

**A CORRELATIONAL STUDY OF THE EDUCATIONAL NEEDS, SUPPORT NEEDS, AND
INFANT CARE SELF-EFFICACY
OF PARENTS OF HIGH RISK INFANTS**

by

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A Thesis

**Submitted to the Faculty of Graduate Studies
in Partial Fulfillment of the
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DORIS MARIE SAWATSKY-DICKSON

A Thesis/Practicum submitted to the Faculty of Graduate Studies of the University of Manitoba in partial
fulfillment of the requirements for the degree of

MASTER OF NURSING

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Dedication:

This project is dedicated to all of the parents who welcomed me into their homes.

They entrusted me with their stories, emotions and their experience.

Several months after participating in this study one of the mothers who participated died, leaving her family and three children. This study is also dedicated to her memory.

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Abstract

A Correlational Study of the Educational Needs, Support Needs, and Infant Care Self-Efficacy of Parents of High Risk Infants

Parents of high risk infants experience a crisis situation both immediately following the birth of their newborn, and with the planning and discharge home of a high risk infant. For parents to resolve this crisis and pursue their new life with a vulnerable infant, they require both formal and social support. The learning and support needs of parents during both the initial stages of hospitalization, and as they prepare to care for their infant at home, are numerous. These needs have been well documented in the literature. This study examined the experience of parents using semistructured interviews and three survey tools. The Formal Support Questionnaire (FSQ) measured perceived parent education and formal support, the Norbeck Social Support Questionnaire (NSSQ) measured perceived social support and documented their support network, and the Infant Care Survey (ICS) measured infant care confidence over 51 knowledge and skill variables. Most of the contacts were done in the parent's home, with two taking place in an office at the hospital. All parents completed the three questionnaires. Semi-structured interviews were conducted with 29 parents, with 21 of these being tape-recorded and transcribed. The remaining eight parents provided only a few comments which were recorded by the investigator.

The sample consisted of 49 mothers and one father, all primary caregivers of infants who had spent at least ten days in hospital after birth. Eighty two percent were either married or living common-law. Sixty percent of parents had no previous children. They were evenly divided among high medium and low income levels. Seventy two percent lived in the city 28 percent in rural areas. Mean age was 27.6 years ranging from 19 to 37 years. Mean years of education was 13.4 ranging from 8 to 24. The infants ranged in birthweight from .729 kg to 3.64 kg with a mean of 1.97 kg. They spent a mean of 37.3 days in hospital. Eighty two percent of the infants were premature. Other reasons

for admission included apnea, sepsis, and cardiac anomalies. Seventy two percent had no obvious problems at discharge. Fifty percent of mothers were breastfeeding at least partially at discharge, 36% were still breastfeeding at the time of contact 4-6 weeks later.

Parents generally experienced a high degree of stress during their infant's hospitalization. There were both stress producers and stress relievers that affected their experience. Two major themes emerged from the interviews, the first was the parent's role in developing a relationship with their infant, and the second was the interpersonal relationships that they had with others in the hospital and as a result of their infant's illness. Parents searched for both information and support during their infant's hospitalization in order to cope with their stress. Both the infant's condition and the hospital environment were common producers of stress for parents. In developing relationships with health care providers there were situations and encounters that produced stress, as well as positive relationships that facilitated coping with stress. Frustrations surrounding breastfeeding produced stress for many mothers.

This study answered three research questions. 1) What are the education and support needs of parents of high risk infants? The FSQ indicates that there are areas in which parents perceived that they did not receive enough information. These include information about their infant's illness and medications. This is reflected in the ICS scores which were low for areas of skill and knowledge in treating potential illnesses. FSQ scores indicate parents did receive enough information in general infant care issues and felt quite prepared to take their infant home. The ICS confidence scores indicate that parents had the most confidence in providing basic infant care at home. Parents also had high confidence in their knowledge of safety issues for their infant, and the least confidence in treating potential illnesses such as croup, ear infections or allergic reactions. Overall parents were looking for experienced, reliable support and information, both from written material and personal contact.

2) What is the relationship between parent education, social support, and self-efficacy related to caring for a high risk infant at home? Correlation of the variables using Pearson's r for the continuous variables and Chi Square for grouped data indicates that parents who have no previous experience with children, and who perceive less support and education by health care professionals are less confident in caring for their infant at home.

3) What is the best predictor of infant care self-efficacy in parents of high risk infants? Perceived formal support and parent education is a moderately good predictor of infant care confidence, particularly for parents with no previous children.

There was no relationship demonstrated between perceived social support and either perceived formal support or infant care confidence.

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Chapter 1: Statement of the Problem

Premature birth continues to be the leading cause of perinatal morbidity and mortality worldwide (Ladden, 1990). More than four percent of infants born in Manitoba are classified as low birthweight, most frequently as a result of premature birth (Miller, Strachen, & Wadhwa, 1991). These infants continue to be prone to deficits in growth, development and health well into their childhood (Gennaro & Bakewell-Sachs, 1991). There are many other situations that place infants at risk. Some of the most frequent conditions include, chronic lung disease, respiratory compromise at birth, neonatal sepsis, congenital malformations, and prenatal exposure to substance abuse. These infants are also considered "high risk" for continued problems in infancy and possibly longer.

The challenge posed by these infants to the health care team in neonatal intensive care units (NICU) is enormous. The initial goal of care is prompt treatment of acute illness. There is, however, a growing trend, as a result of improved technology, for the majority of the infant's hospitalization to be spent in convalescence from the sequelae of premature birth. This may encompass weeks or even months, during which the primary role of nurses includes support, prevention and education. This care is directed to the families of premature infants, starting them on the journey of parenting a high risk infant.

Parents must move from a situation of crisis, when their infant is hospitalized, to a new reality when they must care for a vulnerable infant at home. Both social support and education assist parents in developing the degree of self-efficacy required to successfully complete this transition and to function well at home as parents develop a growing awareness of themselves as capable of dealing with the situation.

The learning and support needs of parents of premature infants have been well documented (Bass, 1991; Brown & Ritchie, 1991; Gennaro, Zukowsky, Brooten, Lowell & Visco, 1990). It also has been demonstrated that discharge teaching focusing on these learning needs does prepare parents to more effectively perform the necessary caregiving

tasks. Formal discharge teaching ensures that a greater amount of information is taught to parents (Cagan & Meier, 1983). Gearing teaching to the specific needs of the involved parents is the key to successful learning, greater confidence and less anxiety for the parents (McKim, 1993a).

Difficulties arise when there is a discrepancy between what the nurses perceive and what the parents identify their needs to be. Sheik, O'Brian & McCluskey-Fawcett (1993) demonstrated this discrepancy and suggested that it presents a major obstacle for successful parent education. As shortened hospital stay becomes the norm, discharge teaching takes on a greater role in ensuring that high risk infants receive the care required for optimal growth and development at home.

The effects of social support in Neonatal Intensive Care also have been documented. It is generally agreed by parents, grandparents and professionals that an important role of family members is to provide social support to parents. Most of the studies on social support have been either descriptive in nature, or they tested a particular support program or initiative, without using control groups. Lindsey et al. (1993) however, compared a group of mothers who received enhanced support from an experienced peer, to a control group of NICU mothers. They found that mothers who received enhanced support reported better mood states, less anger, less depression, and less anxiety. Also they had better maternal-infant relationships and a better home environment twelve months after discharge.

Parents of hospitalized infants in Manitoba have similar experiences and learning needs as those reported in the literature (Hamelin, 1991; Saydak, 1991). Parents expressed frustration and feelings of abandonment upon discharge. Nursing staff at both the Health Sciences Centre and St. Boniface General Hospital in Winnipeg, Manitoba have become increasingly aware of the needs of parents of high risk infants and have used various formal and informal methods to try to alleviate the deficiencies. The relationship between parent education, social support, and self-efficacy remains unexplored. It is not

known whether the improvement of support and education materials for parents and nurses has resulted in meeting the needs and improving the self-efficacy of parents of premature infants.

Research Questions

- 1) What are the education and support needs of parents of high risk infants in Manitoba?
 - a) What are the common worries and problems parents experience when their high risk infant is discharged from neonatal special care?
 - b) Who do parents turn to for help and support after their high risk infant is discharged from special care?
 - c) Which sources of support and information are most useful to parents after their high risk infant is discharged from special care and why are these sources considered helpful?

- 2) What is the relationship between parent education, social support and self-efficacy related to caring for a high-risk infant at home?

- 3) What is the best predictor of infant care self-efficacy in parents of high risk infants?

Conceptual Definitions

High Risk Infants: Infants who are at risk for developmental and/health problems in childhood as a result of significant illness requiring hospitalization during the first weeks and months of life (author).

Crisis: Time limited periods of disequilibrium, or behavioral and subjective upset which place demands on an individual to which that person cannot respond adequately. (Caplan, Mason & Kaplan, 1965).

Social Support: Verbal and/or non-verbal information or advice, tangible aid, or action that is proffered by social intimates or inferred by their presence and has emotional or behavioral effects on the individual (Gottlieb, 1983).

Formal Support: Information and services provided by professionals or trained persons outside of an individual's usual support network (author).

Learning: A change in a person that comes about as a result of experience (Woolfolk, 1987).

Self-Efficacy: People's judgments of their capabilities to organize and execute courses of action required to attain designated types of performances (Bandura, 1977).

Chapter 2: Theoretical Framework

Overview

Parents of high risk infants experience a crisis when their infant requires hospitalization for a serious illness. Caplan (1960) described this particular crisis situation in his Crisis Theory. Behaviors that parents exhibit during crisis included gathering information, and seeking support. Social support involves providing a person with emotional support, self-esteem, active care, and /or material support (Cobb, 1979). Information that parents seek is provided in the form of formal support, or parent education by professionals. Learning involves change (Woolfolk, 1987), and parents of high risk infants must face numerous changes both in becoming familiar with their infant's problems in the hospital, and in caring for their infant at home.

Bandura's Social Cognitive Theory describes this process of learning as an interaction of behavioral, cognitive, personal, and environmental factors (1986). These factors contribute to the parent's perceived self-efficacy in caring for their infant at home. Self-efficacy is described as the person's perception of the ability to perform in a given situation (Bandura, 1977). Both social support and parent education have an influence on the parent's level of perceived self-efficacy and ability in caring for their infant at home. A diagrammatic representation of this theoretical framework is found in Appendix A.

Crisis

Childbirth and transition to parenthood represents a crisis of some degree for most people who experience it. They also represent a turning point in the life of the individuals and families. Crisis has been explored by the psychiatric professional community for many years.

Caplan, Mason and Kaplan (1965) studied the crisis experience in depth. They outline some of the basic principles common to situations of crisis. Behavior during a crisis is influenced by the situation, pre-existing personality, cultural factors, and interactions with significant others. There are relatively few potential patterns of behavior during crisis which can be predicted. Crises are time-limited periods of disequilibrium, or behavioral and subjective upset. The person cannot respond adequately to a demand or burden which initiates the crisis. There is a period of tension during which the person seeks resources to deal with the precipitating cause. Crises differ from each other in the type of precipitating factor and the type of challenge it poses to the person. Common to all are certain psychological and environmental tasks.

There are four assumptions outlined by Geissler (1984) that accompany the concept of crisis: crisis occurs in healthy individuals and is not equated with psychopathology; crises are time limited and acute; the individual defines the seriousness; and there is potential for psychological growth or deterioration. The provisional criteria for crisis to occur are that there must be an impediment to a desired goal, a decisive point requiring action, an inability to act constructively, and a period of psychological instability. According to Darbonne (1968) the principle of homeostasis and problem solving is central to crisis theory.

In her review of applications of crisis theory in psychiatry, mental health nursing, sociology and psychology, Brownell (1984) separates the experience of crisis from the actual precipitating event. She describes the core of crisis as a response state which is characterized by the individual's inability to react and a feeling of discomfort. She also emphasized the potential discrepancies in assessment of situations between perceptions of clients and caregivers.

Oberholzer (1983) echoes many of these descriptions of crisis by placing an emphasis on behavioral symptoms, which are indicative of overall inability to cope, precipitated by specific life situations.

Caplan (1960) applies the fundamental principles of crisis to the experience of parents of premature infants in his development of crisis theory. He found those parents who achieved a positive mental health outcome after the crisis situation has passed, experienced specific behaviors. These parents continually survey the situation and gather as much information as possible. Perceptions must be reality based. Successful parents show a continuous awareness of negative feelings throughout the crisis and express them freely. Parents seek help from within the family or the community in relation to tasks associated with care of their premature infants and in dealing with negative feelings.

Any crisis is made up of a series of smaller upsets, and the tasks necessary to deal with them overlap. Caplan, Mason and Kaplan (1965) outline the basic tasks in the order in which parents, especially mothers of premature infants must complete. The first task which confronts the mother at the time of delivery is preparing for the potential death of the infant. The mother must blend anticipation with hope for survival. At the same time the mother must face the task of dealing with her sense of failure as a mother, precipitated by her inability to carry the pregnancy to term. During this initial phase when the infant's survival is tenuous, the mother's interaction with her infant has been interrupted, or not even allowed to be established. The third task involves establishing a relationship with the infant. This often occurs when the mother realizes the infant will survive. The final task is to understand the infant's needs and learn how a premature baby differs from a 'normal' term baby.

Disturbance in early parent-child relationships can result following pre-term delivery and the separation of mother and infant (Jeffcoate, Humphrey and Lloyd 1979). The disruptions in maternal self-esteem and self-confidence, and the situational effects of the infant's hospitalization contribute to delays in bonding. Mothers, who do not successfully complete the tasks of the crisis experience and overcome the role disturbance accompanying it, may continue to experience difficulties once the child is at home.

This transition is further examined and described by Weiss (1976). He describes three distinct stages of the crisis experience: 1) the acute, severely upsetting situation characterized by emotional suspension and separation; 2) transition to a period of relational and personal change; 3) a new situation and organization which may or may not meet the person's needs. People in the first stage have little energy left over to deal with anything other than simple support in the form of communication. In the second stage, people are much more open to various forms of help, and cognitive materials become useful. These people may feel socially isolated because of the many changes occurring, and are in great need of social support. When the third stage leaves people in a deficit situation, they need a continuing, problem-focused support system.

Although the concept of crisis can be a vague one, it can also be extremely evident in situations where high levels of emotional upset are evident. Through examining the various theoretical descriptions of crisis, it becomes evident that clinical linkages between crisis situations and both formal and informal support are suggested. In parents of high risk infants both social support and patient education become important in their transition from the original crisis time, to a new family situation.

Social Support

Through studying people in crisis situations, Caplan (1974) discovered three major factors which influenced the resolution of the crisis. One was the stress situation itself and how it changed. The second was the current ego strength of the person in crisis. The third was the quality of the emotional support and task-oriented help the individual received. This third factor is what he and others came to call 'social support'. Caplan described three elements to support: help to mobilize personal psychological resources to master emotional burdens; task sharing; and provision of material help and advice to deal

with situations. He saw the purpose of a social support network or community as providing information and guidance, as well as a refuge or sanctuary.

Cobb (1976) describes support as information that leads the subject to believe one or more of the following: that he is cared for and loved; that he is esteemed and valued; that he belongs to a network of communication and mutual obligation. Having such a network provides a person with a sense of history in addition to the material and defense benefits. He identifies social support as crucial in facilitating coping with crisis and adaptation to change.

Cobb (1979) develops the concept of support into 4 distinct types of support: 1) social support consisting of emotional, esteem and network support which is informational in nature; 2) instrumental support or counseling which guides a person to better coping; 3) active support or mothering; 4) material support consisting of goods and services. His theoretical approach is that social support operates to facilitate stress reduction by improving the fit between the person and the environment, leading to both adaptation and control.

Since publication of the scholarly writings of Caplan and Cobb on support and social support, many others have developed the concepts further and applied them to various clinical and life situations. House (1981) provided a simple definition of social support as “who gives what to whom regarding which problems” (p.22). To this definition Pearlin (1985) added “with what effects” (p.58). Both of these authors use the term ‘social support’ as the umbrella which includes emotional support, instrumental support, informational support, and appraisal support. They both also state that distinctions must be made between these various aspects of social support when looking at specific situations.

House (1981) describes the differences between perceived support versus objective support, with the likelihood of support being effective only to the extent that it is perceived as useful. The type of support that is useful varies depending on the situation,

the individual, and the quality and stability of the relationship within which support is being offered. House also asserts that we should make the distinction between direct affects of social support, which can enhance health, well-being and reduce stress, and buffering effects, which mitigate the impact of stress and modify the relationship between stress and health..

