). Relationship of early bonding to initial infant feeding patterns in bottle-fed newborns. JOGNN, 11(4), 248-252.

Brooten, K., Gennaro, S., Brown, L., Butts, Gibbons, A., Bakewell-Sachs, S., & Kumar, S. (1988). Anxiety, depression, and hostility in mothers of preterm infants. Nursing Research, 37(4), 213-216.

Brooten, K., Gennaro, S., Knapp, H., Brown, L., & York, R. (1989). Clinical specialist pre- and postdischarge teaching of parents of very low birth weight infants. JOGNN, 18(4), 316-322.

Brooten, D., Kumar, S., Brown, L., Butts, P., Finkler, S, Bakewell-Sachs, S., Gibbons, A., & Delivoria-Papadopoulos, M. (1986). A randomized clinical trial of early hospital discharge and home follow-up of very-low-birth-weight infants. The New England Journal of Medicine, 315(15), 934-939.

Brown, L., Brooten, D., Kumar, S., Butts, P., Finkler, S., Bakewell-Sacks, S., Gibbons, A., & Delivoria-Papadapoulos, M. (1989). A sociodemographic profile of families of low birthweight infants'. Western Journal of Nursing Research, 11(5), 520-532.

Brown, L., Gennaro, S., York, R., Swinkles, K., & Brooten, D. (1991). VLBW Infants: Association between visiting and telephoning and maternal and infant outcome measures. Journal of Perinatal and Neonatal Nursing, 4(4), 39-46.

Bryce, R., Stanley, F., & Enkin, M. (1988). The role of social support in the prevention of preterm birth. Birth, 15(1), 19-23.

Butts, P., Brooten, D., Brown, L., Bakewell-Sachs, S., Gibbons, A., Finkler, S., Kumar, S., & Delivoria-Papadapoulos, M. (1988). Concerns of parents of low birthweight infants following hospital discharge: A report of parent-initiated telephone calls. Neonatal Network, 7(2), 37-42.

Cagan, J. (1988). Weaning parents from intensive care unit care. MCN, 13(4), 275-277.

Casiro, O., Becker, C., & McFayden, L. (1988). Shortened hospital stay for low birth weight infants: A demonstration project.

Censullo, M. (1986). Home care of the high-risk newborn. JOGNN, 15(2), 146-153.

Chapman, J. (1984, Summer). Longitudinal follow-up of prematurely born children: Outcomes of home stimulation programme to age four-a preliminary analysis. Nursing Papers, 16(2), 49-65.

Chapman, J. (1980). Potential of the premature infant: A 1980 perspective. Toronto: Author.

Chapman, J. (1978). The effect of pre-term infants' decreasing mortality on their future morbidity: Preliminary examination of long-term outcomes of stimulation programs for pre-term infants. Nursing Papers, 10(3), 31-54.

Choi, M. (1973). A comparison of maternal psychological reactions to premature and full-size newborns. Maternal-Child Nursing Journal, 2, 1-13.

Cochran, M., & Brassard, J. (1979). Child development and personal social networks. Child Development, 50, 601-616.

Cohen, M. (1982). Parents' reactions to neonatal intensive care. In Marshal, R., Kasman, C., & Cape, L. (Eds.). Coping and Caring. Philadelphia: Saunders.

Couriel, J., & Davies, P. (1988). Costs and benefits of a community special care baby service. British Medical Journal, 296, 1043-1046.

Consolvo, C. (1986). Relieving parental anxiety in the care-by-parent unit. JOGNN, 15(2), 154-159.

Consolvo C. (1984). Nurturing the fathers of high-risk newborns. Neonatal Network, 2(6), 27-30.

Cranley, M. (1981). Development of a tool for the measurement of maternal attachment during pregnancy. Nursing Research, 30(5), 281-284.

Crittenden, P. (1985). Social networks, quality of child rearing, and child development. Child Development, 56(2), 1299-1313.

Crnic, K., Greenberg, M., Ragozin, A., Robinson, N., & Basham, R. (1983). Effects of stress and social support on mothers and premature and full-term infants. Child Development, 54(1), 209-217.

Croft, C. (1982). Lamaze childbirth education: Implications for maternal-infant attachment. JOGNN, 11(5), 333-336.

Curry, M. (1983). Variables related to adaptation to motherhood in normal primiparous women. JOGNN, 12(2), 115-120.

Davies, C. (1987). He's not my baby any more: Care of the critically ill infant and family support. Nursing Mirror, 3 (13), 498-502.

Dizon, M. (1984). The use of attachment theory in a clinical situation: Secure attachment, anxious attachment. Journal of Psychosocial Nursing, 22(3), 27-30.

Dormire, S., Strauss, S., & Clarke, B. (1989). Social support and adaptation to the parent role in first-time adolescent mothers. JOGNN, 18(4), 327-337.

DuHamel, T., Lin, S., Skelton, A., & Hantke, C. (1974). Early parental perceptions and the high risk neonate. Clinical Pediatrics, 13(12), 1052-1056.

Dunst, C., & Trivette, C. (1986). Mediating influences of social support: Personal, family, and child outcomes. American Jouranl Of Mental Deficiency, 90(4), 403-416.

Egeland, B., & Farber, E. (1984). Infant-mother attachment: Factors related to its development and changes over time. Child Development, 55, 753-771.

Elliot, M. (1983). Maternal infant bonding: Taking stock. Canadian Nurse, 79(8), 28-31.

Eilers, B., Deai, N., Willson, M., & Cunningham, M. (1986). Classroom performance and social factors of children with birth weights of 1,250 grams or less: Follow-up at 5-8 years of age. Pediatrics, 77(2), 203-208.

Failla, S., & Jones, L. (1991). Familes of children with developmental disabilities: An examination of family hardiness. Research In Nursing And Health, 14(1), 41-50.

Field, T. (1982). Interaction coaching for high-risk infants and their parents. In H. Moss, R. Hess, & C. Swift (Eds.). Early Intervention Programs for Infants, 1(4). New York: Hawthorne Press.

Ferrara, T., Hoekstra, R., Gaziano, E., Knox, G., Couser, R., & Fangman, J. (1989). Changing outcome of extremely premature infants (<26 weeks' gestation and <750 gm): Survival and follow-up at a tertiary center. American Journal of Obstetrics and Gynecology, 161(5), 1114-1118.

Fleischman, A. (1986). The immediate impact of the birth of low birth weight infant on the family. Zero to Three, 6(4), 1-2.

Gaffney, K. (1986). Maternal-fetal attachment in relation to self concept and anxiety. Maternal-Child Nursing Journal, 15(2), 91-101.

Gardner, J., & Karmel, B. (1983). Attention and arousal in preterm and full-term neonates. In T. Field, & A. Sostek (Eds.). Infants Born At Risk: Physiological, Perceptual, and Cognitive Processes. Toronto: Grune & Stratton.

Gay, J. (1981). A conceptual framework of bonding. JOGNN, 10(6), 440-444.

Gennaro, S. (1991). Facilitating parenting of neonatal intensive care graduate. Journal of Perinatal and Neonatal Nursing, 4(4), 55-61.

Gennaro, S. (1988). Postpartal anxiety and depression in mothers of term and preterm infants. Nursing Research, 37(2), 82-85.

Gennaro, S. (1986). Anxiety and problem-solving ability in mothers of premature infants. JOGNN, 15(2), 160-164.

Gennaro, S. (1985). Maternal anxiety, problem-solving ability, and adaptation to the premature infant. Pediatric Nursing, 11(5), 343-348.

Gennaro, S., Brooten, D., & Bakewell-Sachs, S. (1991). Postdischarge services for low-birth-weight infants. JOGNN, 20(1), 29-36.

Gennaro, S., Zukowsky, K., Brooten, D., Lowell, L, & Visco, A. (1990). Concerns of mothers of low birthweight infants. Pediatric Nursing, 16(5), 459-462.

Goldberger, J. (1990). Lengthy or repeated hospitalization in infancy. Clinics in Perinatolgy, 17(1), 197-206.

Goodman, J., & Sauve, R. (1985). High risk infant: concerns of the mother after discharge. Birth, 12(4), 235-242.

Goyco, P., & Beckerman, R. (1990). Sudden infant death syndrome. Current Problems in Pediatrics, 20(6), 299-340.

Grassi, L. (1988). Life, money, quality: The impact of regionalization on perinatal/neonatl intensive care. Neonatal Network, 6(4), 53-58.

Gross, D., Rociassano, L., & Roncoli, M. (1989). Maternal confidence during toddlerhood: Comparing preterm and fullterm groups. Research In Nursing and Health, 12(1), 1-9.

Hack, M., & Fanaroff, A. (1989). Outcomes of extremely-low-birth-weight infants between 1982 and 1988. New England Journal of Medicine, 321(24), 1640-1647.

Hack, M., Fanaroff, A., & Merkatz, I. (1979). The low-birth-weight infant: Evolution of a changing outlook. New England Journal of Medicine, 301(21), 1162-1165.

Hagle, M., Barbour, L., Flynn, B., Kelley, C., Trippon, M., Braun, D., Beschorner, J., Bosler, J., Hange, P., McGuire, D., Bressler, L., & Kirchhoff. (1987). Research collaboration among nurse clinicians. Onocology Nursing Forum, 14(6), 55-59.

Hamelin, K. (1991). A descriptive study of the formal and informal support received by parent who have had an infant in a neonatal intensive care unit. Unpublished Master's Thesis: University of Manitoba.

Hampson, S. (1988). Nursing interventions for the first three postpartum months. JOGNN, 18(2), 116-122.

Harper, R., Sia, C., Sokal, S., & Sokal, M. (1976). Observations on unrestricted parental contact with infants in the neonatal intensive care unit. The Journal of Pediatrics, 89(3), 441-445.

Harrison, H. (1984). Premature care: Past and present. Support Lines, Winter, 1, 5-7, 13.

Harrison, L., & Twardosz, S. (1986). Teaching mothers about their preterm infants. JOGNN, 15(2), 165-171.

Harrison, L., & Woods, S. (1991). Early parental touch and preterm infants. JOGNN, 20(4), 299-306.

Heaman, M. (1987). Life stress, social support,and mood disturbance in hospitalized and non-hospitalized women with pregnancy-induced hypertension. Unpublished Master's Thesis: University of Manitoba.

Hernadez, J., Offutt, J., & Butterfield, L. (1986). The cost of care of the less-than-1000-gram infant. Clinics in Perinatology, 13(2), 461-476.

Honig, A., Caldwell, B., & Richmond, J. (1986). Infancy intervention: Historical perspectives. Early Child Development and Care, 26, 89-93.

Hunt, J., Cooper, B., & Tooley, W. (1988). Very low birth weight infants at 8 and 11 years of age: Role of neonatal illness and family status. Pediatrics, 82(4), 596-603.

Hunt, J., Tooley, W., & Harvin, D. (1982). Learing disabilities in childrenwith birth weights <1500 grams. Seminars in Perinatology, 6(4), 280-287.

Jacques, N., Amick, J., & Richards, M. (183). Parents and the support they need. In J. Davis, M. Richards, & N. Roberton, (Eds.). Parent-Baby Attachment In Premature Infants. New York: St. Martins Press.

Jeffcoate, J., Humphrey, M., & Lloyd, J. (1979). Disturbance in parent-child relationship following preterm delivery. Developmental Medicine And Child Neurology, 21, 344-352.