The linkage between social support and health is made by many authors. Broadhead et al. (1983) compiled an extensive review of research studies which demonstrated the effects of social support on health. Although the measures of social support varied greatly between studies, and they were not all of the same scientific quality, trends in the research suggested a strong association between social support and health. The literature review concluded that poor social support precedes adverse psychological outcomes and mortality. There is similar direction and magnitude of effect across all studies, including a variety of age, gender, ethnic and health status groups, with a greater effect for women than men.

Pearlin (1985) described support in terms of an interactional exchange between donors and recipients. He looked at the structure of support systems and described them as networks where support is seen as interpersonal relations rather than of the actions of separate and unrelated individuals. It is the previously established societal norms and practices which provide the coping repertoires for people within that network. Different types and sources of support exist for different problems.

Cohen & Syme (1985) provide a simple definition of social support as “the resources provided by other persons” (p.4). They also place informational needs, material needs and emotional needs under the umbrella of social support needs.

As the concept continues to be developed, some distinctions have been made between social support and related concepts. Barrera (1986) described some of these more refined social support concepts. He defines ‘social embeddedness’ as the connections that individuals have to significant others in their social environments. This

concept is a value of social network analysis. Perceived social support is defined by the cognitive appraisal of the individual, which includes both perceived availability, and adequacy of ties. Another sub-concept is 'enacted support' which refers to the actions that others perform in providing assistance.

A term that is commonly used, especially in clinical situations is 'support system'. Gottlieb (1983) claims that there is no such thing, but rather a social network. He describes the support system as including all professional and informal resources, and claims it is of little use in examining social support. This description differs from most other definitions of support systems, which do not include the relationships that result from professional and formal resource contacts because the expectation of reciprocity is not there. The social network examines direct ties a person has with others who generate both support and stress for the individual. With the exception of Gottlieb, few authors devote much discussion to the potentially negative effects of social support.

Mitchell and Trickett (1980) examine the way social network analysis can determine the extent to which people are involved with those who surround them. They identify the social network as a way of cutting across formal boundaries and providing opportunity to look at the total social field within which the individual exists. Networks vary in size, density and degree of connection. Linkages within the network vary in intensity, durability, multidimensionality, reciprocity, dispersion, frequency, and homogeneity. Examining social networks takes attention away from the behavior itself and focuses on the interpersonal and social context of the behavior.

Measurement of social support can be done in various ways. House and Kahn (1985) measured social support in terms of the structure and functional content of a person's social relationships. Bruhn & Philips (1984) examine the ways that social support have been measured by various researchers. They note a tendency to focus on quantitative aspects because of the greater ease of measurement and analysis as compared to examining the quality of social support. One of the factors relating to social support

that makes it difficult to measure qualitatively is that it does not have the same importance or the same components in all cultures. Authors note the potential negative effects of support. Not everyone is sensitive to a person's needs when they are in crisis, and may visit at inappropriate times, or place added stress on them with too long or too frequent visits when their presence is not wanted. There may be stress within a family or social network which does not abate during crisis situations.

There are other points that must be considered when measuring social support. Support is dynamic and changes with time. Both quantitative and qualitative dimensions must be considered simultaneously. The need for social support changes as life situations change. It must be perceived to have value. Support cannot be fully understood at one level. It is a cluster of factors and a facet of everyday life. Individual differences affect both the need and perception of support (Bruhn & Philips, 1984).

Norbeck (1981) outlines these characteristics of social support in her description of a model for application to nursing practice. Her model incorporates four components that comprise most nursing theories: person, environment, health/illness, and nursing actions. She suggests a grid for predicting the intensity and duration of support required for situational demands and stressors. This grid can be found in Appendix B. Although this is an intervention model, it does assist in understanding the concept of social support and its application in various life situations. It also utilizes the close linkages between social support needs and crisis situations.

Social support is one of the main components in the resolution of crisis. A second important aspect is information and education. These form the second major relationship in the theoretical framework, referred to as formal support.

Formal Support

Just as emotional support is an important necessity for the resolution of the crisis experienced by parents of high risk infants, informational support also fulfills specific needs. Social support theory includes informational support when it is provided by persons in an individual's social network. When a family has a new infant the support network is an important source of information on various aspects of baby care and child development. Parents often talk to other parents in order to compare growth and development of their infants and to discuss various problems. This network, however, is insufficient in fulfilling the information needs of parents of high risk infants. Needs of infants who have been hospitalized and have chronic or potentially chronic problems are unique and differ somewhat from the needs of 'normal' infants. In these situations formal support, that provided by professionals or trained persons outside of an individual's usual support network, is necessary.

Learning theories provide the theoretical basis for this discussion of formal support and complete the linkages between crisis and social support. Learning can be defined in various ways according to various theories. This theoretical framework employs the most basic definition of learning provided by Woolfolk (1987): "learning is a change in a person that comes about as a result of experience" (p.165). In behavioral theories this change is the change in behavior. In cognitive theories, it is the internal process that changes a person's ability to respond in a particular situation. The view that best fits this particular theoretical approach is Bandura's Social Cognitive Theory, which adapts some concepts from each of these opposing approaches to learning.

Bandura (1986) describes human functioning in a model where "behavior, cognitive and other personal factors and environmental events all operate as interacting determinants of each other" (p.18). Behavior is modified both by external controls and events, as well as by internal standards. People are able to analyze their experiences and

think about their own thought processes. Bandura's theory was originally called 'social learning theory' because of its focus on observational learning. Skill and rule acquisition by observing 'models', is the central tenet of this aspect of the theory. Further development of the theory led to the evolution of the title to 'social cognitive theory' to incorporate the cognitive processes which contribute to learning. From the cognitive theorists, Bandura borrows the term 'information-processing' to describe the four processes that govern learning. These are; attention, retention, production, and motivation.

People cannot learn unless they attend to, and accurately perceive the relevant aspects of modeled activities or the information presented. The greater the cognitive skills and prior knowledge, the more subtleties the learner will perceive and remember. The anticipated benefits of skills, strategies and information provide incentives for paying attention. Attention deficits can be caused by deficient cognitive skills, prior faulty learning, distracting preoccupation, or insufficient incentives. Retention only occurs when information given or what is observed is transformed into symbols and images. Retention improves by transforming the meaningless into what is already known. Both cognitive rehearsal and practice are important in transferring information and skills into long-term memory.

The final process that governs learning, as described by Bandura, is motivation. It is important to note that although behavior is affected by events that follow it, control of the behavior does not reside with those events. Consequences alone produce little change until people become aware of the rewards and punishments of action. Motivators to learning and behavior change can be intrinsic or extrinsic, concrete or symbolic. People can use symbolic motivators because of their cognitive capacity to foresee the likely outcomes of prospective actions. Strength of motivation is a result of the combination of the belief that particular outcomes will result, and the value placed on those outcomes.

There are both biologically based and cognitively based outcomes, of which forethought is the instigator.

Self-Efficacy

One of the key concepts of Bandura's theory, which leads to the final aspect of the theoretical framework is self-efficacy. In one of his earliest references to self-efficacy Bandura (1977) describes the principal assumption that "psychological procedures serve as means of creating and strengthening expectations of personal efficacy" (p. 191). His hypothesis is that expectations of personal efficacy "determine whether coping behavior will be initiated, how much effort will be expended, and how long it will be sustained in the face of obstacles" (p. 191). Bandura (1986) develops the concept further when he incorporates it as a major component in his Social Cognitive Theory. He refers to 'perceived self-efficacy' as a person's own judgment of what they can do with the skills that they possess.

Stretcher, McEvoy DeVillis, Becker and Rosenstock (1986) examined Social Cognitive Theory and specifically self-efficacy in relation to health behavior change. They described the theoretical approach with efficacy expectations linking the person with the behavior, which in turn leads to outcome expectations after the behavior change is made. They found that this view fit well with various research studies investigating a person's perceived self-efficacy with their ability to make behavior changes such as to stop smoking, or lose weight, exercise, quit drinking, or use contraception.

Bandura (1986) describes four main sources of efficacy information. The first is referred to as enactive efficacy. This is when a person attempts something in order to prove to themselves that they are capable of doing it. Repeated failures tend to lower efficacy expectations, while success raises them, and once established can be generalized to other situations. The second source is vicarious observation of others who are in similar situations or are attempting similar actions. This tends to be a more effective

source the closer the person can relate to and is similar to the person they are observing. The third source is persuasion from others. This source is the least effective and the one most prone to producing failure. It does have value in encouraging a more sustained effort. The final source of efficacy information is a person's physiological state. In stressful or challenging situations a person assesses their level of somatic arousal and their capabilities and vulnerabilities. High levels of arousal and upset can be aversive and inhibit a person's ability to respond or perform. All of these sources of information are instructive to the person and are still subject to cognitive appraisal.

There are some key points regarding self-efficacy that must be noted: it operates partially independently of a person's actual skills; it cannot produce performance if skills are lacking; and it is situation and task specific. A person with overall high degrees of self-efficacy becomes more adept at finding the necessary coping skills to respond appropriately to new situations. Self-efficacy is not just an end result, but is also a tool in achievement, especially in new situations.

Self-efficacy completes the cycle for parents of high risk infants. Parents must move from a situation of crisis, when their infant is hospitalized, to a new reality when they must care for a vulnerable infant at home. Both social support and education assist parents in developing the degree of self-efficacy required to successfully complete this transition and to function well at home as parents perceive themselves as capable of dealing with the situation.

Chapter 3: Literature Review

High Risk Infants

Infants that have been hospitalized for illness during the newborn period are referred to as "high risk". Significant illness during the newborn period places them at risk for additional problems during infancy and childhood. There are many situations that place infants at risk. Some of the most frequent conditions are preterm birth, chronic lung disease, respiratory compromise at birth, neonatal sepsis, congenital malformations, and prenatal exposure to substance abuse.

Preterm delivery has been determined to be responsible for more than 75 percent of all cases of perinatal morbidity and mortality in the world today (Ladden, 1990). In Canada, the total number of infants born weighing <1500 grams in 1989 was 2,498, or 7 percent of all live births. In Manitoba 4.3 percent of all births in 1989 weighed <2500 grams, classified as low birthweight. This statistic has remained relatively constant since 1971 (Miller, Strachan & Wadhera, 1991). The lower the birthweight the higher the risk to the infant. In a comprehensive review of current literature, Gennaro and Bakewell-Sachs (1991) examined the common health problems of low-birth-weight infants during the first year of life. These problems include: neurodevelopmental disabilities, vision and hearing deficits, respiratory infections and chronic lung disease, and feeding difficulties.

In a randomized controlled study of 40 infants born weighing less than 1500 grams at birth, Brooten et al. (1986) determined that prolonged hospitalization places premature infants at greater risk for infections, impaired attachment with their parents, difficulties in establishing breast feeding, failure to thrive, and child abuse than their normal birthweight counterparts. Rehospitalization and acute care visits after discharge were the result of respiratory problems, need for surgery, general infections, and gastrointestinal problems

(Termini, Brooten, Brown & Gennaro, 1990). The health care system continues to play a major role in the lives of high risk infants even after they are discharged.

The tenuous nature of the lives of premature infants is clearly demonstrated by Cooke (1994) in his review of 823 infants born at 28 weeks or less gestation between 1980 and 1989. Survival rate was 56 percent, with 19 percent experiencing major disabilities, of which 9 percent were severe, which included spastic quadriplegia, blindness, deafness, uncontrolled epilepsy or severe learning disability. Results of logistic regression indicated that survival was improved with greater gestational age, higher birthweight, and less significant intraventricular hemorrhage. Infants also fared better if they were female, and were born more recently, as conditions and treatments have improved over the years. Major disability was associated with higher grade of intraventricular hemorrhage and presence of a parenchymal cerebral lesion on ultrasound. Although much of the data relied on reports from pediatricians, results provide some support for predicting outcome and potential for future disability among infants less than 28 weeks gestation at birth.

Saigal et al. (1994) report data from follow-up of extremely low birthweight infants after eight years. This cohort study paired the children with 145 normal birthweight children matched for age, sex, and socioeconomic status. They evaluated the children on six attributes: cognition, sensation, mobility, self-care, emotion, and pain. Their results indicated the study group had significantly higher rate of multiple deficits. In the study group 58 percent had one or two attributes affected and 28 percent at least three. In the normal weight cohort 48 percent had one or two attributes affected and 2 percent with at least three. The most frequent deficits for both groups were reported in cognition, sensation, mobility, and self-care.

Respiratory failure is common among preterm infants, but also occurs for various reasons among infants of later and term gestations. Walsh-Sukys et al. (1994) completed a review of follow-up data from seventy four neonates who were greater than thirty four weeks gestation at birth and experienced severe respiratory failure. They compared those

who were treated with conventional methods with those who were treated with extracorporeal membrane oxygenation. They followed the progress of both groups and at twenty four months concluded that a significant percentage (24%) of the infants who experienced severe respiratory illness have significant and neurodevelopmental impairment regardless of the treatment used. Some of the causes of this degree of respiratory failure include; congenitally acquired sepsis, hypoxic-ischemic encephalopathy, meconium aspiration syndrome, and congenital diaphragmatic hernia. These particular problems are more common in term rather than preterm infants, who typically suffer from Respiratory Distress Syndrome.

Sepsis in the newborn period can be particularly devastating, depending on the organism of cause and the site of infection. Neonatal meningitis is one of the potential causes of significant morbidity and mortality. Franco, Cornelius and Andrews (1992) evaluated the outcome of twenty one survivors of bacterial meningitis compared with matched controls of high risk infants who did not have meningitis. Infants were followed for an average of 7.8 years. Authors found survivors of meningitis had lower IQ scores and more severe sequelae than matched controls. Congenital cytomegalovirus is another leading cause of congenital infections, and is also associated with residual impairment. Hicks et al. (1993) completed auditory screening on 134 infants who had experienced congenital cytomegalovirus infections. They found that 10.4 percent had significant hearing loss.

Prenatal exposure to drugs and alcohol is an ever-increasing problem in this country. Cocaine is one of the substances that can cause significant problems for infants. Kelley, Walsh and Thompson (1991) report on chart review of thirty children who were exposed to cocaine prenatally and compared them to thirty matched cohorts who were not cocaine exposed. They found that the cocaine-exposed infants were more likely to be born prematurely, had significantly lower birthweights and were generally smaller infants. Follow-up data indicated that the cocaine-exposed infants also continued to experience

poor growth and significantly more of them were at or below the 10th percentile for growth. Also they were more likely to be hypertonic on physical exam, with a higher maternal report of high-pitched cry, excessive crying or sleep problems. The study group had a significantly higher rate of suspected abuse or neglect after discharge home, with a higher rate of unstable homes.

Singer et al. (1994) looked at the population of cocaine-exposed infants in a larger longitudinal study of very low birthweight infants . They found that the cocaine-exposed infants were at significantly higher risk of developing an intraventricular hemorrhage. When the effects of this complication was controlled, the cocaine-exposed infants still had lower mean cognitive and motor scores and a significantly higher incidence of developmental delay. Although the data is complicated by the fact that women who use cocaine are also likely to abuse other substances as well, data are still indicative of the long term risk for these infants.

Although not all categories of high risk infants have been examined, it is clear that significant problems in the neonatal period represent risk for continued problems in childhood. It is important to identify these infants so that follow-up and support can be offered to families, who are also experiencing a crisis during and following the hospitalization of their infant.

Parents in Crisis

The stress that is experienced by parents of children who are hospitalized was demonstrated by Graves and Ware (1990) in their study of fifty parents of hospitalized children. They developed an inventory to describe stress levels parents experienced during various situations involved in their child's hospitalization. They compared the responses of parents to those of twenty seven nurses and twenty three doctors using the same inventory. They found that parents rated their stress levels higher than both groups of

professionals. Almost all aspects of the hospitalization created significant stress for parents.

Bass (1991) explored the experience of parents while their infant was a patient in NICU. Her sample did not indicate the gestation of the critically ill infants, and it is assumed that the sample includes parents of both premature and term infants. Parents ranked the needs they had identified, and indicated that the three most important needs for them while their infant was in NICU were; information, attachment/parenting, and staff support. Parents shared their experience of not feeling a part of their infant's life, yet wanting to bridge that gap.

This apparent role paradox was explored by Brown and Ritchie (1991) in their study of 25 pediatric nurses. They found that nurses described parents and nurses as fulfilling many similar roles, and interacting with each other as they performed those roles. The nurses studied felt a responsibility, though with limitations, for caring for the parent as well as the child. The majority of the nurses also saw, within their role, an element of gatekeeping or exerting control over the parent's role in the hospital. Brown and Ritchie suggest that for family-empowerment, parent participation in care and decision-making, and supportive nurse-parent communication to take place, the hospital environment must be supportive.

Parents of premature infants experience a specific crisis in relation to the premature birth of their child. Their experience may include: psychological effects of denial, blame and guilt, feelings of failure and ambivalence; parenting disorders from altered perceptions of their child; and depletion of both financial and emotional resources (Ladden, 1990). An infant born preterm immediately enters the health care system rather than the family system.

Aspects of the crisis faced by parents of premature infants was examined by Jeffcoate, Humphrey and Lloyd (1979a, 1979b). Their study matched 17 parents of infants weighing less than 2.1 kg at birth, with 17 parents of full term infants and used semi-

structured interviews. Compared to the experience of parents of “normal” term infants, pre-term parents experienced a much higher degree of emotional disturbance, delayed mother-child bonding and later management problems. Not all parents faced each type of problem. The extent to which the experience was described as a “crisis” was influenced by the extent to which family members treat the event as a threat to their status, goals and objectives. Preterm birth poses a greater threat to the self-esteem of mothers than fathers. Parents of pre-term infants perceived their role in caring for their child after discharge similarly to parents of term infants. This role included both caring and nurturing behaviors. The greater crisis experienced by mothers as compared to fathers of pre-term infants may be explained by the greater role expectations that they have. In most cultures and societies the mother is seen as the primary caregiver. This results in a greater ego threat to mothers when there is a “failure” in parenting. Pre-term birth has a greater impact in terms of the crisis experience for mothers, and also presents them with a greater challenge in mastering the tasks associated with it.

Blackburn and Lowen (1986) conducted a retrospective survey to describe the impact that premature birth had on parents and grandparents. The emotions that both parents and grandparents identified include: anxiety, unhappiness, guilt, failure, disappointment, grief, shock, fear, frustration, lack of control and helplessness. Although there were variations in the responses of mothers, fathers, grandmothers and grandfathers, they all identified a high intensity of a combination of these emotions.

Cronin, Shapiro, Casiro and Cheang (1995) conducted a matched case control study with a sample of parents of ninety six very-low-birthweight infants, using Stein's Impact on Family Scale. They looked at the long-term impact of premature birth and found that significant levels of stress are evident even up to five years after the child's birth. This stress was found to affect self esteem, work, family life and other siblings. Also they found that premature birth, complicated by functional handicap of the child, can

put significant financial stress on the family. Their findings suggest that long-term social and formal support is needed by these families.

Facilitating the transfer of care of high risk infants from hospital staff to parents is one of the most important roles of nurses caring for infants requiring hospitalization for significant illness. There are four key time frames within which health care professionals work with families. The first is during the crucial first days and weeks when the survival of the infant is the most tenuous. The second is during the infant's convalescent period during which infants recover from the sequelae of prematurity. The third consists of the time preceding actual discharge when the majority of formal parent teaching takes place. The last time frame consists of the months and years of follow-up and early intervention in the community. There are two key needs of parents which may protract these time frames. They are the need for information and education, and the need for support

Formal Support

Parent Education

The Level III NICU is most often the place where parents face the initial crisis of having a premature infant. Gennaro, Zukowsky, Brooten, Lowell and Visco (1990) found the greatest number of concerns raised by mothers of low birthweight infants was during the first week after birth. One method parents use to deal with this crisis is to seek information. During the time when the infant's survival is tenuous, most information provided for parents concerns the infant's disease state and condition. Much of this information is provided by medical staff. It is during the convalescent period when nursing staff are called upon to teach parents about their premature infant. There are few studies that have focused specifically on the education parents require or receive during this time frame. Two studies, however, illustrate the effect of education on parent's perception of and interaction with their preterm infants.

Culp, Culp and Harmon (1989) developed a tool for assessment of preterm infant behavior used in NICU for educating parents about their premature infants. They tested the tool by applying it to an intervention group that received teaching regarding premature infant behavior, and to a group that did not. They found that parents who received the intervention teaching had a higher level of perception of their newborns based on scores from their tool, than those who did not. They also found that the mean anxiety level in fathers who received the teaching was significantly lower than in those who did not. Teaching had no significant effect on anxiety levels of the mothers.

Harrison, Sherrod, Dunn, Olivet and Jeong (1991) implemented a similar study with mothers of preterm infants. Using verbal instruction, video and demonstration, the intervention group was taught how to interpret the behavioral cues of their infant during interaction. There was no significant difference in the ability of the intervention mothers to interpret the behavioral cues of their infants, as compared to non-intervention mothers. This study suggests structured teaching does not necessarily have a significant impact on interaction of mothers with their premature infants.

Discharge Teaching

The second major crisis that parents experience is the transition from hospital to home care of their infant. Much of the research regarding parents of premature infants has focused on the discharge learning needs of families.

Cagan and Meier (1979) published one of the earliest accounts of a discharge planning tool for families with high risk infants. They focused on the essential care needs of the infant such as feeding, bathing, special treatments and medications, as well as the psychosocial needs of the parents and their plans to incorporate the infant into their family. Cagan and Meier (1983) tested this tool using a questionnaire for two groups of parents shortly after the discharge of their infant. One group received discharge teaching using the discharge planning tool, the other received discharge teaching in the manner traditionally

provided in the unit. The intervention group perceived themselves as more adequately prepared to perform caretaking activities for their infant, and indicated they had received more information than the group receiving traditional discharge teaching.

McKim (1993a) adapted the questionnaire developed by Cagan and Meier (1983) to examine whether parents of premature infants in St. John's Newfoundland were receiving the information they needed to care for their infants at home. Her survey of 56 mothers of premature infants was compared to a similar survey of mothers of healthy term infants. Results indicated mothers of premature infants received information similar to that given to mothers of healthy term infants. The mothers of the high risk infants indicated their desire for more information and support specifically directed towards their particular needs. They also requested more appropriate written material for their reference. The data suggested mothers who reported that they needed more information and did not receive it were more anxious and less confident in caring for their infants. Further analysis of the data also indicated that the more premature the infant, the longer the length of hospitalization, the more likely that the mother indicated that the first week at home was difficult (McKim, 1993b). One factor that diminished these affects was the visit of a community health nurse, indicating that even this amount of professional support can alter a mother's perception of difficulty.

The perceptions of parents of high risk infants regarding both their learning needs and the teaching they receive, can vary greatly from the perceptions of the nurses. Sheikh, O'Brien and McCluskey-Fawcett (1993) investigated this potential discrepancy by surveying both parents and nurses. Both groups were asked to rate, in order of importance, 42 items pertaining to discharge teaching. They asked nurses to indicate whether that topic was currently being discussed with parents, and asked parents to indicate whether they recalled learning it. There was agreement between parents and nurses on which information was more important for parents to learn. The most important topics included feeding, monitoring baby's health, and taking care of baby's health. The

survey indicated however, that although NICU staff consider a large number of topics important for parents to learn, parents did not recall having learned them. Kenner and Lott (1990) came to similar conclusions after reviewing interviews and diaries of parents after discharge. The parents in their study perceived a large gap between their needs, perceptions, and concerns, and the health care professional's perceptions. This becomes a more important point as high risk infants are being discharged increasingly earlier.

Early Discharge

Health care reform in the 1990's has made the topic of early discharge a very timely one. Brooten et al. (1986) began an investigation of the possibility of earlier discharge for preterm or low birthweight infants. Their study of 80 infants randomly assigned to the control or experimental group provided instruction, counseling, home visits and daily on-call availability of a hospital-based nurse specialist for 18 months for experimental families whose infants were discharged early. Experimental infants who met the criteria were discharged a mean of 11 days earlier, weighed 200 grams less at discharge, and were two weeks younger at discharge than control infants.

Content analysis of the teaching provided to the early-discharge families indicates topics related to the immediate needs of the infant (Brooten, Gennaro, Knapp, Brown & York, 1988). Infant caretaking, infant health, growth and development and managing in the health care system, were the dominant topics both pre and post-discharge. The learning needs of families caring for high risk infants did not change significantly after discharge.

Casiro et al. (1993) describes a similar study in which 100 infants were randomized to either an intervention or control group. The intervention group received enhanced public health nursing and homemaker services for up to eight weeks after discharge. The most significant reductions in length of hospital stay and weight at discharge were for infants of 1501 - 2000 gram birthweight, who went home a median of 7 days sooner than

the controls, and weighed 130 grams less at discharge. There were no significant differences between the intervention and controls for the group of <1500 gram birthweight. There were no significant differences in terms of rehospitalizations or use of health care services after discharge.

Both of the early discharge studies indicate that discharging premature infants earlier than the norm can be safe and cost effective when short-term support services are provided. After completing this research however, Brooten (1995) concludes that earlier discharge may also increase the burden of care, stress and expenses for families, and that there is a risk that further complications in the neonate's health may be undetected. She recommended providing continuing home support services to these families.

Parent Needs and Concerns After Discharge

When the anticipation of caring for their high risk infant at home becomes reality, parents encounter their second major crisis since the birth of the infant. Discharge teaching and preparations for discharge attempt to address anticipated needs of parents. Much of the research that directs discharge teaching has been done retrospectively, projecting the needs that parents identified after discharge. In many cases discharge teaching focuses on basic provision of care, with some teaching done to prepare parents to deal with potential problems. As has been demonstrated, the teaching done in the hospital often falls short of meeting the needs perceived by parents (Sheikh, O'Brien, McCluskey-Fawcett, 1993; Kenner & Lott, 1990).

Concerns of mothers of high-risk infants continue after the infant has been discharged. Goodman and Sauve (1985) used a semi-structured questionnaire format to ask thirty mothers of high risk and normal newborns to rate their concerns at two weeks and again at six weeks following their infant's discharge from hospital. They determined that although all mothers of newborns have concerns, those concerns expressed by

mothers of high risk infants differed in degree and frequency of expression. Their concerns focused on feeding, sleeping, appearance, and attachment.

Gennaro, Zukowsky, Brooten, Lowell and Visco (1990) found that the concerns of mothers of premature infants are greatest at the two points of crisis, the initial period following birth, and again immediately following discharge. Their descriptive longitudinal study of 65 mothers indicated that the most common concern for these mothers was for the health of the infant. Other concerns mothers indicated were the infant's growth and development, maternal career and childcare, separation from the infant, parental roles, and material concerns.

In an analysis of the content of parent-initiated telephone calls to an on-call service for parents of very low birthweight infants, Butts et al.(1988) report the most frequent reason that parents called was to discuss newborn health problems and normal infant care. All mothers who called seemed anxious and needed reassurance.

McCain (1990) reviewed anecdotal information collected from parents of premature infants 24-48 months after discharge and found that the most frequent concerns were in the area of the child's health and development. In spite of the majority of infants having good health and normal development, parents continue to have concerns and questions regarding both present care and future potential of their child.

Early home intervention is one response to these ongoing concerns of parents. Barrera, Rosenbaum & Cunningham (1986) randomly assigned infants to one of three groups; developmental intervention, parent-infant intervention, and control. The interventions continued for a year after discharge. Developmental, temperamental, maternal interactive and home environment tests were done at 4, 8, 12 and 16 months corrected age. The findings suggest that both developmental and parent-infant intervention improved the infant's development. The parent-infant intervention had the greatest impact on home environment and mother-infant interaction. The added encouragement and reassurance provided by this intervention appeared to assist parents in

providing a greater variety of stimulation for the infant, and in more successfully incorporating the infant into the home.

Formal support following discharge can take the form of provision of information and consultation for mothers. Affleck, Tennen, Rowe, Roscher, and Walker (1989) conducted a study of 138 mothers who were randomly assigned to a control or intervention group. The intervention consisted of The Transitional Consultation Program, with weekly home visits averaging 2 hours each for 15 weeks following discharge of high risk infants. Results of the questionnaires administered before and after the intervention period indicated that for mothers needing a high level of support, the program had positive effects on their perceptions of personal control, sense of competence and responsiveness to the infants. The program had a negative effect on mothers needing a low level of support. The study indicated that mothers may be served better by determining what they need, rather than health care personnel assuming what their needs are.

Able-Boone and Stevens (1994) conducted a study to describe the well-being of families of graduates of intensive care nurseries. They compared fifteen families whose child was a graduate of an intensive care nursery and had identifiable disabilities, with fifteen similar families whose child was a graduate of intensive care but had no identifiable disabilities. The children ranged in age from 1 to 3.5 years of age. A variety of instruments were used to measure various aspects of family well-being in two separate interviews. Results indicate that all families experienced changes in their sense of family, children, and life itself as a result of their experiences. Families of children with disabilities had more concerns and faced greater challenges in obtaining services and dealing with financial burdens. Both sets of parents indicated that they relied on each other for support. Parents of children with disabilities wanted more information and support from community resources, while those without disabled children wanted more positive and understandable information from health care workers. Numerous studies support the

contention that education and social support can influence a family's caring for a high risk child at home.

Parents of high risk infants in the Canadian province of Manitoba do not differ greatly from their counterparts across the continent. The perspectives of a group of 50 parents of infant hospitalized in Neonatal Intensive Care has been documented in two unpublished studies.

Hamelin (1991) discovered mothers had significant and continuing concerns after their infant was discharged home. Data supported the assertion that birth of a high risk infant is a stressful experience for the family and that this crisis can continue in the post discharge period. Although the majority of mothers felt confident that they could care for their infant upon leaving the hospital, they continued to experience feelings of apprehension, fear and anxiety. Their predominant concerns were for the respiratory status, continued growth, and developmental progress of their infant. Most mothers thought they needed more information concerning the unique characteristics and needs of their infants to care confidently for them at home. Mothers felt they would have been more prepared had they been given more comprehensive, consistent and realistic information. Mothers stated they felt abandoned by the health care system after discharge. The data also indicated that high risk infants were more difficult and less rewarding to care for at home.

Saydak (1991) found that 6 weeks after discharge, these same parents continued to have persistent worries and concerns. There was evidence at this point that there were frequent alterations in attachment between mothers and their infants. Parents with greater levels of concern did not appear as closely bonded to their infants as those with fewer worries.

In analysis of data obtained in the early discharge study previously described as conducted by Casiro et al. (1993), Shapiro (1995) concluded that a community-based program utilizing homemaker support as well as some home nursing visits had a positive

impact on the home environment. Families who received the home support after early discharge scored significantly higher on the HOME assessment scale, which measures quality of home environment, than those families who received no home support following discharge at the usual time.

Breastfeeding Support

Studies which examine the concerns of mothers after discharge of their high risk, and especially premature infants indicate that one of their main concerns is growth and development of their infant. Few of the studies reviewed have made mention of breastfeeding concerns. One of the hypothesized reasons is that in the past, few mothers of preterm or infants who were critically ill at birth were breastfeeding their infants at time of discharge. As breastfeeding supports for these mothers have increased, more mothers are successfully breastfeeding their high risk infants for longer periods of time.

Kavanaugh, Mead, Meier and Mangurter (1995) used an interview guide in a naturalistic inquiry to determine the nature of breastfeeding concerns of twenty mothers of preterm infants. They found three main categories of concerns; adequate milk consumption by the infants, milk composition, and problems with the mechanics of breastfeeding a preterm infant. Strategies that mothers used included complemental and supplemental bottle feedings, and finding ongoing cues that the infant is getting enough.

Meier, Engstrom, Mangurten, Estrada, Zimmerman and Kopparthi (1993) responded to their concerns about the high rates of breastfeeding failure, up to 70 percent among mothers of high risk infants, by developing a model for providing support during the infant's hospitalization. They used a participant-observation approach to document interventions and breastfeeding outcomes in NICU. The five categories of interventions that emerged included: expression and collection of mother's milk; gavage feeding of expressed mother's milk; in-hospital breastfeeding sessions; postdischarge breastfeeding management; additional consultation regarding miscellaneous concerns. At time of

discharge from hospital 71.2 percent of the 132 mothers in the study were breastfeeding. They concluded that the intervention model was successful in preventing in-hospital breastfeeding failure for mothers of infants in NICU, and that this level of support is best done by a lactation consultant or specialist who can provide more time than the nurses in the unit.