Jenkins, R., & Tock, M. (1986). Helping parents bond to their premature infant. MCN, 11(1), 32-34.

Jenkins, R., & Westhus, N. (1981). The nurse role in parent-infant bonding: Overview, assessment, intervention. JOGNN, 10(2), 114-118.

Klaus, M., & Kennel, J. (1983). Bonding: The beginning of parent-infant attachment. St. Louis: C. V. Mosby.

Klaus, M., & Kennel, J. (1982). Interventions of the premature nursery: Impact on development. Pediatric Clinics of North America, 29(5), 1263-1273.

Kelting, S. (1986). Supporting parents in the NICU. Neonatal Network, 4(6), 14-18.

Kemp, V. (1987). Mothers; perceptions of children's temperament and mother-child attachment. Scholarly Inquiry for Nursing Practice: An Internation Journal, 1(1), 51-68.

Kemp V., & Page, C. (1987). Maternal prenatal attachment in normal and high-risk pregnancies. JOGNN, 16(3), 179-184.

Kennedy, J. (1973). The high-risk maternal-infant acquaintance process. Nursing Clinics of North America, 8(3), 549-556.

Kolotylo, C., Parker, N, & Chapman, J. (1991). Mothers' perceptions of their neonates' in-hospital transfers from a neonatal intensive care unit. JOGNN, 20(2), 146-153.

Lee, K., Gartner, L., Paneth, N., & Tyler, L. (1982). Recent trends in neonatal mortality: The Canadian experience. Canadian Medical Journal, 126(4), 373-376.

Levene, M. I., & Dubowitz, L. (1982). Low birth weight babies: Long-term follow-up. British Journal of Hospital Medicine.

Levy-Shiff, R., Hoffman, M., Mogilner, S., Levinger, S., & Mogliner, M. (1990). Fathers' hospital visits to their preterm infants as a predictor of father-infant relationship and infant development. Pediatrics, 86(2), 289-293.

Levy-Shiff, R., Sharir, H., & Mogliner, M. (1989). Mother-and father-preterm infant relationship in the hospital preterm nursery. Child Development, 60(1), 93-102.

Lipsett, L., & Field, T. (1981). Infant behavior and development: Perinatal risk and Newborn Behavior. New Jersey: Ablex.

Luker, K. A. (1989). Personal communication.

Luker, K. A., McLoughlin, A. M. (1988). A descriptive study of the formal and informal support received by parents who have had an infant in a neonatal intensive care unit. Sanford Health Authority Application For Ethical Consideration Of A Research Project, 1-14.

Magyary, D. (1984). Early social interactions: Preterm infant-parent dyads. Issues in Comprehensive Pediatric Nursing, 7, 233-254.

Marecki, M., Wooldridge, P., Dow, A., Thompson, J., & Lechner-Hyman, C. (1985). Early sibling attachment. JOGNN, 14(5), 418-423.

McCain, G. (1990). Parenting growing preterm infants. Pediatric Nursing, 16(5), 467-469.

McCarton, C. (1986). The long-term impact of a low birth weight infant on the family. Zero to Three, 6(4), 6-10.

McCormick, M. (1989). Long-term follow-up of infants discharged from neonatal intensive care units. Journal of The American Medical Association, 261(12), 1767-1772.

McCormick, M., Stemmler, M., Bernbaum, J., & Farran, A. (1986). The very low birth weight transport goes home: Impact on the family. Journal of Developmental and Behavioral Pediatrics, 7(4), 217-223.

McHaffie, H. (1990). Mothers of very low birthweight babies: How do they adjust? Journal of Advanced Nursing, 15, (1), 6-10.

McLoughlin, A. (1988). Sudden infant deaths in Tameside. Health Visitor, 61, 235-237.

Mercer, R. (1981). A theoretical framework for studying factors that impact on the maternal role. Nursing Research, 30(2), 73-77.

Mercer, R. (1983). Parent-infant attachment. In L.Sonstegard, K. Kowalski, & B. Jennings (Eds.), Women's Health: Volume II: Childbearing (Chapter 2 pp. 17-42). New York: Grune & Straton.

Mercer, R. (1977). Nursing care for parents at risk. Thorofare: C. B. Slack.

Mercer R., & Ferketich, S. (1988). Stress and social support as predictors of anxiety and depression during pregnancy. Advances in Nursing Science, 10(2), 26-39.

Mercer, R., May, D., & Ferketich, S. (1988). Theoretical models for studying the effect of antepartum stress on the family. Nursing Research, 35(6), 339-346.

Miles, M. (1989). Parents of critically ill premature infants: Sources of stress. Critical Care Nursing Quarterly, 12(3), 69-74.

Miles, M., & Carter, M. (1983). Assessing parent stress in intensive care units. MCN, 8(5), 354-359.

Minde, K., Marton, P., Manning, D., & Hines, B. (1980). Some determinants of mother-infant interaction in the premature nursery. Journal Of The American Academy Of Child Psychiatry, 19(1), 1-21.

Minde, K., Shosenberg, N., Marton, P., Thompson, J., Ripley, J., & Burns, M. (1980). Self-help groups in a premature nursery-A controlled evaluation. Journal of Pediatrics, 96(5), 933-939.

Minde, K., Trehub, S., Corter, C., Boukydis, C., Celhoffer, L., & Marton, P. (1978). Mother-child relationships in the premature nursery: An observational study. Pediatrics, 61(3), 373-352.

Mitchell, S., & Najak, Z. (1989). Low-birthweight infants and rehospitalization: What's the incidence. Neonatal Network, 8(3), 27-30.

Moore, M. (1983). Realities in childbearing (2nd Ed.). Philadelphia: W. B. Saunders.