Social Support

Support provided by professionals, especially within the hospital often goes beyond the boundaries of education and expectations of caring required by the job. Although this form of support is often of a more social nature, it does not fit into the confines of the definition of social support because it is done within the boundaries of the professional position, it is time limited to the clinical situation, and has no expectations of reciprocity. Although professionals may become 'friends' with parents of high risk infants, they are not easily admitted into their social network. Social support, as described in the theoretical framework of this study, refers to the services and support offered by persons within the social network of the individual. Since the 1970's it has been studied in relation to a wide variety of populations and groups, with a frequent focus on how social support affects health. Numerous studies have examined the role of social support in pregnancy, parenting, life changes, and stressful situations.

Hirsch (1980) studied various aspects of the social support networks of 34 women. He looked specifically at the relationship between support and coping. His findings indicated that helpful support enhances adaptation to stress which is produced by various life changes. He found that helpful guidance received by the women during times of change assisted them in delineating between necessary and unnecessary tasks, to find alternative coping behaviors and environmental resources, as well as serving as an

outcome criteria for judging the effectiveness of their own coping efforts. He suggests that the heightened sense of self-efficacy may help to sustain positive coping behavior.

There are times when social support and professional support are linked. This was the case in the study reported by Higgins, Murray and Williams (1994). They used the Coopersmith self-esteem inventory, the Personal Resource Questionnaire, and the prenatal care satisfaction inventory with their sample of 95 women who had received adequate prenatal care and 98 who had inadequate prenatal care. They discovered that women who had received adequate prenatal care by utilizing more professional support and services, had significantly higher self-esteem, significantly more social support, and were significantly more satisfied with prenatal care than women who had inadequate care. Their measurement included perceived level of social support as a composite of attachment and intimacy, social integration, opportunity for nurturant behavior, reassurance of worth as an individual and in role accomplishments, and availability of informational, emotional, and mutual help.

Cronenwett (1985) looked specifically at pregnancy outcomes as they related to social network structure and perceived access to social support for a sample of 50 primigravid couples using the Social Network Inventory and the Postpartum Self-Evaluation Questionnaire. She found that both access to emotional and instrumental support were positively associated with postpartum outcomes at six weeks. Her results indicated that information and appraisal support were not significant variables at this time.

Burke and Liston (1994) used a descriptive survey to explore the perceptions of social support and the impact of parenting on the lives of 78 adolescent mothers. They found that the most important sources of support were the adolescent fathers, as well as their own mothers. Although the adolescent mothers rated community services as very important, they rarely used them. One explanation given for this was lack of access. Overall results indicated that parenthood in adolescence is a situational crisis with both a positive and a negative impact.

Looking more specifically at parents of children who are critically ill, Tomlinson and Mitchell (1992) used the Family Crisis Support Interview with their sample of 10 families. One of the themes that emerged was 'inappropriate support', which was an indication of the potentially negative effects of social support. They found that mobilization of support through network communication was important, especially in acute stages of crisis. For these families, there were pivotal relatives who could mobilize support. They found significant differences in the way mothers and fathers dealt with the stress. For mothers in particular, one common problem identified was role strain. This resulted from adding the additional tasks of visiting the hospital, to their existing roles within the family, which included caring for other children, and working outside the home. Although this was a small convenience sample, these studies have supported social support theory.

Social support theory has been applied in various ways to NICU situations. McHaffie (1992) looked specifically at the role of grandparents in providing support to parents of very-low-birthweight infants in NICU. She surveyed 181 parents, 242 grandparents, 265 nurses, and 63 doctors. She reported that grandparents, nurses and doctors considered grandparent's primary role to be providing emotional support to parents. Parents also looked to grandparents to provide support during visits, but also indicated the need for other services and material support from grandparents as well. Parents indicated a strong need for expert information which they expected to received from professionals. Parents were in general agreement about their expectations for support and in their desire for emotional support, but different parents saw different actions as supportive.

Prudhoe and Peters (1995) also studied both parents and grandparents in NICU using an intergenerational family systems approach with 12 families of preterm infants. In their sample, parents indicated that utilizing social support was one of their main coping strategies in dealing with the stress of NICU. Both parents and grandparents indicated

that grandparents provided emotional and physical support to parents. Grandparents also indicated their own need for emotional support and information, which were not always met. The types of support needs that parents cited most frequently were; emotional support, physical help, information, spiritual guidance counseling, and support groups. Some indicated that written information was more helpful than support groups because they could access it on their own time. Talking to other parents was not always helpful because they were not necessarily going through the same things at the same time. The small size of this sample makes some of these results difficult to generalize, although the findings repeat those from previous studies.

Self-help groups, or parent support groups have been attempted and studied numerous times. Minde et al. (1980) completed a controlled evaluation of a group of 28 families of preterm infants who met weekly for 7-10 weeks with a nurse coordinator and a "veteran mother". They were compared with 29 control families who also had preterm infants. Data was collected at one, two and three months after discharge. The group families rated themselves as more competent on a number of different infant care measures. They also continued to be more involved with and more concerned about their infant's general development three months later. Group parents exhibited increased feelings of confidence in their higher use of baby-sitters by the third month after discharge.

Meier (1994) also studied parents who participated in group meetings. Parents volunteered to attend meetings with a nurse and other parents from NICU. Parent feedback results indicated that they found it more helpful to talk to other parents who were currently experiencing a similar crisis, rather than having experienced it in the past. The main concern of fathers was how to support their wives. Although there was no control group, and the data was collected informally, some of the feedback supports that of parents in previous studies.

Lindsay et al. (1993) took a slightly different approach to parent support with their Perinatal Positive Parenting Program. They provided parents of infants in NICU with an

opportunity to talk with an experienced NICU parent about feelings and concerns, access to information, constructive help in caring for their infant, assistance in identifying community resources, and encouragement to take care of themselves and other family members. The program consisted of a professional coordinator and volunteer experienced parents who were given special training. The study group was compared to a control group during the research phase of the project. They found that mothers who received support reported better mood states, less anger, less depression, and less anxiety. They also had better maternal-infant relationships and a better home environment twelve months after discharge. Although the type of support provided by these programs also does not fit strictly into the definition of social support, results indicated the linkages between social and professional support. In the situations where parents interact with other parents, or experienced parents, it can be viewed as an expansion of their social network. In some cases it is difficult to distinguish between social and professional or formal support.

Self-Efficacy

As the final link in the chain between crisis and successful parenting of a high risk infant, the measure of self-efficacy provides not only a gauge for the effectiveness of education and social support, but also a predictor of potential need. Gross, Rocissano and Roncoli (1989) analyzed results of a mailed questionnaire completed by 70 mothers of full term infants and 62 mothers of preterm infants. The infants were between 12 and 36 months of age at the time of the study. Their purpose was to explore predictors of maternal confidence within these two groups, and to determine if mothers of infants born weighing less than 2500 grams had less confidence than mothers of full term infants. Bandura's theory of self-efficacy was used as the theoretical basis by which maternal confidence was defined. Maternal confidence was measured using the Toddler Care Questionnaire. Authors reported that both groups of mothers in their study indicated

equal confidence in caring for their toddlers. The most potent predictor of maternal confidence was childcare experience prior to becoming a mother. Among the preterm group, having an older child was an important predictor of confidence as well. This was not as strong a predictor among the full term group. In the full term group, maternal confidence was higher if the mother was older and the child had a higher birthweight. Authors suggested the similarities between the two groups might be explained by the relative good health of the group of preterm infants in the sample, and that mothers may have received early intervention support at home. They also suggested that some of the stress of preterm birth compares with that of simply parenting a toddler, by one year of age.

In a follow-up study Gross, Conrad, Fogg and Wothke (1994), used a longitudinal sequential design to test a model of maternal self-efficacy with 126 mothers of one year olds and 126 mothers of two year olds. They examined the linkages between maternal depression, and self-efficacy, and perceived difficult temperament of the child. Their results suggest that mothers reporting depression were more likely to rate their child's temperament as difficult. Children with more difficult temperament had mothers with lower self-efficacy. Mothers reporting depression at any one point in time were more likely to report similar symptoms in six months. These results support previous literature which indicates that high risk infants are often also at risk of having difficult temperaments.

Infant temperament, as well as social support was linked to parenting self-efficacy in Cutrona and Troutman's (1986) model of postpartum depression. They tested their hypothesis that both infant temperament and social support would affect the level of maternal depression. They assessed 55 women during pregnancy and at three months postpartum, and tested infant temperament with the Revised Infant Temperament Questionnaire. In their analysis, they found that infant difficulty alone accounted for 30 percent of the variance in post-partum depression score. The buffering affect of social

support was highlighted by the women who reported higher levels of social support during pregnancy, also reporting higher levels of self-efficacy and less depression three months after delivery. They also found that greater infant difficulty was related to lowered maternal self-efficacy. Although the sample was relatively small, the model provides impetus for future research linking variables associated with parenting.

A tool for testing specific self-efficacy as it relates to mothers caring for their infants was developed by Froman & Owen (1989). This 52 point scale was designed to assist caregivers in assessing self-efficacy about specific infant care behaviors including the two major areas of knowledge and skills. They tested this tool using a convenience sample of 200 mothers and the nurses caring for them prior to the mothers discharge from the maternity unit. They found positive correlations between number of children or previous infant care experience and high self-efficacy scores. They also found that mothers of female infants tended to have higher scores than mothers of male infants. Health of the infant had a negative correlation with scores. There were some discrepancies in the estimates of nurses, some of which may be the result of underreporting of mother's skill and experience. Their study supported the validity and reliability of the tool, as well as Bandura's theory on the sources of self-efficacy, which include observation and previous experience.

Summary of the Literature

The literature provides a view into families of high risk infants. Cooke (1994) demonstrated the difficulties and disabilities experienced by infants born at 28 weeks or less gestation. Walsh-Sukys et al. (1994) also described the long-term problems of term infants who had been hospitalized for respiratory compromise. These situations provide parents with a crisis which carries through both the hospitalization and subsequent discharge of their high risk infant (Graves & Ware, 1990; Bass, 1991; Jeffcoate,

Humphrey & Lloyd, 1979a, 1979b; Blackburn & Lowen, 1986; Cronin, Shapiro, Casiro & Cheang, 1995). Discharge teaching has been demonstrated to provide parents with the skills and confidence necessary to care for their infant at home (Cagan & Meier, 1979, 1983; McKim, 1993a; Brooten et al., 1986). There are however, often discrepancies in the perception of parents and nurses regarding the teaching that has occurred in hospital (Sheikh, O'Brian & McCluskey-Fawcett, 1993; Kenner & Lott, 1990). Enhanced formal support at home has also been demonstrated to be effective in allowing shortened hospital stays (Brooten et al. 1986; Casiro et al., 1993). Parents continue to have concerns about their infants after discharge (Goodman & Sauve, 1985; Gennaro, Zukowsky, Brooten, Lowell & Visco, 1990; McCain, 1990). Hamelin (1991) and Saydak (1991) found that concerns are persistent following discharge, and that the needs of parents are not always met during the infant's hospitalization. Social support is an important component of life in the crisis situation, and can enhance coping for parents (Prudhoe & Peters, 1995; McHaffie, 1992; Minde et al., 1980; Lindsay et al., 1993). Both infant temperament and social support has an impact on the confidence that parents have in caring for their infant at home (Cutrona & Troutman, 1986). The full relationship between formal support, social support and maternal self-efficacy however, has not been explored. The literature has provided the basis for this exploration.

Chapter 4: Methodology

Study Design

This study describes the education and support needs of parents of high risk infants in Winnipeg Manitoba, and examines the relationship between parent education, social support and self-efficacy. A correlational design was used to describe the relationship between the variables in question; parents needs, and information and support given by hospital staff and other health care workers, social support, and self-efficacy. An ex post facto approach as described by Roberts and Ogden Burke (1989) was used. Mothers of high risk infants were asked to fill out a self report questionnaire and participate in semi-structured interviews four to six weeks after the discharge of their infants. This time period allowed parents time to resolve some of the issues involved in the crisis of the transition from hospital to home. It also gave them time to compare what they needed to know with the information they received. The time was short enough that parents remembered much of what they were told in the hospital. The majority of parents were asked to respond to open-ended questions as well. Qualitative data was generated. Triangulation of the data between qualitative and quantitative lends validity to the results. Results from the questionnaires were compared to the content analysis of interview responses to determine amount of congruence between the two sources of data.

Setting

The setting from which the sample for this study was drawn is the Neonatal Intensive Care Unit (NICU) and Intermediate Care Unit (IMCN) at the Health Sciences Centre and St. Boniface General Hospitals in Winnipeg, Manitoba, Canada. Interviews were conducted in the subjects homes or a place mutually agreed upon by both the subject and investigator.

Personal contact was chosen as the method of both recruitment and data collection rather than utilizing a mailed survey in order to improve participation (Diekmann & Smith, 1989). Personal presence allowed the investigator to answer questions, allay anxiety and clarify items on the questionnaire (Catanzaro, 1988). Conducting the interviews in the person's own home also added to their level of comfort and enhanced the quality of their responses.

Subjects

A convenience sample of 50 parents of high risk infants was chosen based on the following criteria:

- 1) infant was admitted to NICU or Intermediate Care Unit immediately after birth.
- 2) infant remained in hospital at least 10 days.
- 3) parent was 18 years of age or older.
- 4) parent planned to keep the baby.
- 5) parent understood written and verbal English.
- 6) infants with lethal congenital anomalies were excluded.
- 7) infants receiving palliative care were also excluded.

Use of a random sample would be preferred, however less than 200 infants per year meet these requirements. The time required to enroll a larger number of subjects in the study might prove to be a confounding variable with the swift changes that have been taking place in Winnipeg hospitals over the past months. Both of the hospitals involved in the study are in the process of work-restructuring, which includes both budget cuts and changes in the scope of practice for many professionals. Nurses have been taking on larger patient assignments, which leaves them with less time to interact with parents. Representativeness of the sample was assessed by a detailed description and comparison with the samples in similar studies conducted in Winnipeg and with provincial

demographic data. Due to cultural differences in various populations and to help insure homogeneity, the sample was restricted to a white population.

Recruitment of subjects took place in cooperation with staff nurses in the intermediate and intensive care units at Health Sciences Centre and at St. Boniface Hospital. The nurses in the units caring for the infants were given an explanation before the study began so that they were aware of the study and were able to give support to it.

To recruit subjects, the principal investigator identified potential subjects through discussions of study criteria with charge nurses in the units to make sure that the parents were not experiencing undue stress. This was to ensure that the request to participate in the study would not add unnecessary additional stress. Parents were approached during a time when discharge was already being planned and survival of the infant was a relative certainty.

Staff nurses were asked not to put undue pressure on mothers to participate in the study. An explanation form, found in Appendix C, was either left at the infant's bedside or given to the parent by the investigator. It provided parents meeting the criteria with a brief description of the study while the infant was still in the hospital. The form asked for their signature to provide permission for the principal investigator to obtain their name and telephone number. Those parents who gave permission were then contacted by telephone or in person by the investigator, to reaffirm their consent and provide them with a more detailed description of the study. The investigator made arrangements for a meeting four to six weeks after the discharge of infants, with parents who agreed to participate. The consent form, found in Appendix D, was signed at the time of interview. During the interview, the parents were again provided with a description of the study, found in Appendix D, and asked to sign the consent form. They were given the option of having a summary of the results sent to them upon completion of the study.

Instrumentation

The first questionnaire used in this study was adapted from one developed by Dr. Karen Luker, University of Manchester, England. The original instrument was piloted in England by mothers of infants who had required intensive care at birth and subsequently used in Hamelin's 1991 study of 50 mothers in Winnipeg. The questionnaire has been modified after consultation with Kathy Hamelin (personal communication, June 23, August 20, 1995), based on her experience in using it and to reflect changes that have taken place in the intervening years, as well as to fit the theoretical approach of this study. It is titled the Formal Support Questionnaire (FSQ) and is found in Appendix E. The first part asks questions about the information and formal support mothers received both while their infant was in the hospital and since discharge. The questions focus on the education, feeding support, and follow-up support the mother received both while the infant was in the hospital and since discharge. The Likert-type scoring scale was developed for the purpose of this study in consultation with Dr. Annette Gupton and Dr. Linda Kristjanson, experts in Nursing Research and tool development at the University of Manitoba.

The second tool used was the Norbeck Social Support Questionnaire (NSSQ). In initial testing of the instrument, Norbeck, Lindsey and Carrieri (1981) used it with a sample of graduate and undergraduate nursing students. They demonstrated high test-retest reliability using Kendall Tau B with $p < .0001$ for each of the categories in the scale. Social desirability bias was tested using the Marlowe-Crowne Test of Social Desirability concurrently with the NSSQ. The correlations ranged from .01 to .17 suggesting that the NSSQ is relatively free from the influence of social desirability response bias. Concurrent validity was tested by comparison with another measure of social support with moderately high correlations (.44-.56). Further testing of the tool by Norbeck, Lindsey and Carrieri (1983) provided increased construct validity with significant correlations between the NSSQ and two similar interpersonal constructs with $p < .05$ for network variables and $p < .01$ for functional variables when compared in paired *t*-tests. It was also found to be

sensitive over time in a seven month follow-up with $p < .01$. The NSSQ is found in Appendix G. It is scored using a numeric system designed by Dr. Norbeck.

The tool that focuses on the third major concept in this study is the Infant Care Survey (ICS) developed by Froman and Owen (1989). This questionnaire contains questions which measure a parent's reported confidence in providing care for an infant, with 52 specific items scored with a 5 point Likert-type scale. The confidence scale is designed to indicate self-efficacy in the areas of knowledge and skill. The tool was tested with 200 mothers and their nurses in order to establish its validity (Froman & Owen, 1990). The internal consistency correlation coefficient was reported as .975. Validity estimates supported use of this scale as a significant predictor of mothers' sense of efficacy. Multiple regression analysis was conducted to determine the predictability of overall ICS score with variables that included gender, age, race, number of children, and educational status. The multiple R value was .28, significant at $p < .001$. (Froman & Owen, 1989).

Qualitative interviews were conducted with 29 of the subjects. 21 of these subjects agreed to have the interviews tape recorded. The remaining eight provided only a few comments which were not tape recorded because the household environment did not allow for it, or because the parents stated that they did not have time to answer many questions. In these cases the investigator took written notes of the subjects responses. The intention of the investigator was to collect qualitative data from a subsample of at least 15 subjects based on an assessment of their willingness to share their experience and to attempt to gain a wide range of perspectives. More subjects were interviewed because many parents expressed their desire to tell their stories and talk about their experiences. The interview schedule, found in Appendix F, was derived from the tool used by Hamelin (1991) and Saydak (1991). This served as an outline for the interview, with additional questions dependent on the mother's responses. It contains questions with the intention of eliciting information concerning parent's perception of care provided to themselves and

their infants after discharge from intensive or intermediate care, and to identify common problems they experienced at that time. Subjects were asked to describe how the care they and their infant received matched their expectations and how they think care could be improved; what worries they had at discharge and during the six weeks subsequent to that; which sources of formal and informal support had been most beneficial. There also were questions within the interview schedule which addressed the mother's degree of self-efficacy.

Demographic and parenting information is used to describe the sample. It includes personal information about the parent, methods of feeding, and level of stress, as well as information about the infant. This data collection tool is found in Appendix H.

Ethical Considerations

Approval from the University of Manitoba Faculty of Nursing Ethics Committee was obtained prior to recruitment of subjects. The ethical approval is found in Appendix J. This study involved no manipulation of variables, or experimental conditions imposed on the subjects or their infants. All research subjects were adults over the age of 18 who had given informed consent. There were no perceived harmful effects of this study. There may, however, have been some psychological stress on the parents in discussing sensitive issues, and possibly stimulating some painful memories of their time in NICU. The investigator has over 10 years of experience in dealing with this population of parents and has developed the expertise necessary to insure sensitivity to difficulties and emotional reactions to participation. Parents who indicated particular difficulty at home were referred to the public health nurse, social worker, or pediatrician for follow-up. The discussion may have been beneficial for parents in providing them with the opportunity to express their feelings and opinions about the care that they and their infant received.

Many parents stated that it was good for them to talk to someone about their experience. Most shared their feelings without needing much provocation by the interviewer.

The staff nurses and the investigator made it clear to parents that participation was entirely voluntary and would have no bearing on their future hospital care. It also was made clear that parents had no obligation to participate. Anonymity of respondents was maintained by ensuring that there were no items of identification on the data collection tools. Results were stored in a computer software program, and subjects identified by number only. All questionnaires and data containing identification are stored in a locked container and will be destroyed 10 years following data analysis.

The benefit to the mothers and infants involved in the study will be minimal, as their time in hospital is over. The potential benefit to future parents of high risk infants is great however, as it is anticipated that the results should lead to further improvements in parent education and support in the various areas of the health care system which serve parents of high risk infants.

Rigor

A number of points have been considered in ensuring the reliability and validity of this study. External reliability is defined by Catanzaro (1988) as the degree to which independent researchers would discover the same phenomenon. The tool in this study has been used with the same population in Winnipeg in 1991, as well as a similar population simultaneously in England. The results of that study were similar to those found by Cagan and Meier (1983). Kenner and Lott (1990), using a qualitative approach also had similar results. In order to further ensure the external reliability of this study, all results were accurately recorded and reported.

Ensuring that this study gathered the information that was intended, or its validity, is a key concern in quantitative studies (Catanzaro, 1988). The tool and interview

technique was tested for clarity and understandability by administering it to five parents of high risk infants, and five nurses who work in the area. This allowed for minor changes to be made to the tool based on their recommendations, and to estimate the time it will take for both the questionnaires and interview schedule.

Creating a comfortable trusting environment for mothers in order to elicit truthful responses also is important. Assuring them of the anonymity of their responses increased the validity of the study. Roberts and Ogden Burke (1989) identify non-experimental designs as having the potential for the least internal validity. Triangulating the data, or utilizing both quantitative and qualitative data for systematic comparison is one method they recommend to combat this problem. The design of the questionnaire allowed for triangulation.

The convenience sample inhibits the ability to generalize the data. In order to strengthen this aspect of the study, the population was compared to the demographics of several other studies conducted with this population in recent years.

Data Analysis

Data was scored, coded and entered onto computer statistical analysis software SPSS-PC for Windows. The sample is described using demographic and parenting data. From the quantitative data collection, three variables were measured on ordinal scales; formal support, social support and self-efficacy. The FSQ is divided into the subscales parent education, and follow-up support. For each of these categories, a high score indicates high support, and a low score low support. The NSSQ includes three subscales; total function, total network and total loss. In the first two categories the higher the score the greater the support. In the total loss category, the higher the score the greater the loss. The ICS is divided into two major subscales of efficacy, knowledge and skills. In each category, the higher the score the greater the self-efficacy.

In order to answer the first research question, “what are the education and support needs of mothers of high risk infants”, mean scores from the FSQ and NSSQ were calculated. Descriptive statistics were used, with frequency distributions, measures of central tendency and variability. Each of the subscales is identified and assessed separately. Determination of parents needs was done by examining the items that received the lowest mean scores on the FSQ. Specific comparisons using non-parametric measures also were made between mothers who left hospital breastfeeding and quit, with those who are still breastfeeding. Other variables that were examined include hospital readmissions and number of follow-up visits.

Interview data provides answers to the secondary questions which are derived from the first research question: “What are the common worries and problems mothers experience when their infant is discharged from neonatal special care?”, “Who do mothers turn to for help and support after their high risk infant is discharged from special care?”, and “Which sources of support and information are most useful to mothers after their high risk infant is discharged from special care and why are these sources considered helpful?”. Interview tapes were transcribed by the investigator.

Qualitative analysis was done using a content analysis format as described by Polit and Hungler (1987). Interviews were transcribed and then reviewed for content. Major themes were identified and the data was coded and organized into “conceptual files” which related to the major themes. Sub-themes were derived from topics which emerged within these major themes. The coding system was used to manage the responses from parents. In reporting the results representative statements were used to reflect common responses from numerous parents within each of the themes and sub-themes. Data were compared to the results of the quantitative analysis to examine the trends and to integrate them into general findings.

The second research question asks “What is the relationship between parent education, social support and self-efficacy”. Variables examined in the correlation matrix

are described in Table 1. Scores from each of the scales and subscales were placed in a correlation matrix to examine relationships. Pearson's r was used.

The relationship of variables was examined to explore if any of the factors are significantly correlated. To answer the third research question "What is the best predictor of self-efficacy in mothers of high risk infants?", multiple regression analysis was conducted with the significant variables within the correlation matrix to determine the level of predictability of the variables within formal and social support that contribute to self-efficacy.

Table 1
Measurement of Variables

Variable	Measurement approach	Data Type	Range
<u>Formal Support</u>	Formal Support	ordinal	0-80
<u>subscales:</u>	Questionnaire		
parent education	FSQ #1-10	ordinal	0-50
follow-up support	FSQ #11-16	ordinal	0-30
<u>Social Support</u>	Norbeck Social Support	ordinal	
<u>subscales:</u>	Questionnaire		
total functional support	sum of aid and emotional support	ordinal	0-576
total network	sum of number, duration and frequency of contact	ordinal	0-504
loss of support	sum of loss, number & amount	ordinal	0-infinite
<u>Self-Efficacy</u>	Infant Care Survey		
<u>subscales:</u>			
Knowledge	ICS #1-27	ordinal	27-135
Skills	ICS #28-52 (not #48)	ordinal	24-120

Chapter 5 Results

The purpose of this study was to examine the relationship of the educational and support needs of parents of high risk infants. Three major research questions are: 1) What are the educational and support needs of parents of high risk infants?; 2) What is the relationship between parent education, social support and self-efficacy related to caring for a high risk infant at home?; and 3) What is the best predictor of infant care self-efficacy in mothers of high risk infants?

Results of the data analysis are described in this chapter. Demographic and parenting information is summarized in order to describe the sample. Two major themes that emerged from the qualitative analysis are: 1) Relationship with the infant; and 2) Interpersonal relationships with others. Within each of these themes there are stress reducers and stress producers which are identified as they arise. The qualitative data is presented for each theme and subthemes. Results from each of the survey tools are described. The research questions are then addressed using descriptive information from the qualitative and quantitative data.

Demographic and Parenting Data

Data for this study was collected between December 1995 and May 1996. Fifty-six mothers were approached and invited to participate in the study while their infant was a patient in either St. Boniface General Hospital or the Health Sciences Centre. Only three mothers refused to participate. They included a mother of an infant with multiple non-lethal congenital anomalies, the mother of an infant born at 25 weeks who had been critically ill for a prolonged period of time, and a mother who had three other children at home and felt she was too busy. Fifty three mothers who agreed to participate were contacted four to six weeks after their infant was discharged to arrange a time for the

investigator to meet with them. At this time, three mothers refused to participate, two of them citing illness of other family members as their reason for doing so, and one not giving a reason. Fifty subjects participated, forty nine were mothers and one was a father who was the primary caregiver at home whose wife had returned to work and suggested that he would be the appropriate one to participate. Forty eight contacts took place in the subject's home, and two took place in a private office at the Health Sciences Centre at the request of the subjects. Contacts were made four to six weeks after the infant's discharge from hospital. One contact was made later because the mother spent three months visiting relatives after her infant was discharged.

Characteristics of sample parents and infants are summarized in Tables 2 to 8 on the following pages. The tables include a description of the method of feeding both at discharge and at the time of contact. Parents were asked to indicate their level of stress at the time of birth, the time of discharge and the time of the interview, as high medium or low. These results are reported in Table 7. The final table examines the numbers of follow-up contacts between the subjects and various health professionals.

Kangaroo care, which is a program of "skin-to-skin contact" between parents and their premature infants, was done by 34 percent of parents.

Table 2
Demographic and Parenting Characteristics of Sample

Variable	Groups	N (%)
Marital Status	married	36 (72%)
	common-law	5 (10%)
	single	9 (18%)
Family Income	< \$ 23,000	17 (34%)
	\$ 23,000 - \$ 42,999	18 (36%)
	> \$43,000	15 (30%)
Number of Children	no previous	30 (60%)
	one previous	17 (34%)
	> one previous	3 (6%)
Place of Residence	Urban (Winnipeg)	36 (72%)
	Rural (Outside Winnipeg)	14 (28%)

Table 3
Age and Education of Subjects

Variable	Mean	Standard Deviation	Range	
			Min.	Max
Age in Years	27.6	4.48	19	37
Years of Education	13.4	2.73	8	24

Table 4
 Characteristics of Infants

Variable	Mean	Standard Deviation	Range	
			Min.	Max.
Gestational Age in Weeks	32.7	3.49	26	39
Birthweight in Kilograms	1.97	.72	.729	3.64
Discharge Weight in Kilograms	2.50	.45	1.78	3.97
Days in Hospital	37.3	31.54	10	161
Days at Home	45.34	13.80	15	100

Min = Minimum
 Max = Maximum

Table 5
 Characteristics of Infants Related to Hospital Stay

Variable	Group	N (%)
Hospital of Admission	St. Boniface	27 (47%)
	Health Sciences Centre	28 (49%)
	Both	2 (4%)
Unit(s) of Admission	NICU only	5 (9%)
	IMCN only	11 (19%)
	both	41 (72%)
Infant Type	Singleton	44 (77%)
	Twins	10 (18%)
	Triplets	3 (5%)
Primary Reason for Admission	Prematurity	48 (84%)
	Apnea	2 (3%)
	Cardiac Anomaly	4 (7%)
	Other Anomaly	1 (2%)
	Respiratory Distress	1 (2%)
	Sepsis	1 (2%)
Readmission to Hospital	yes	3 (5%)
	no	54 (95%)
Significant Complications During Neonatal Period *	None	34 (60%)
	Patent Ductus Arteriosus	7 (12%)
	Necrotizing Enterocolitis	3 (5%)
	Intraventricular Hemorrhage	1 (2%)
	PPHN	1 (2%)
	Sepsis	5 (9%)
	Seizures	1 (2%)
	Renal Failure	1 (2%)
Condition at Discharge	No Obvious Problems	42 (74%)
	Required Surgery	7 (12%)
	Retinopathy of Prematurity	2 (4%)
	Required Medication	2 (4%)
	Cardiac Murmur	1 (2%)
	VP Shunt	3 (5%)

Note: PPHN = Persistent Pulmonary Hypertension of the Newborn

VP Shunt = Ventricular - Peritoneal Shunt

NICU = Neonatal Intensive Care Unit

IMCN = Intermediate Care Nursery

*Significant complications do not include respiratory distress, apnea, or feeding intolerance, which are commonly associated with prematurity.

Table 6
Method of Feeding

Method of Feeding	Breast N(%)	Bottle N(%)	Both N(%)
At Time of Discharge	16 (32%)	9 (18%)	25 (50%)
At Time of Interview	10 (20%)	22 (44%)	18 (36%)

Table 7
Level of Stress

Level of Stress	High N(%)	Medium N(%)	Low N(%)
At Time of Birth	27 (54%)	18 (36%)	5 (10%)
At Time of Discharge	8 (16%)	29 (58%)	13 (26%)
At Time of Interview	7 (14%)	13 (26%)	30 (60%)

Table 8
Number of Follow-up Visits

Variable	Mean	Std. Dev.	Min	Max
Public Health Nurse	2.44	1.90	0	10
Pediatrician	2.24	1.70	0	7
Family Doctor	0.44	0.76	0	2
Specialty Doctor	0.14	0.45	0	2

Std. Dev. = Standard Deviation

Min = Minimum

Max = Maximum

Qualitative Data

Most of the parents found themselves in the situation of being a hospital parent unexpectedly. Parents of multiple-birth infants stated they had been advised by their doctor of the potential for premature birth. Ten mothers had been hospitalized for at least a week prior to the birth of their infants and had also been prepared for the infant to spend some additional time in the hospital. The remainder of parents described a variety of unexpected obstetrical experiences which led to the admission of their infant to NICU or IMCN.

In the interview parents were first asked to tell their story. Additional questions from the interview schedule were asked to answer the research questions. Two main themes emerged from the analysis: Relationship with the infant and Interpersonal relationships. Four sub-themes emerged from the description parents gave of their experiences with their infants in the hospital; getting to know their baby, providing physical care, finding a parenting role, and worries and concerns.

The majority of mothers (n=27, 54%) described their level of stress at the time of birth as high. Although this number dropped significantly by the time of discharge, 14% (n=7) continued to describe their level of stress as high at the time of the interview. Both stress producers and stress reducers were identified by parents for each of these sub-themes and will be described in the participants own words in the following section.