Murray, E. (1929). Care of the premature infant. Canadian Nurse, 25(10), 605-606.

Nelson, S. (1985). Attachment theory. Nurse Practitioner, 10(8), 34-36.

Noga, K. (1982). High-risk infants: The need for nursing follow-up. JOGNN, 11(2), 112-115.

Nurcombe, B., Howell, D., Rauh, V., Teti, D., Ruoff, P., & Brennan, J. (1984). An intervention program for mothers of low-birthweight infants: Preliminary results. Journal of the American Academy of Child Psychiatry, 23(3), 319-325.

Parke, R., & Tinsley, B. (1982). The early environment of the at-risk infant: Expanding the social context. In D. Bricker (Ed.), Intervention With At-Risk And Handicapped Infants: From Research To Application. Baltimore: University Park Press.

Pederson, D., Bento, S., Chance, G., Evans, B., & Fox, A. (1987). Maternal emotional responses to preterm birth. American Journal Of Orthopsychiatry, 57(1), 15-21.

Penticuff, J. (1989). Infant suffering and nurse advocacy in neonatal intensive care. Nursing Clinics of North America, 24(4), 987-997.

Perehudoff, B. (1990). Parents' perceptions of environmental stressors in the special care nursery. Nenatal Network, 9(2), 39-44.

Perrin, E., West, P. & Culley, B. (1989). Is my child normal yet? Correlates of vulnerability. Pediatrics, 83(3), 355-363.

Pinch, W., & Spielman, M. (1989). Ethical decision making for high-risk infants. Nursing Clinics Of North America, 24(4), 1017-1023.

Polit, D., & Hungler, B. (1987). Nursing research: Principles and methods (3rd Edition). London: J. B. Lippincott.

Priel, B., & Kantor, B. (1988). The influence of high-risk pregnancies and social support systems on maternal perceptions of the infant. Infant Mental Health Journal, 9(3), 235-244.

Richards, M. (1983). Parent-child relationships: Some general considerations. In J. Davis, M. Richards, & N. Roberton, (Eds.). Parent-Baby Attachment In Premature Infants. New York: St. Martins Press.

Roberts, S. (1984). Social support-meaning, measurement, and relevance to community health nursing practice. Public Health Nursing, 1(3), 158-167.

Ross, G. (1980). Parental responses to infants in intensive care: The separation issue reevaluated. Clinics in Perinatology, 7(1), 47-60.

Rubin, R. (1984). Maternal identity and the maternal experience. New York: Springer.

Rutledge, D., & Pridham, K. (1987). Postpartum mothers' perceptions of competence for infant care. JOGNN, 16(3), 185-194.

Saigal, S., Rosenbaum, P., Stoskopf, B., & Milner, R. (1982). Follow-up of infants 501 to 1,500gm birth weight delivered to residents of a geographically defined region with perinatal intensive care facilities. Journal of Pediatrics, 100(4), 606-613.

Saigal, S. Rosenbaum, P. Stoskopf, B., & Sinclair, J. (1984). Outcome in infants 501-1000 gm birth weight delivered to residents of the McMaster Health Region. Journal of Pediatrics, 105(6), 969-976.

Salitros, P. (1986). Transitional infant care: A bridge to home for high-risk infants. Neonatal Network, 4(4), 35-41.

Sammons, W., & Lewis, J. (1985). Premature babies: A different beginning. St. Louis: C. V. Mosby.

Samson, L. (1989). Perinatal outreach education: Linking hospital and community in the care of high-risk infants. Journal of Perinatal and Neonatal Nursing, 2(3), 51-57.

Saydak, M. (1990). The perceptions of mothers with an infant receiving neonatal intensive care: A descriptive study: Phase one. Proposal for Ethical Review: Ethical Review Committee of the School of Nursing, University of Manitoba.

Schraeder, B. (1986). Developmental progress in very low birth weight infants during the first year of life. Nursing Research, 35(4), 237-242.

Seashore, M., Leifer, A., Barnett, C., & Leiderman, P. (1973). Effects of denial of early mother-infant interaction on maternal self-confidence. Journal of Personality and Social Psychology, 26(3), 369-375.

Secco, L. (1988). Investigation of the effects of a home-based nursing intervention on mother-premature infant interaction behavior and maternal feelings of competence. Unpublished Masters Thesis.

Sexton, P., & Stephen, S. (1991). Postpartum mothers' perceptions of nursing interventions for perinatal grief. Neonatal Network, 9(5), 47-51.

Siegel, R., Gardner, S., & Merenstein, G. (1989). Families in crisis: Theoretical and practical considerations. In G. Merenstein & S. Gardner (Eds.), Handbook Of Neonatal Intensive Care (2nd Edition). St. Louis: C. V. Mosby.

Shosenberg, N. (1980). Self-help groups for parents of premature infants. Canadian Nurse, 76(7), 30-34.

Sloan, J. (1990). Personal communication.

Sims-Jones, N. (1986). Back to the theories: Another way to view mothers of prematures. MCN, 11(6A), 394-397.

Spinner, M. (1978). Maternal-infant bonding. Canadian Family Physician, 24(11), 1151-1153.

Sprague-McRae, J. (1988). Nurse practitioners and collaborative interdisciplinary research roles in an HMO. Pediatric Nursing, 14(6), 503-508.

Stainton, C. (1986). Parent infant bonding. Dimensions, (April), 19-20.

Statistics Canada. (1990). Health reports: Supplement 14. 2(1), Ottawa: Minister of Industry, Science and Technology.

Statistics Canada. (1990). Information Received From Advisory Services. Winnipeg: Author.

Steele, K. (1987). Caring for parents of critically ill neonates during hospitalization: Strategies for health care professionals. Maternal Child Nursing Journal, 16(1), 13-27.