The following page summarizes the themes and sub-themes which are discussed in this chapter. The stress reducers and stress producers are indicated for each of the areas. These are discussed as they relate to each other within the subthemes as they arise.

diagram

Figure 1: Summary of Qualitative Data

<u><i>Stress Reducers</i></u>	<u><i>Stress Producers</i></u>
Theme 1: Relationship with the Infant	
Getting to Know Baby	
<ul style="list-style-type: none"> • spending time • focusing on baby 	<ul style="list-style-type: none"> • infant's condition • hospital environment • other responsibilities
Physical Care and Touch	
<ul style="list-style-type: none"> • spending time • providing basic care • kangaroo care • breastfeeding success 	<ul style="list-style-type: none"> • separation • breastfeeding pressure with poor success
Finding a Parenting Role	
<ul style="list-style-type: none"> • searching for information & support • information readily given and consistent • participation in care planning 	<ul style="list-style-type: none"> • helplessness and lack of control and knowledge <ul style="list-style-type: none"> • not receiving enough information • lack of support from hospital staff and own support network <ul style="list-style-type: none"> • conflicting information
Worries and Concerns	
<ul style="list-style-type: none"> • adequate discharge preparation <ul style="list-style-type: none"> • previous experience 	<ul style="list-style-type: none"> • continued lack of knowledge • feelings of guilt, fear and uncertainty
Theme 2: Interpersonal Relationships	
<ul style="list-style-type: none"> • feeling of belonging and being welcome <ul style="list-style-type: none"> • consistent caregivers • communication between caregivers • individual responses to parents • positive attitude to their infant • getting to know hospital staff • "sharing" the experience with hospital staff 	<ul style="list-style-type: none"> • personality conflicts with staff • impersonal "cold" impression of hospital unit • nurses "too busy" to spend time with parents <ul style="list-style-type: none"> • strict, inflexible, insensitive hospital policies • feeling that the nurses "own" the infant

Theme 1

Relationship with the Infant

Getting to Know Baby

One of the ways that mothers identified to reduce their stress during their baby's hospitalization was to get to know their baby, as this comment illustrated: "We spent 18 hours a day with her, we knew her so well". Ten mothers described ways of getting to know their baby either by spending as much time as possible with them and incorporating them into their own life. A comment that illustrated this feeling came from one parent who said "That's your baby and you wanted to be there every minute". Others described this process as making the most of the time they had and focusing on their baby, watching them closely, such as this parent who said "I would stare at her for hours". Twelve mothers indicated that the most positive part of their experience was the time they spent with their baby, as this parent stated: "Watching her grow was really good".

When mothers wanted to spend time or focus on baby, but were inhibited for various reasons, their level of stress increased. These stress producers originated from three main sources, the infant's condition, the hospital environment, and outside influences. Each of these presented some form of obstacle to the parent in their attempt to get to know their infant. For many parents this represented the most negative part of their experience, as one parent stated: "The most negative...that would be where you are in intensive care. That babies are ill. Babies aren't making it, families are crying. It's not a nice environment as you know". The stress produced by having a sick child is obvious. Parents did not articulate their feelings about their child's illness and the potential for their infant's death. They articulated these feelings in other ways such as in this statement by one parent: "She had so many tubes in intensive care that there wasn't as much "hands on" in NICU...For the first few days it was really hard because she's so tiny".

To some the atmosphere presented the obstacle, as one parent said: "Intensive care was very hard. It just seemed so cold". In some cases it was the facility or factors inherent in an intensive care area as another parent pointed out: "In the hospital you're trying to find some privacy and there is none". Another felt stress in the way the facility affected their infant as this parent stated: "He was called the traveling man because he would be in a different spot every time. One time I went up to the wrong baby. Sometimes he was in the middle of the room. In that case I found it very stressful". Providing care for their infant was stressful for some parents as this comment indicates: "I didn't get much privacy breastfeeding. I had nurses, even floor washers interrupt me. That was with the curtain drawn. That's hard for a first time mom".

The added stress of having other responsibilities made the experience difficult for some parents: "You feel guilty leaving the other kids to go see her, and you feel guilty leaving her". Having to drive back and forth to the hospital was stressful for many of the parents.

It is evident by the content and frequency of these comments that stress was inescapable for parents. They made efforts to get to know their baby in spite of the stressful hospital environment and the implications of their baby's condition.

Physical Care & Touch

For parents an important step in the development of the relationship with their infant was getting involved in their care. In the "normal" birth experience parents are thrust into this role shortly after the birth. For parents whose infant is in an intensive or intermediate care unit this is not an expectation, and not always possible. One parent's comment illustrated this well, "I was removed from him. It's not that I thought he would die, it's just that I was not attached to him at all. You can't hold him, you can stand there and look at him. He's not doing a whole lot, he's just sleeping". As with getting to know their infant, time spent is a crucial factor in providing physical care and touch. It is also

both a producer and reducer of stress. Comments from parents were fairly evenly split between the two with ten parents commenting on the benefits of providing care and ten others identifying difficult situations they encountered with providing care for their infant.

For first time parents this task was just as important as it is for any new parent, as this parent states, "I was learning everything because I didn't even know how to give her a bath. It was nice to have the opportunity to be taught and to learn it". For some the care they gave to their infant was the most positive aspect of their experience, as this parent stated, "I was very happy with it [the care] there. We changed their diapers and bottle fed them". This experience helped some parents to overcome the stress of the environment, "It started out really stressful but once I got to take care of her it was really good". For others just the physical closeness provided them with a positive experience as this parent had, "The kangaroo care was one of my highlights. It was a first chance to bond with her".

Breastfeeding provided mothers with both the opportunities to provide care as well as some frustration. It provided some mothers with the best moments of their experience, as their comments indicated. One mother summed it up very well in this comment, "It was pretty good [breastfeeding] the nurse helped a lot with breastfeeding. It took a long time to get it right, but he latched on right away. It was good just to get to do it". For some it was the first tangible contribution they could make to their infant's life as this mother points out, "At first I felt that I could not do anything. That was one of the reasons that I choose to breastfeed because it was one thing that I could do".

It also provided some with the most difficult part of their experience. One mother highlighted the pressure put on to breastfeeding when she stated, "Breastfeeding was hard because there is so much pressure. They put the fear of God in you". For some the added pressure and difficulty was too much for them to handle after everything else they had been through as this mother stated, "That was a little bit frustrating. I was so tired and I felt I wasn't mentally or physically able to do it [breastfeeding] anymore". Another

supported this feeling when she said, "It [breastfeeding] just does not work for some people...it makes you feel like a failure if you can't do it".

Two mothers provided descriptions of their breastfeeding experience which illustrate the difficulty of this procedure for them:

I trust my values in breastfeeding, I trust the method. I would see them weighing other babies and I would see other moms getting all upset about it and I remember thinking at the beginning that I wasn't going to get like that. At the beginning I was just happy that she was putting her head down there. A first I thought I wasn't going to get hung up on it, but it happens, you break down bawling. You're just so tired and you're feeling that you missed out on so much with her and I was not going to miss out on this.

Then I started nursing. And that was frustrating, not that I felt, like they said don't feel like it will never work. I didn't feel that way...and you're bugging and bugging this baby. It should be a pleasant experience, not bugging and keeping him cold, and putting wash cloths on his head, it was just horrible. This was not a fun thing to do to breastfeed and be kept cold and woken up when you just want to sleep all day.

Finding a Parenting Role

It is clear from the comments from parents in the first two segments of this theme that finding their role as a parent is their task throughout the experience, from getting to know what an infant who is ill or premature is like, to learning to take care of him or her. Parents identified two subthemes which emerged directly from this task. The first is "searching", the second is "helplessness".

Searching

Parents searched for a variety of things. Every one of the parents identified some type of search. Most searched for information. Seventeen parents made comments related to their search for information. For many of them this was one way to reduce their stress, to conquer the unknown by making it known. One parent stated, "I read everything I could get my hands on". Another said: "We always asked questions... We tried to get answers". Many cited specific sources as this parent who said, "I was grateful for that book [Premature Baby Book], I looked up everything". To many, it was important that communication took place with hospital staff, as this parent stated, "It never failed when we came in, they told us everything that had happened in that day". This did not always occur for every parent as this parent's experience indicates, "Sometimes they told me nothing, but when I pushed them they told me things". Other parents had a similar perspective. One parent noted her displeasure with the situation, "I always had to ask about how he was doing. They never told me anything on their own. Some nurses would ask if I was the mother, others would tell me their name". Another with a similar experience said, "At the beginning I didn't feel like they were telling me enough. I feel like they should have been telling me everything that was going on. What happens if they would have died? You know, there would have been so much stuff that I didn't know about my babies. I was very upset". These parents clearly indicate the importance regular information and communication has for them.

Most parents when asked specifically if they felt they received enough information during their infant's hospitalization stated that they had. In spite of this, many provided additional comments about their desire and search for more information. The search for information did not always alleviate the stress, however. At times it produced stress in itself, as this parent describes, "We may have asked too many questions. We were informed right from the beginning. Maybe we got a bit too much information". Some parents illustrated in their comments the gap that exists between themselves and

caregivers. For some, as already illustrated, this gap was between what they wanted to know and what was volunteered to them by caregivers. For others it was in the difference in knowledge about their infant. One comment that illustrated how this gap cannot always be overcome was, "At times they couldn't answer my questions because they just didn't know the answers. That would be a little bit frustrating". Another comment clearly illustrates the difficulty parents experience in their search for information and knowledge.

I did ask questions about what I would see when the baby was born, but I never paid much attention to premies before. I would ask questions like what would he look like. You hardly know what to ask. You just wish they would offer information, but they are so familiar with it and we are so ignorant of it. We're just worlds apart really, because they don't even know what to offer as information.

Bridging this gap is an important task for parents who are faced with raising a premature infant. One mother of an infant born at 25 weeks gestation who had many problems during the months of hospitalization emphasized the difficulty of this task for her.

You have to be prepared for the answers to certain questions, and you might not always be ready. Some questions I asked weren't for quite a bit down the road. I had them but I wasn't ready to ask them. Like, I wanted to know what happened to her when she was born. I couldn't deal with that until she was off the respirator. It was just too hard, even asking the question.

Parents also searched for support. Nine parents made comments regarding their search for sources of support. Some of the parents indicated that they were not getting enough support, as this parent who had no family in the city, "We didn't have much support for a long time other than the nurses. When they finally sent a social worker to see us, it was better". Another parent talked about her search for other parents to talk to

in the hospital, "We didn't have anyone to talk to, and I think it's very important. Just someone who said I've been through it and I got through it. There was one person, but they went home just two days after we met them". Another parent talked about looking for peers who could understand their experience, "I tried talking to some of the other parents, but they just totally didn't want to talk. They would just say hi and that was it". The difficulty in the search for support became more frustrating when support persons were there but not allowed to visit. One parent found this particularly difficult, "We had trouble with them letting my family visit. First they ask for our support people, and then when I can't be there when they can, they didn't let them in". Just as the hospital environment became a barrier for some in developing a relationship with their infant, it was also not always conducive to finding support as this parent points out:

The social worker was there, but we had to meet in the hallway and stuff. I would have really liked to be able to go into an office to talk to her. Then I could get it out because it does help to talk, especially to somebody else who understands what you're going through. Like if there was a group for parents going through this, that probably would have helped.

Helplessness

The final sub-theme in the development of a parent role is the helplessness that parents identified. Parents felt a helplessness in their lack of knowledge and control in the situation. Much of this helplessness stemmed from difficulties which have already been identified. Parents felt helpless that they were in a hospital that they did not choose for their delivery, that their child was born in a manner that they did not choose, and was now in a unit being cared for because of health conditions that they did not choose. Every parent identified some degree of this feeling of helplessness, "I felt like I was totally incapable of doing anything. I just let all the nurses and doctors do everything". This helplessness was more evident in comments that related to the early days of their

experience, "It was a shock. I didn't understand what was happening at first. There were so many doctors and I got so much information. I had to sort it all out. I got too much in a short time". One parent summed up the overall feelings.

You're always so torn. No matter what you do. You know you're doing what you have to do, but you're very exhausted. When you are in the hospital you think you're never going to be able to take her home and that I'm going to watch her 24 hours a day. You do get over it, they tell you that you will and it's true.

Specific situations often contributed to this feeling of helplessness. Breastfeeding was one of these situations, as has already been discussed. One mother, who switched to bottle feeding two weeks after her infant came home further described her experience, "When I look back on it, it [breastfeeding] wouldn't have happened. He was too weak. It wouldn't have mattered what they would have done, it wasn't going to work."

To some parents the difficulties they had with nursing staff contributed a large part of their helplessness. They are at the mercy of the hospital and the system when their child is in the hospital, "It almost seemed like they just go from one baby to the other and they just forget, well not forget, but they don't tell you everything." Another parent cited the helplessness in leaving her child in the care of others.

The most difficult thing was not feeling confident when I went home, that he wouldn't get adequate care. But there was nothing you could do about it. Sometimes his alarms would ring and we knew that he wasn't breathing, and the nurse wouldn't come for a long time and would give an excuse, like she was busy with another baby.

This mother had spent a lot of time in the hospital watching the staff care for her infant and others, and was evidently not satisfied with what she saw. She felt that making complaints while her child was still in hospital would jeopardize the care he received. Another parent indicated a different type of problem that she experienced with nursing

staff, that of inconsistency and difficulty establishing a relationship with the nurses because of the number who cared for her infant, "There are so many nurses, and sometimes when they switch off they don't always know what you are talking about. It would have helped to have only one or two nurses most of the time."

Another mother pointed out the difficulty of inconsistency between nurses in this description:

"Like one day I was there to breast feed all day and to prove that she would latch on...one nurse let me do this, hold her, and then another shift that had come on...I had gone down to eat and when I came back up I went to pick her up and she told me to put her back in there and that she needed all the rest she could get and I shouldn't pick her up so much. I thought that I always had to ask permission and I was just really hurt."

In some cases, parents interpreted situations in ways that nursing staff probably did not anticipate. That may have been the case in this comment by a parent who felt that a nurse had deliberately deprived her of an opportunity to be present for the infant's feeding, "I knew what time their feeding was and she would feed them early so that they'd be fed by the time I got there".

One common situation that led to feelings of helplessness and frustration was when parents were given conflicting information.

I was given a whole bunch of wrong information. They told me that I didn't have to pump at night. When my supply started to go down after a couple of months I asked them what to do and they told me that I should start pumping at night. It was too late and my supply never came back.

The constant search for information often led parents to receive a large amount of information from a large number of people. One parent found this situation overwhelming she describes her feelings clearly, "It was chaos. Every nurse told us a different story. One nurse told me something, another nurse told my boyfriend something completely

different, and the doctor would say something else". Another mother had a similar experience when trying to establish breastfeeding, "One nurse would say it was great that he had taken 10, and the next nurse would say, only 10, we better keep trying."

The frustration with this situation led another parent who had a similar experience in trying to establish breastfeeding to advise, "There needs to be some consistency in what they tell you. It was hard because you would be trying one thing and someone else would tell you to try something else so you didn't have a chance to see if it would work".

At the beginning of the infant's hospitalization there is often a lot of information given to parents. They are novice parents of high risk infants and have a lot to learn about the infant, the illness, and the hospital system. As the infant gets older and the parents settle in to being hospital parents, this flow of information tends to slow down. One mother noted this trend.

Everyone just assumed that I knew what was going on, but I really didn't know what was happening. They always thought that the nurse before told you something. So sometimes a nurse who had taken care of him would be there but wouldn't have him because he was in a different location.

Frustration and helplessness come from a variety of causes within the situation. Some are from the inherent nature of having an infant who is ill and not in your own care. Some are from the inherent nature of having contact with a wide variety of other individuals. This is where the second theme connects with the first. Interpersonal relationships with a wide variety of hospital personelle are unavoidable when you are a hospital parent.

Worries and Concerns

The concerns and worries of parents vary over the course of the experience of having an infant in the hospital. In the course of telling their story parents alluded to the concerns that they had during various aspects of the experience. Fear and uncertainty

were common emotions that parents expressed. One parent identified this in the early days of the infant's life, "We didn't know if she was going to be okay or if she was going to be there when we came back, or if there was going to be any complications." Another felt similar emotions at a different stage, during the early days at home, "We were scared even though we had done everything for her in the hospital. Now we had to do it all the time. We didn't know what to expect, but it's been okay".