Sterling, Y. (1990). Resource needs of mothers managing chronically ill infants at home. Neonatal Network, 9(1), 55-59.

Stewart, A., Reynolds, E., & Lipscombe, A. (1981). Outcome for infants of very low birthweight: Survey of world literature. Lancet, 1, 1038-1040.

Swanwick, M. (1984). Attachment and social behavior. Nursing 22, 2(22), 651-653.

Symanski, M. (1991). Use of nursing theories in the care of families with high-risk infants: Challenges for the future. Journal Of Perinatal and Neonatal Nursing, 4(4), 71-77.

Tait, M. (1922). Care of premature babies. Canadian Nurse, 18(7), 397-398.

Tarbert, K. (1985). The impact of a high-risk infant upon the family. Neonatal Network, 3(4), 20-23.

Taubenheim, A. (1981). Paternal-infant bonding in the first-time father. JOGNN, 10(4), 261-264.

Termini, L., Brooten, D., Brown, L., Gennaro, S., & York, R. (1990). Reasons for acute care visits and rehospitalizations in very low-birthweight infants. Neonatal Network, 8(5), 23-26.

Thorton, J., Berry, J., & Dal Santo, J. (1984). Neonatal intensive care: The nurse's role in supporting the family. Nursing Clinics of North America, 19(1), 125-137.

Toby, G., & Schraeder, B. (1990). Impact of caretaker stress on behavioral adjustment of very low birth weight preschool children. Nursing Research, 39(2), 84-89.

Tomlinson, P. (1990). Verbal behavior associated with indicators of maternal attachment with the neonate. JOGNN, 19(1), 76-77.

Toney, L. (1983). The effects of holding the newborn at delivery on paternal bonding. Nursing Research, 32(1), 16-19.

Toseland, R., Rossiter, C., Peak, T., & Smith, G. (1990). Comparative effectiveness of individual and group interventions to support family caregivers. Social Work, 35(3), 209-217.

Tracy, E. (1990). Identifying social support resources of at-risk families. Social Work, 35(3), 252-258.

Turner, V. (1988). The needs of babies discharged from special care baby units: A subject review. Intensive Care Nursing, 4, 160-168.

Ungerer, J., & Sigman, M. (1983). Developmental lags in preterm infants from one to three years of age. Child Development, 54, 1217-1228.

Watts, J. (1985). The pre-term infant: Outcome 1985. Canadian Family Physician, 31(5), 1013-1017.

Weingarten, C., Baker, K., Manning, W., & Kutzner, S. (1990). Married mothers' perceptions of their premature or term infants and the quality of their relationships with their husbands. JOGNN, 19(1), 64-73.

Weissbourd, B., & Kagan, S. (1989). Family support programs: Catalysts for change. American Journal of Orthopsychiatry, 59(1), 20-31.

Weitzman, J., & Cook, R. (1986). Attachment theory and clinical implications for at-risk children. Child Psychiatry and Human Development, 17(2), 95-103.

Whaley, L., & Wong, D. (1985). Essentials of pediatric nursing. (2nd ed.). St. Louis: C. V. Mosby.

Whetsell, M., & Larraabee, M. (1988). Using guilt constructively in the NICU to affirm parental coping. Neonatal Network, 6(4), 21-27.

Williams, T., Joy, L., Travis, L., Gotoweic, A., Blum-Steele, M., Aiken, L., Painter, S., & Davidson, M. (1987). Transition to motherhood: A longitudinal study. Infant Mental Health Journal, 8(4), 251-265.

Wilson, H. (1985). Research in Nursing. Menlo Park: Addison-Wesley Publishing.

Yoos, L. (1989). Applying research in practice: Parenting the premature infant. Applied Nursing Research, 2(1), 30-34.

Zarling, C., Hirsch, B., & Landry. (1988). Maternal social networks and mother-infant interactions in full-term and very low birthweight, preterm infants. Child Development, 59(1), 178-185.

Zeskind, P., & Iacino, R. (1984). Effects of maternal visitation to preterm infants in the neonatal intensive care unit. Child Development, 55, 1887-1893.

APPENDIX A

LETTERS OF PERMISSION

The University of Manitoba

SCHOOL OF NURSING

ETHICAL REVIEW COMMITTEE

Proposal Number N#90/04

Proposal Title: "The perceptions of mothers with an enfant receiving neonatal intensive care: A descriptive study."

Name and Title of Researcher(s): Marion I. Saydak, RN,BN
Master of Nursing student
University of Manitoba

Date of Review: March 05, 1990

Decision of Committee: Approved: Apr.10/90 Not Approved: ______

Approved upon receipt of the following changes:

APPROVED with revisions submitted March 21,1990 and April 9, 1990.

Date: April 10th 1990

Theresa George, RN, PhD. Chairperson
Associate Professor
University of Manitoba
Position

NOTE:

Any significant changes in the proposal should be reported to the Chairperson for the Ethical Review Committee's consideration, in advance of implementation of such changes.

Hôpital Général – St. Boniface – General Hospital
409 Tache Avenue,
WINNIPEG, MANITOBA R2H 2A6
(204) 233-8563

March 26, 1990

Ms. Marion Saydak
1
Winnipeg, MB, R2J 3B9

Dear Ms. Saydak: Marion

Your two-part collaborative study entitled:

**Perceptions of mothers with
infants receiving neo-natal intensive care:
A descriptive study: Phase 1**

has been approved for access at SBGH.

The results will provide information useful to nursing planners and caregivers both in hospital and community.

Please contact us if we can be of help in providing you with a carrel, bookshelves, and at some periods of the day, computer access. Our statistical package is the SPSS-PC. We wish you every success with your research and will look forward to the findings.

Sincerely,

Eleanor J. Adaskin, RN, PhD
Director of Nursing Research
Tel.

EA/mj

840 Sherbrook Street
Winnipeg, Manitoba R3A 1S1
Dial Direct (204) - 787-3011

March 12, 1990

Mrs. M. Saydak
The School of Nursing
The University of Manitoba
246 Bison Building
Winnipeg, Manitoba
R3T 2N2

Dear Mrs. Saydak:

RE: The Perceptions of Mothers With an Infant Receiving Neonatal Intensive Care: A Descriptive Study

Your proposal has been reviewed by the Pediatric Research Coordinating Committee at their meeting of March 5, 1990 and was given full approval.

Yours sincerely,

Heather J. Dean, M.D., FRCPC
Chairperson,
Pediatric Research Coordinating Committee

HJD*jdd

HEALTH SCIENCES CENTRE

DATE: APRIL 11, 1990

FROM: Dr. D. Harper, Director of Research, H.S.C.

TO: MARION I. SAYDAK

SUBJECT: Research Protocol Approval

NO: N#90/04

TITLE: THE PERCEPTIONS OF MOTHERS WITH AN INFANT RECEIVING NEONATAL INTENSIVE CARE: A DESCRIPTIVE STUDY.

The above study has been reviewed by the appropriate H.S.C. Research Committee and has been approved.

COMMENTS:

Dr. D. Harper, Director of Research

Date: April 11, 1990

c.c. Mr. I. Shwortz
Revised: 13/4/87

APPENDIX B

INTERVIEW QUESTIONNAIRE

(Adapted from Luker & McLoughlin, 1988)

Code Number........

Phase 1

To be completed when the infant has been in the Neonatal Intensive Care Unit (NICU) and or Intermediate Care Nursery (IMNC) for a minimum length of 10 days.

Thank you for taking part in this study. All information you give will be held in the strictest of confidence. You may choose not to answer questions which you find unacceptable and may end the interview at your request.

1. Had you ever visited a Neonatal Intensive Care Unit or an Intermediate Care Nursery before your baby was admitted to one?

   Yes 1
   No 2
   Don't Know 3

2. If Yes, why did you visit?

   Previous child in NICU or IMCN 1
   Through family 2
   Through work 3
   Hospital arranged tour 4
   Other, please specify 5

3. How did you feel about your baby being admitted?

4. What were your first impressions?

5. What in particular worried you?

6. How did you feel about touching your baby?

7. Was there anything in particular that bothered you about touching your baby?

8. Did you want to become involved in the care of your baby on admission?

   Yes, all of the time 1
   Most of the time 2
   Some of the time 3
   None of the time 4

9. How long did it take for you to want to be involved in the care of your baby?

   Number of days

10. Did baby's father want to become involved in the care of his baby?

   Yes, all of the time 1
   Most of the time 2
   Some of the time 3
   None of the time 4
   Not applicable 5

   If not applicable go to question 11

11. How long was it before the baby's father wanted to be involved in the care of his baby?

   Number of days ....

   Not applicable ....

12. Did the staff encourage you to become involved in the care of your baby?

   Yes, all of the time 1
   Most of the time 2
   Some of the time 3
   Rarely 4
   Never 5

13. How did you react to them?

14. Did the staff encourage baby's father to become involved in the care of his baby?

   Yes, at all times 1
   Most times 2
   Sometimes 3
   Rarely 4

Never 5
Not applicable 6

If not applicable go to question 15

15. How did he react to this?

16. Did you feel free to ask questions about your baby?

Yes, at any time 1
Most times 2
Some of the time 3
Rarely 4
Never 5

17. How often did you visit your baby in the unit?

At least once a day 1
Every other day 2
Twice a week 3
Once a week 4
Not applicable, mother staying in hospital 5
Other, please specify 7

18. If you were unable to visit did you telephone?

At least once a day 1
Every other day 2
Every third day 3
Once a week 4
Not applicable, mother staying in hospital 5
Not applicable, was always able to visit 6
Other please specify 8

19. On average, how long did you stay at each visit?

Number of minutes . . . .

22. If your visits were short was this because of:

Lack of money 1
Babysitting problems 2
Collecting children from school 3
Other, please specify 4

Heat of unit 5
Not applicable 6

23. How did you get to the Unit?

Walked 1
Car 2
Bicycle 3
Bus 4
Taxi 6
Given a ride 7
Not applicable 8
Oher, please specify 9

24. How long did it take you to travel to the Neonatal Intensive Care Unit or Intermediate Care Nursery?

Number of minutes . . . .
Not applicable . . . .

25. Were there times when you could not get to the Neonatal Intensive Care Unit or Intermediate Care Nursery?

Yes 1
No 2
Not applicable 3

26. If the answer to question 25 is YES, how did you feel about this?

27. How much did you have to pay, each day, to get to the Neonatal Intensive Care Unit or Intermediate Care Nursery?

Total travelling expenses . . . .

Not applicable . . . .

28. Did you receive help towards your travel expenses from any source?

Yes 1
No 2

29. If the answer to 28 is YES which of the following helped you with travelling expenses?

Family 1
Social Worker from NICU or IMCN 2
Social Services 3
Medical Services 4
Social Assistance 5
Others, please specify 6
. . . .
None 7

30. Do you think that you were told enough about your baby by the doctors on the NICU or IMCN?

Yes 1
No 2

31. Did you understand what you were told at the time?

Yes 1
No 2
Asked nurses to explain 3

32. Did you feel able to go back for more information?

Yes 1
No 2

33. Do you think that you were told enough about your baby by the nurses on the unit?

Yes 1
No 2

34. Did you understand what you were told at the time?

Yes 1
No 2

35. Did you feel free to go back for more information?

Yes 1
No 2

36. How satisfied were you with the way the staff in the NICU or IMCN cared for your baby?

    Very satisfied 1
    Fairly satisfied 2
    Dissatisfied 3
    If dissatisfied, please specify ....