This uncertainty was often accompanied, or caused, by a lack of knowledge, "You heard a buzzer going off you didn't know if it was serious...We were really worried about her, that was the main thing". Continued lack of knowledge created added concern for some parents, as this one who identified the cause for their continued concern, "No one ever said, okay, she's going to live."

Parents often felt a sense of guilt over what was happening to their infant. One parent stated, "You always second guess and wonder if you did something wrong". Another had a similar comment in relating their concern about taking blame for the situation, "I still keep asking, what did I do wrong that she was so small and had to be born early". This guilt continued for this mother even though the infant was home and healthy.

Some parents voiced other concerns which focused on other family members, "I was concerned about him and how he was feeling [boyfriend]. I think that's how most mothers are, they're more concerned about their partners and how they're feeling, like that they're a part of everything". Another parent stated that it was difficult to focus on the infant in the hospital, "At first I was more concerned about getting home to my other child."

Parents were asked what their major concerns were now that they were at home. Some parents made comments about the way they felt when they first brought their infant home which indicate the level of worry they felt at that time. One mother's early concerns at home indicate the importance of having parents participate in care in the hospital as she

identified the cause of her early lack of confidence at home, "Lack of confidence I guess.. Being a new mother and stuff. I was pretty scared after having everybody take care of her so much". Similar feelings were expressed by another mother who became overly cautious at home, "We didn't do much sleeping. We were always checking on her. She was a poor eater. We were forcing feeding on her, always, always. We didn't want her to go back to the hospital". Another parent identified a similar level of vigilance in monitoring their infants once they were home, "I worry about them when they are sleeping. When it gets too quiet I worry about whether they are breathing. Mostly I worry about the one who was the sickest."

Confidence grows in time, especially when a mother perceives that she has been adequately prepared in the hospital, "I think I was prepared. I knew that I could feed him. They still had the tube in and said he wouldn't eat, but he ate for me. I'm a first time mom, it just takes practice".

Knowledge plays an important role in alleviating fears and concerns. When parents do not receive adequate preparation before discharge, situations can arise at home which are not anticipated, and can cause additional worries, "We changed her diaper about 40 times because we didn't know. Whenever she cried or moved I was up right away to check her. Now I know that she can cry for a bit and be okay. We were on edge for a couple of days not knowing what to expect".

The table on the following page outlines the concerns and worries that parents identified, and their frequency.

Table 9
Worries and Concerns

Concern	frequency
getting enough to eat / weight gain	10
elimination / bowel patterns	6
baby getting sick	6
apneas and bradycardia / breathing	2
SIDS	2
follow-up of complications	1
development	1
teething	1
reason for crying	1

These worries and concerns are not very different from parents of healthy infants. All parents worry about their child's weight gain, and common infant problems such as teething and elimination patterns. Parents of high risk infants indicate a concern beyond these general ones. The context of their concern surrounds the circumstances of their child's hospitalization. Those who's infant experienced severe apnea and bradycardia in hospital, had greater concerns about breathing. Those who had necrotizing enterocolitis, or poor weight gain in hospital had a more acute concern for these things when they were home. The concern about development by parents whose infant experienced a cerebral hemorrhage continues for a long time as they watch their child develop, waiting for potential problems to emerge. The decrease in identified stress level, as previously listed in Table 7 indicates that the worry is not as acute as it is shortly after the birth of the infant. This concern becomes a part of the parent-infant relationship.

Theme 2

Interpersonal Relationships

The first theme focused on the parent's relationship with the infant. In doing so it became evident that others in the environment had a profound impact on that relationship. The way parents related to others is a major part of their experience. Every parent interviewed talked about relationships and encounters they had in the hospital. Nurses were the most frequently mentioned, followed by doctors and other health professionals. Some parents also responded to experiences with other people that were either in their support network, or people they met during their experience. The responses and comments cover a wide range of emotions. For many of the parents, it was a bitter-sweet experience. This was evident both from parents who had a shorter time in hospital, and from parents who had spent a long time there.

Some parents didn't disclose the depth of their experience. Their comments were brief, but generally positive, stating that, "They were very good there. They looked after our babies wonderfully", and that, "They were all very friendly and very nice". Some parents formed close relationships with nurses who had cared for their infant, "Some of the nurses were really nice. We got really close to a couple of them". This relationship became important to some of the parents, as this parent indicates in this comment: "It worked out that one particular nurse was always there when we needed her". A lot of learning can take place when parents have good communication with nurses. This comment mirrors those made by several other parents as well, "The hospital nurses taught me the most. They were very good about answering all my questions". Other health care workers also contribute to the care of parents in the hospital. Some have unique opportunities to interact with parents when infants are hospitalized for a long time. This parent listed numerous health care workers in her social support network, "My social

worker has become like a friend to me. The nurses were great. All the support [I got from them]”.

The feeling of belonging, and being welcome in the hospital was important to a lot of parents. One parent, who came from outside the city and had few friends in the city stated, “They talked to me lots. When I was there it felt like I was part of a family. They’d talk about their kids. You felt like you were part of a family. Everyone was always talking, and I felt like I knew them”. To many, the relationships they formed and the interactions they had with others was a positive highlight of their hospital experience.

The only positive thing that comes to mind is that contact with the nurses, the interaction with them, and their support. Right from the beginning they told me everything. The most difficult is the lack of understanding of what you’re going through from family and other people. That’s why the nurses are so important because other people have no idea of what you’re going through.

There were some who had overwhelmingly negative experiences. When the interactions with hospital staff involved conflict, the perception by the parents was very different. One parent described it as an overall feeling, “Intensive care was so hard. It just seemed so cold. I don’t know if it was the nurses or the machines”. Another young unmarried mother described the nature of the conflict that she had with the nurses. She felt that she was being treated differently because of her young age, and that the hospital policies were not fair for her situation. She was unable to resolve this conflict with the staff in the hospital, and it affected her perception of the care her child received and the atmosphere in the hospital.

I thought that I always had to ask permission. I was just really hurt. A couple of times it happened...we thought we would go early and they had already fed her. Like watch what’s going on. I just was not impressed. I heard them arguing. I thought she wasn’t getting the love that she needed,

the holding and stuff like that. I just thought, yeah I understand, I am an adult, you don't have to treat me like a kid. I went in and I hardly talked to any of the nurses again because I was just not impressed at all.

Another parent had a similar perception of the possessiveness that the nurses portrayed to them when the infant was in their care for a long period of time, "The nurses were too busy talking to each other to talk to us. It seemed like she wasn't our baby, she was theirs".

The most compelling descriptions were from the parents who had both positive and negative experiences. Some of them had spent a great deal of time, over a period of months, in the hospital. This length of time afforded greater opportunity for parents to experience a wide variety of personal relationships. These comments provide a great deal of insight into the parent experience. One parent indicated how she adapted to an early perception, "Some nurses were really flexible. I really like some of them. One was so strict, she should have had a military uniform. She was really nice once you got to know her though. The people there were really great". Another tried to offer an explanation for her experience with the nurses, "There were a couple of nurses I didn't care for. It may have been a personality thing. They do the job so much that they have to be cold I guess. Most of them were pretty good". Another parent offered a similar explanation when she described her interactions with personnel in the hospital, "The most negative experience was probably a reaction from a pediatrician that wasn't compassionate or sensitive. I know that when you work with it all the time you get a little hardened maybe. On the other hand two nurses in NICU were extremely supportive and very encouraging. It wasn't like they forgot about us the minute you left."

With a long term hospital admission, parents were more likely to have experienced a wider variety of staff. As in previous comments, this comment also provides an explanation for some of the conflict that this parent experienced:

Just like, it seemed like they were in and out kind of thing. Like they were just doing their jobs sort of thing, get done as fast as they could. I guess it's understandable. They're tired, they work long shifts. Some were super nice. That was helpful, having someone happy around. Glad to take care of the baby and glad to help me take care of the baby. I liked that.

Parents are thrust into a situation in which they have no control. They also have no control over the type of nurse who cares for their infant. Few parents offer these criticisms during the time that their infant is in the hospital. When looking back on the experience many had comments to make about it. As some of the previous comments indicate, parents are aware of what is going on around them in the hospital. Sometimes when a parent spends a lot of time in the hospital unit, they become privy to a lot of discussions and events that go on around them. Some parents, as previous quotes indicate, make judgments about these experiences. One mother voiced a lot of difficulty in dealing with the approach taken by nursing staff, even though she respected them for their expertise in caring for her child. She stated, "I found the nursing staff was really good there, but there were so many different nurses taking care of him. I found them a bit too aggressive. I know that breastfeeding is what they push now. Basically they wouldn't take no for an answer on breastfeeding".

Another parent also had both positive and negative impressions from the hospital experience. This comment provides an interesting view on the parent's perspective.

Basically I was very impressed with everything the nurses did. There was a couple nurses there that, I don't want to criticize anybody, but there was a couple nurses that maybe if everyone tries to put themselves in the place of a new parent that doesn't know what the bells mean or doesn't know the terminology, but wants to know because of their child. If everyone remembers that it might help a bit. But it was just the odd incident. The

most positive part of the experience was bonding with the baby. And the nurses too. I feel very close to them.

This comment highlights how interpersonal interactions can inhibit the parent's search for information and support. This parent was able to overcome the negative impressions with the positive experiences in interacting with their infant. The following comment also comes from a parent who was dealing with the task of forming a parenting relationship with their child, when interpersonal conflict with the hospital staff made it difficult. This comment also indicates the importance of positive relationships.

They made me feel inadequate. For the first time in my life I felt like I wasn't supposed to do something. I felt like I wasn't supposed to go visit my babies. I was confused because they told me to come anytime, even if it's 4 o'clock in the morning. And then every time I'd go she made me feel like I shouldn't be there. I was upset. I'd cry. I'd go back to my room and I'd cry. I know it's their job to be very careful with the babies, but they should make the mothers feel more welcome. But the girls in intermediate were great. D had one nurse. She was great. She had us laughing while we were in there. She just loved him, you could tell.

In the interviews, parents showed a lot of emotion in their descriptions of their experiences. They also described strong emotional reactions such as the previous comment indicated. This presents a vulnerability that parents have in the situation. They are reacting to the situation that their child has been placed in, and seem to become more vulnerable to the actions of those who are caring for their child. They may not show this degree of reaction to interpersonal conflicts in more normal circumstances. This vulnerability persists, and may even become greater when the hospitalization becomes longer. One mother who's infant was in hospital for more than 100 days was initially vague in her responses about her experience. As the interview progressed and she became more comfortable with the researcher, she described her experience in greater depth,

highlighting the importance that interpersonal relationships were for her during those months.

The most positive part could have been some of the nurses. Some of them were unbelievable, they made you feel so welcome. They always had a story about K. They would come to you laughing with a story. That kind of made coming to the hospital that much easier. We had a lot of positive responses towards people and a lot of negative, terrible memories of a lot of the health care workers. We ran into a lot of terrible people, and mean people. Negative people. It makes you feel angry. You didn't even want to go to the hospital. The thought of walking in and knowing that they're going to be there made going there that much worse. And then you had the wonderful people when you couldn't wait to get there, because you were going to see your baby of course, but they were there.

One parent was very direct in her interpretation of the situation that she experienced in the hospital.

If you had a good relationship with a nurse who was a more primary caregiver the care for the baby was better. I saw babies being neglected because the nurse didn't like him. I saw very much a favoritism. I learned that you have to build a good relationship with the nurse so that they like your baby and give him better care. My overall experience was positive. All the things about taking care of him was because of what the nurses taught us. ninety percent of the information we learned was from the nurses.

When parents talked about the encounters they had, they became very intense. Some shed tears. It is evident from the depth of these comments that the relationships that parents have with health care workers is one of the most memorable, both positive and negative, part of their experience. Without being prompted, every parent made some

reference to it. No study of the experience of parents in the hospital would be complete without a look at the effect of nurses and other health care providers.

The interaction with others either from their own social support network, or acquaintances was significant for some of the parents. There are no role models or norms to follow when an infant is ill. Both the parents and the family members are on their own in dealing with the situation. The result can be either a positive one, or a negative one. One parent identified the difficulty with these interpersonal relationships in the situation.

You are so careful about family members. We never got cards, we never got gifts. People don't know how to....we knew that. There are times that you would get over it. You'd be a little hurt, and then you'd say, well, they have no idea. They haven't been through this before either so they don't know what's the right was to deal with issues.

Another parent had a more positive experience, and found a source of unexpected support, "Outside of the hospital you learn how kind and concerned friends, and anybody you meet can actually be. You get a renewed faith in mankind. We couldn't believe that people could be so nice".

Summary of Qualitative Data

Many of the themes are overlapping. There are two major areas in which the parents interact. One is with their infant, where their task are to get to know their baby and to develop a parenting role. The second is with interpersonal relationships with hospital staff, and with their own support group. Their tasks here are to find the support and information that they need in order to successfully complete the tasks involved in parenting a hospitalized infant. The interactions with the nurses affect the parent's interactions with their infant. Outside influences affect the stress felt by parents, which in turn affects the way they respond to both nurses and to their infant. It is a complex set of

relationships which is evident in the comments by parents. Stress producers and stress reducers can affect the way parents react to and interpret situations as well.

It must be noted that the comments cited were the parent's interpretations of the situations. It provides insight into what parents are perceiving. Their descriptions of the search and the helplessness are compelling. Addressing these tasks influence the way that parents perceive relationships and confrontations. It is with this background that the statistical data, presented in the following pages can be better understood.

This analysis also provides additional insight into the conceptual framework used in this study. The following figure illustrates how the conceptual framework, found in Appendix A, is enhanced by the qualitative perspective provided by parents of high risk infants in this study.

Figure 2

Infant Care Self-Efficacy

Successful Parenting:

- adequate information
- positive interaction with infant in hospital
- positive relationships with health care personnel
- adequate home follow-up support

Continued Crisis:

- inadequate information
- insufficient interaction with infant in hospital
- negative experiences with hospital staff
- lack of home follow-up support

Formal Support Questionnaire

The Formal Support Questionnaire (FSQ) used to measure parent education and support by professionals, is found in Appendix F. This questionnaire was originally used by Dr. Karen Luker in Manchester England and by K. Hamelin and M. Saydak in studies completed in 1991. The original format was as a descriptive questionnaire. A 5 point Likert scale scoring system was added for the purposes of this study.

The questionnaire is divided into two sections. The first section examines various aspects of parent education. Parents were asked about both breast and bottle feeding education. Many answered both questions, and these two scores were averaged to obtain the score for that question. Those who answered only one or the other question were given that score so the results were not affected by using only one method of feeding. They were also asked to give an overall rating of feeding education.

The third section relates to formal support from various physicians and other disciplines. The questionnaire elicits parent's perceptions of whether they received enough help or how helpful various aspects of the parent education experience were. The three sections together comprise the total formal support score. Table 10 outlines the mean scores for each of the items in the questionnaire as well as the subscores and total scores. The scores are listed in descending order with the items scoring the highest at the top. The questionnaire included the choice of "not applicable" for parents to answer if they had no contact or experience with that particular item. For instance, a parent who met no member of the clergy would choose this answer. The parents were instructed to answer the way that they felt so that if they had wanted help, but received none they should answer accordingly. Those who scored "not applicable" were not included in computing the mean scores for that question. The number of subjects who responded with an answer that was applicable is listed for each question. The choices included; 0="not applicable", 1="not at all", 2="a little", 3="moderately", 4="quite a bit", 5="a

great deal". There were 16 questions, with the first ten comprising the parent education sub-score, and the last six pertaining to follow-up support from health care professionals. Together they make up the total formal support score (TFSQ).

Table 11 shows the total and sub-scores for the FSQ. The total parent education sub-score is broken down into two areas. The first eight questions of the FSQ refer to general information, and the last two focus on infant feeding. This was done in order to isolate the education provided for parents regarding feeding. Both the literature review and the interview data from this study indicate that feeding is a primary concern for parents at home. For this reason the parent's perceptions on feeding preparation are important to examine separately. The follow-up sub-score is made up of questions 11 to 16 on the FSQ which focus on support from social workers, clergy and follow-up support after the infant is discharged, from physicians and nurses.