37. How satisfied were you with the way the staff on the NICU or IMCN cared for you?

    Very satisfied 1
    Fairly satisfied 2
    Dissatisfied 3

38. If dissatisfied, please specify ....

39. How satisfied were you with the care and understanding you received from the staff on the postpartum ward when your baby was in NICU or IMCN?

    Very satisfied 1
    Fairly satisfied 2
    Dissatisfied 3

40. If dissatisfied, please specify ....

41. How satisfied were you with the way the staff in NICU or the IMCN cared for your husband/partner or other family members?

    Very satisfied 1
    Fairly satisfied 2
    Dissatisfied 3

42. If dissatisfied, please specify ....

43. How do you feel about taking your baby home in a few days time?

44. Who do you think will give you most support when you take baby home?

    Spouse/partner 1
    Close relative 2
    Friend 3
    Neighbor 4
    Community Health/Public Health Nurse 5

Family Doctor 6
Baby's Pediatrician 7
Social worker 8
Other, please specify 9

45. How well do you feel the nurses have contributed to preparing you to take your baby home?

Have been very well prepared 1
Have been adequately prepared 2
Have had some preparation 3
Have had very little preparation 4
Have had no preparation 5
Didn't need much preparation 6

46. How confident do you feel about caring for baby after discharge?

Very confident 1
Fairly confident 2
Nervous, some doubts about coping 3
Very nervous, may not cope 4

47. Do you think that you will have any worries after baby is discharged from the hospital?

Yes 1
No 2
Mixed feelings 3

48. What do think you will worry about?

49. If any problems arise with whom would you first discuss them?

Spouse/partner 1
Close relative 2
Friend 3
Neighbor 4
Community Health/Public Health Nurse 5
NICU or IMCN 6
Family Doctor 7
Baby's Pediatrician 8
Other 9

50. Have you met the Community Health/Public Health Nurse yet?

    Yes 1
    No 2
    Not applicable 3

51. Have you seen the baby's doctor since the baby's birth?

    Yes 1
    No 2

52. Have you seen your family doctor since the baby's birth?

    Yes 1
    No 2

53. Try to imagine you are talking to a mother who has just had a baby admitted to this unit. What are the most important things you think she needs to know?

54. Some babies who are admitted to special care and who are nursed in cribs alongside your baby do not always do well. Would you mind telling me how this makes you feel?

55. Is there anything you can think of which will in any way improve the service for babies in this unit and their families?

Place of interview:

    Home 1
    Hospital ward 2
    NICU 3
    IMCN 4
    Other, please specify 5

Thank you for your cooperation.

APPENDIX C

DEMOGRAPHIC DATA

Code Number...........
Date of Interview........
(Adapted from Luker & McLoughlin, 1988)

Portions of this information will be obtained from the baby's hospital chart.

QUESTIONS TO ASK THE MOTHER

Mother:

Age . . . .

Where do you reside?

Inside Winnipeg city limits 1
Rural Manitoba, within 160 km
radius of city of Winnipeg 2

Ethnic origin:

Anglo Saxon . . . .
Native North American . . . .
Other, Please Specify . . . .

Family Income:

Under $23,000 . . . .
$23,000 to $43,000 . . . .
Above $43,000 . . . .
(Statistics Canada, 1990)

How many years of education have you had? . . . .

Did you work before the birth of the baby

Yes 1
No 2

What is your occupation? . . . .

Do you intend to return to your work after a period of maternity leave?

Yes 1
No 2
Don't know 3

THE FOLLOWING INFORMATION WILL BE OBTAINED FROM THE INFANT'S CHART:

Parity: . . . .

Date of Birth: . . . .

Gestation: . . . .

Outcome: . . . .

Livebirth 1
Stillbirth 2
Neonatal Death 3
Spontaneous Miscarriage 4
Termination of Pregnancy 5

Last menstrual period . . . .

Expected date of confinement . . . .

Supported:

Living with spouse/partner 1
Living with spouse/partner and children 2
Living with children 3
Living with parents 4
Living with spouse/partner and parents 5
Living with spouse/partner, parents and children 6
Living with parents and children 7
Living with friends 8
Living alone 9
Other, please specify 10

Planned pregnancy 1
Unplanned pregnancy 2

Maternal Pregnancy Factors:

Nil 1
Smoking 2
Rh. (sensitivity) 3
APH 4
Hypertension 5
Hydramnios 6
Diabetes 7
Placental Insufficiency 8
Membranes Ruptured 24 hours+ 9
Urinary Tract Infection 10
Not known 11
Others (please specify) . . . .

Does the mother smoke cigarettes?

Yes 1
No 2

Does the mother drink alcohol?

Yes 1
No 2

What medicines, if any, did the mother take when she was pregnant?

Does the mother take any medicines now?

Yes 1
No 2

If YES, what does she take?

Method of delivery:

Normal vertex delivery 1
Forceps 2
Caesarean Elective 3
Caesarean Emergency 4
Breech 5
Breech extraction 6
Not known 7
Other (please specify) . . . .

Complications:

None 1
Prolonged labor (24 hours+) 2
Failure to progress 3
Amonitis 4
Precipitate delivery 5
Malpresentation 6
Hemorrhage 7
Cord problems 8
Not known 9
Other (please specify) . . . .

BABY

What is the baby's date of birth? . . . .

What was the date of admission to NIC? . . . .

If applicable what was the date of admission to ICMN? . . . . .

Which unit was the baby first admitted to?

NICU 1
IMNC 2

What was the birthweight? . . . .

What was the discharge weight? . . . .

What was the date of discharge? . . . .

Was the pregnancy

Single 1
Twin 2
Triplets 3

If multiple birth, state destination of other babies?

Stillborn . . . .
Neonatal death 2
Admitted to this NICU 3

Admitted to ICMN 4
Home 5

Length of stay in NICU . . . .

Length of stay in IMCN . . . .

What is the destination of this baby on discharge from NICU?

Home 1
IMCN 2
Other, please specify 3
Don't know 4

What is the condition at discharge? . . . .
(e.g. Oxygen therapy, Tube feeding, Colostomy

Does the baby have any lethal anomalies . . . .

APPENDIX D

PROTOCOL FOR NURSE IN NEONATAL INTENSIVE CARE OR INTERMEDIATE CARE TO APPROACH POTENTIAL SUBJECTS CONCERNING RESEARCH STUDY

Marion I. Saydak and Kathryn Hamelin, are Graduate Students from the University of Manitoba School of Nursing. They are conducting a research project to explore how mothers' of infants who required special care in hospital feel about this experience. Your views would be very helpful.

Would you be willing to have them contact you and have them explain the study?

You are under no obligation now or when they contact you.

Reply to the potential subject if permission is granted:

Thank you. Either Marion Saydak or Kathryn Hamelin will contact you soon. May I have your telephone number to give them?

Telephone number................................

Reply to potential subject if permission is not granted:

Thank you.

APPENDIX E

PROTOCOL FOR INITIAL APPROACH TO POTENTIAL SUBJECTS VIA TELEPHONE ABOUT RESEARCH STUDY

Hello, my name is Marion Saydak. Thank you for giving me permission to telephone you about a research project I am conducting.

I am a Registered Nurse and a Graduate Student in the Master of Nursing Program at the University of Manitoba. As part of my education at the University, I am conducting a research study in conjunction with another Graduate Student, Kathy Hamelin. The research project explores how mothers feel when their infant requires special care and the concerns they have after their infant is discharged home from the hospital.

Your participation in the study involves being interviewed twice. The first interview is conducted at the hospital by Marion Saydak before your infant is discharged home. This interview takes approximately 40 minutes and is arranged at a time and place acceptable to you. The first interview asks you about the feelings you have when your infant requires special care in the hospital.

The second interview is administered by K. Hamelin six weeks after your infant is discharged home. The second interview asks you about the care and support you have received after your infant is discharged home. This interview takes about 40 minutes and occurs at a time and place that is acceptable to you.

You are not required to take part in the study. If you do take part in the study you are not required to reply to any questions which you may find unacceptable. Your involvement in the study may end whenever you request. This study will not be of any benefit to you, but may assist nurses and other health professionals in caring for other mothers like you. Any answers you provide will be held in the strictest of confidence by Marion Saydak and Kathryn Hamelin.

I will give you a written description of the study. Please do not hesitate to contact me with any questions or concerns you have. If you agree, we will contact you to determine a time and place for the first interview that is acceptable to you.

Thank you.

APPENDIX F

PROTOCOL FOR RESEARCH STUDY DESCRIPTION TO BE GIVEN TO POTENTIAL SUBJECTS

This study is designed to identify the feelings and concerns of mothers of infants before and after discharge of the infant from the hospital.

Mothers of infants who have required special care in the hospital for at least 10 days are being asked to take part in the study.

The study involves being interviewed on two separate occasions by Marion Saydak and Kathryn Hamelin, Graduate Students in the Master of Nursing Program at the University of Manitoba. The first interview which Marion will be doing, will take place before your infant is discharged home and will take about 40 minutes. The second interview will be done by Kathryn and will take place 6 weeks after the discharge of your infant and will take about 40 minutes.

The questionnaires asks mothers how you feel about having an infant who requires special care, such as your baby received in the hospital. In addition, the questionnaires will ask you about the care you and your infant received after discharge from the hospital.

You do not have to take part in the study if you do not want to. If you do take part in the study you do not have to answer any questions if you do not want to. You can stop the study whenever you want. This study will not be of any benefit to you, but may assist nurses and other health professionals in caring for other mothers like you.

You will not be identified in any of the papers written about the study. If you would like to have a summary of the research study, one will be given to you.

Do you have any questions? I can answer them now or at anytime during the interview.

Thank you.

APPENDIX G

PROTOCOL FOR
CONSENT BY THESIS RESEARCH STUDY SUBJECTS

I,______________________________, have read the description of the research study, being conducted by Marion Saydak, a Graduate Student at the School of Nursing, University of Manitoba, exploring how mothers feel when their baby requires special care in the hospital. I know that this study is phase one of a research project. I will take part in the study and will be asked questions by Marion Saydak at an acceptable time and place. I also give her permission to obtain information from my child's hosptial chart.

I understand I do not have to answer any questions I find unacceptable to me, and may withdraw from the study anytime if I want to. I have asked questions and have discussed any concerns I have. I know the information I give will be held in the strictest of confidence, and that I will not be identified with my name on any of my answers. The acutal answers will have a code number to protect my identity. The only people who will know my name and code number will be Marion Saydak and Kathryn Hamelin. My answers to questionnaires will be stored in a secure locked cupboard.

The information I give will be kept for future studies and analysis. I know that at no time will my answers be linked with my name. I know I will not be identified with any of the information or in any of the papers written about the study. I know this study will not have any benefit to me, but may assist nurses and other health professionals in caring for other mothers like me.

I will indicate to Marion Saydak if I desire a summary of the research study. I will contact her at 257 2179 or 474 6219 if I have any questions. I will also contact her thesis advisor, Professor Ina Bramadat at 474 8202 if I have any questions.

Signature____________________

Time__________Date__________

____

Marion Saydak

Time_________Date___________

If you would like to have a summary of the research study, please give your name and address.

Name:______________________
Address:____________________