Table 10

Formal Support Questionnaire Individual Mean Scores

Variable	N	Mean	Median	Variance	Std. Dev.
involvement with baby	50	4.36	5	0.85	0.92
learn about baby generally	50	4.32	5	0.71	0.84
feeling prepared once at home	50	4.28	4	0.53	0.73
overall feeding	50	4.24	4.5	0.88	0.94
Pediatrician	40	4.12	4	0.81	0.94
feeding: either bottle or breast	50	4.11	4.5	1.13	1.06
Family Doctor	33	4.09	4	0.96	0.98
feeling prepared while still in hospital	50	4.02	4	0.91	.958
learn about bathing	50	3.90	4	1.68	1.29
Public Health Nurse	49	3.69	4	2.05	1.43
learn about baby's medical problems	50	3.54	4	2.74	1.66
Social Worker	19	3.47	4	2.15	1.47
learn about baby's medicine	50	3.38	3.5	2.07	1.44
pamphlets in hospital	50	2.98	3	2.76	1.66
hospital nurses - after discharge	18	2.94	3.5	2.76	1.66
Clergy	13	2.62	2	1.75	1.32

The highest scores were obtained for involvement with baby, learning general information about baby, feeling prepared, general feeding issues and skills, and bathing.

The helpfulness of pediatricians and family doctors also received high scores. Only moderate scores were obtained for learning about baby's medical problems and medications. The helpfulness of the Public Health Nurse and the social worker also only received moderate scores. The lowest scores were obtained for the helpfulness of written pamphlets, follow-up support from hospital nurses, and clergy.

Table 11
Formal Support Questionnaire Total and Sub-Scores

Variable	Mean	Min.	Max.	Var.	Range	Std.Dev
parent education (#1-8)	30.8	8	40	30.39	21	5.50
feeding (#9 & 10)	8.35	2	10	3.79	8	1.95
Total Parent Education (#1-10)	39	27	50	45.2	23	6.73
follow-up sub score (#11-16)	12.7	0	30	24.7	21	4.97
Total FSQ score	52	27	80	83.4	38	9.13

Min. = Minimum Score

Max. = Maximum Score

Var. = Variation

Std. Dev. = Standard Deviation

In isolation these scores hold little meaning. There is a large range for each of the areas scored. This may indicate a lack of consistency in the perception that parents have regarding the education and formal support that they receive from health care professionals. They also reflect the variation that was evident in the breakdown of individual scores. When these scores are placed in the context of the qualitative interview data they support the variation of responses, between those parents who felt they received

enough information and support, to those who claimed that they had to search for their own sources, and did not receive enough information and support from health care professionals.

Norbeck Social Support Questionnaire

The Norbeck Social Support Questionnaire (NSSQ) asked parents to list the members of their personal support group. They rated each of these persons on four questions relating to emotional support and two questions relating to tangible support or aid. These six questions comprise the total functional support score for the subject. The subject was also asked to identify the length of time they have known each of the persons on their list, and the frequency of contact with them, ranging from daily to yearly. The total support network score was computed by adding the total number in the network, the total duration of association, and the total frequency of contact. Subjects were also asked to identify the number of persons who are no longer available to them in their support network, and to rate how much support those persons gave in the past. The sum of these comprises the total loss score. Table 12 lists the mean scores for each of these sub categories.

Table 12
Norbeck Social Support Questionnaire Scores

Variable	Mean	Std. Dev.	Min.	Max
emotional support score	111.5	35.3	48	197
tangible support score	54.54	22.2	20	122
total functional support	166.04	56.05	68	317
total network score	87.16	31.74	32	181
total loss score	1.46	2.84	0	15

N=50

Std. Dev. = Standard Deviation

Min. = Minimum Score

Max. = Maximum Score

These scores are difficult to interpret or assign meaning, without comparison to other groups. This comparison is also difficult because the scoring system for the NSSQ changed with this version in 1995, when it was modified for use with this statistical package. It is useful to note the wide range of scores, and relatively low mean score for total loss. These scores will provide greater meaning when related to the other variables and discussed further in this study.

Infant Care Survey

The Infant Care Survey (ICS) is a tool to measure perceived self-efficacy in caring for an infant. The survey used the word 'confidence' to imply self-efficacy. Parents were asked to rate their confidence on a five point Likert scale on issues of both knowledge and skill. A score of 5 indicates a great deal of confidence while a 1 indicates very little

confidence. Table 13 outlines the scores in ascending order, with the items receiving the lowest scores first. The table separates knowledge and skill components. In many cases there are corresponding variables which refer to identification of a specific infant condition and then to treatment of it.

Table 13
Infant Care Survey Individual Item Scores

Knowledge Variable	Mean	Median	Standard Deviation	Skill Variable	Mean	Median	Standard Deviation
Croup	2.38	2	1.52	Relieve Croup	2.36	2	1.42
Allergic Response	2.9	3	1.39	Treat Diarrhea	3.06	3	1.45
Ear Infection	3.0	3	1.44	Start New Foods	3.20	3.5	1.57
Baby Foods	3.2	3.5	1.55	Teething Pain	3.30	3.5	1.50
Teething	3.46	4	1.34	Constipation	3.32	3.5	1.45
Selecting Formula	3.54	4	1.52	Prepare Baby Food	3.34	4	1.63
Regular Physical Exam	3.62	4	1.34	Spoon Feeding	3.36	4	1.56
Balanced Diet	3.64	4	1.43	Relieve Congestion	3.42	3	1.20
Normal Weight Gain	3.68	3.5	1.07	Relieve Gas Pain	3.80	4	1.13
Normal Breathing	3.78	4	1.13	Sleeping Schedule	3.88	4	1.17
Congestion	3.82	4	1.19	Feeding Schedule	3.96	4	1.05
Dangerous Drugs	3.84	4	1.17	Weighing	4.08	5	1.38
Constipation	3.88	4	1.26	Taking Temperature	4.46	5	0.86
Diarrhea	3.98	4	1.19	Soothing Crying Baby	4.46	5	0.86
Immunization Times	4.0	4	1.21	Diaper Rash	4.48	5	0.84
Growth & Development	4.08	4	0.92	Giving Medicine	4.60	5	0.70
When to get Help	4.08	4.5	1.14	Bathing Baby	4.70	5	0.65

Knowledge Variable	Mean	Median	Standard Deviation	Skill Variable	Mean	Median	Standard Deviation
Gas Pains	4.20	4	1.14	Burping Baby	4.74	5	0.57
Amount to Feed	4.22	4	0.88	Playing with Baby	4.74	5	0.53
Safety Hazards	4.22	4	0.84	Feeding Baby	4.76	5	0.48
Safe Toys	4.26	4.5	0.85	Using Car Seat	4.78	5	0.47
Safe Clothes	4.26	4	0.85	Walking with Baby	4.86	5	0.35
Safe Furniture	4.28	4	0.83	Holding Baby	4.88	5	0.32
Diaper Rash	4.28	5	0.99	Changing Diaper	4.90	5	0.42
Baby Seat Safety	4.30	5	0.97				
Safe Baby Positions	4.30	5	0.90				
Using Baby Bottle	4.58	5	0.84				

The top five scores were given to changing diapers, holding baby, walking with baby, using a care seat, and feeding baby. These are all skill variables. The top five knowledge variables correspond closely to these. They are; using a baby bottle, safe baby positions, baby seat safety, diaper rash, and safe furniture. Generally skill variables scored higher than knowledge variables for the same issues. Skills and knowledge that are required for basic infant care scored the highest. The lowest scores were obtained for knowledge of allergic responses and ear infections, as well as for the knowledge and skill in treating croup. Items such as preparing and feeding baby food also scored relatively low.

When reviewing the scores it is important to note that the parents were surveyed when their infants were home for approximately one month. They were not yet feeding solid foods, but had developed skills in basic newborn infant care. The scores reflect the timing of the interviews. They also reflect the fact that few infants at one month had ever experienced an ear infection or croup. Some of the parents with older children scored

higher on these items because of their previous experience. On some variables such as diarrhea and congestion the knowledge scores were higher than the skill score. This indicates that parents felt more confident in identifying the condition than in treating it themselves. Those skills which new parents practice the most are the ones that scored the highest, with the smallest standard deviation. The situations which they are the least likely to have encountered scored the lowest, but the standard deviations are greater, most likely reflecting the previous experience of those parents with other children.

Table 14
Infant Care Survey Total Scores

Variable	Mean	Std. Dev.	Min.	Max
knowledge score (#1-27)	103.84	19.2	48	134
skill score(#28-51)	97.44	15.5	57	120
total ICS score	201.28	33.8	105	254

Std. Dev.= Standard Deviation

Min. = Minimum

Max. = Maximum

The mean score divided by the number of questions shows that the mean knowledge answer was 3.8, and the mean skill answer was 4.1, so subjects indicated overall greater confidence in their skill than in their knowledge.

Summary of Survey Scores

Each of the surveys provides another piece of the puzzle. They provide descriptive information. From the FSQ it can be determined that parents perceive they generally received “quite a bit” of information about their infant and about feeding and caring for their infant, but only a “moderate” amount about medications and medical

problems. Parents generally felt well prepared to care for their infants at home, both before and after discharge. From the parent's perspective, Pediatricians are the most helpful when compared to Family Doctors, Public Health Nurses, Social Workers and Clergy.

The NSSQ indicates a wide range of social support, but very little recent loss of support experienced by the sample. The majority of support was received from the parent's partners and immediate family members. Friends also provided a great deal of support to parents.

The ICS scores indicate a great deal of confidence in basic infant care skills, but less confidence in identifying and treating health problems. There is also a lot of confidence in knowledge of safety issues among the parents surveyed. Parents are confident to provide the care that their infants were needing at the time of the survey, but were less confident in providing care that they will need as they get older, and if they were to become ill at home.

Both the descriptive data and the correlation of these survey results provide the answers to the research questions in the following pages.

Research Question 1

What are the education and support needs of parents of high risk infants in Manitoba?

What are the common worries and problems parents experience when their high risk infant is discharged from neonatal special care?

Who do parents turn to for help and support after their high risk infant is discharged from special care?

Which sources of support and information are most useful to parents after their high risk infant is discharged from special care and why are these sources considered helpful?

Both the FSQ and the ICS individual item mean scores provide some insight into areas in which there are educational needs. A score in the moderate range or less will be used to indicate a need in that area. It must be noted that these scores indicate perceived support and education and do not represent any actual ability or education received. Actual amount of support and education provided are meaningless if they do not meet the needs that the parents identify, and are not perceived as helpful.

In the FSQ parents scored the education they received about the baby's medications, medical condition and about bathing only around the moderate range. The scores varied widely, indicating that parent's perceptions also vary widely. Education and help regarding feeding, preparation for home, and general information about baby scored better, but these scores also varied widely. These were the highest scores.

In providing support and information, clergy scored the lowest with social workers only slightly better than moderate. Scores only took into consideration parents who had contact with those disciplines in the hospital. Hospital nurse contact after discharge provided less than moderate support. Pediatricians and Family doctors were the most

supportive, followed by Public Health Nurses. Written material available into hospital provided parents with the least amount of information, indicating a need in that area. An interesting result is that parents felt more prepared once they were home than they thought they would be before discharge.

The ICS provides insight into more specific areas where parents had less confidence in their knowledge and ability. The lowest scores were for the identification and treatment of croup. Low scores were also given to identification of allergic response and ear infections. Areas of both knowledge and skill which relate to older infants received only moderate scores. These are all items which a first-time parent in the first month are not likely to have encountered, and thus these results are expected with this sample where 60% of the subjects are first time parents.

Some scores which are surprisingly low were the knowledge of normal weight gain and normal breathing sounds. The majority of infants were premature, where respiratory difficulty and weight gain are great concerns. These relatively low scores indicate that these concerns either decrease the parent's confidence, or the necessary knowledge is not passed on to them in the hospital. Weight gain was the most frequently cited concern by parents in the interviews. Parents may feel that because their infant was premature the norms for term infants do not apply and they do not know what is normal for a premature infant. This may also relate to the only moderate scores in the identification and treatment of congestion. Confidence in identification and treatment of bowel elimination, including gas pains, diarrhea and constipation all received only moderate scores. This area was also the second most frequently cited concern by parents in the interviews.

Parents scored only moderate on knowledge of drugs which are dangerous for baby. This, coupled with the relatively low score on the FSQ for education on the baby's medications, indicates a need for more education on drug therapy.

Both knowledge about sleeping schedules and feeding schedules scored just above moderate. Many parents commented on these items while completing the questionnaire.

They indicated they did not establish schedules, but allowed the baby to dictate them. In some cases, the confidence score may not indicate ability in this area.

Relatively high scores were given to safety items, as well as to basic infant care. Another high score was given to knowledge of normal growth and development, which this investigator would have expected to be lower with this population including many parents of premature infants.

The most insight into the support needs of parents came from the qualitative interviews. The levels of frustration and helplessness felt by parents cannot be ignored. They indicate a need for sensitivity to their individual situations. They stated their need for consistency in the information that is given to them. The FSQ and ICS also support the need for more information about their infant, both in day-to-day changes and in their treatment and medical conditions.

The most common worries and problems that parents have after discharge, as previously outlined are: getting enough to eat / weight gain; elimination / bowel patterns; baby getting sick; apneas and bradys / breathing; SIDS; why he/she's crying; follow-up of complications; development; and teething.

Only two of the infants were readmitted to hospital in the first month, one of them for anticipated surgery, and the other for a urinary tract infection. It is difficult to identify the most common problems parents and infants experience in the first weeks and months at home. Many parents discussed their lack of sleep, and their frustrations establishing breastfeeding. The parents in this sample have a great concern for weight gain and for elimination, probably stemming from these same concerns while the infant was in the hospital. Some parents with previous children indicated they worried more about this baby than they did with the others who had been healthy. It is expected that any parent of an infant who experienced apneas in the hospital would worry about breathing at home as well. This is probably more so now, when infant sleeping positions is a popular issue and is usually discussed with parents in relation to SIDS prevention.

The question of who parents turn to for help and support, and what was the most useful, are interrelated. The high scores for Pediatricians and Family Doctors were supported by the many parents who claimed that when they had questions or concerns they called the doctor. One of the themes that emerged from the interviews was the search for support and information. Many parents found relatives, either parents, sisters, sister-in-laws or cousins who had previous experience with infants, to be the most frequent sources of both support and information once they were home. Some looked to peers for support. Again, one of the most important elements was that their support came from persons with previous experience with infants.

Parents of very premature infants indicated more frustration because they could find no one with that particular experience. One even indicated that although she had frequent contact with the Public Health Nurse, it wasn't that helpful because the nurse was not familiar with an infant born at 26 weeks and could offer few answers to her questions. Some expressed the desire to talk to other parents who had been through the experience in the past. For many of these parents, the physician who had known their infant from the beginning was the most helpful.

Many parents indicated they relied a great deal on written materials for information. Several books were cited by numerous parents. These included The Premature Baby Book, Baby's First Year, and several publications by the LaLeche League on breastfeeding. Once at home, parents turned to written materials that related to normal infant care, while the material specific to premature infants was most helpful during the hospitalization. Parents of very premature infants indicated a need for material written on the ongoing concerns related to prematurity.

Overall, it appears that parents were looking for experienced, reliable support and information, both from written material and from personal contact.

Research Question 2

What is the relationship between parent education, social support and self-efficacy related to caring for a high-risk infant at home?

Relationship Between Variables

In order to examine the relationships between variables several steps were taken using the statistical program SPSS PC for Windows. As already described descriptive statistics were obtained on all of the variables and demographic data. Each of the variables that provided numerical scores were then placed in a matrix and correlated using Pearson's r . This statistical test was chosen for its sensitivity in consideration of the relatively small number in this study. Results were examined and relationships were considered statistically significant at a level of $p < .05$. Scatter plots were generated in order to support the resulting correlations.

Histograms were examined to determine the possibility of grouping the data. For most of them, there were clearly delineated groups, generally with one group above the median and another below it. These histograms were also examined to identify outliers who may have skewed the data. New variables were created using the new groupings. The variables that were examined both as continuous and in groups include: age, education, total parent education scores, total formal support scores, total number of follow-up visits, total infant care survey scores, total functional support scores, total social network scores, birthweight, and discharge weight.

Each of the variables that was originally recorded as nominal data were compared using basic tables in order to visually examine possible trends. Variables include: family income, parity, method of feeding both at discharge and presently, and level of stress at birth, discharge and at time of interview.

All nominal variables were correlated using Chi Square to determine the relationships. Relationships were examined and considered statistically significant at a level of $p < .05$. Statistically significant relationships were then compared to results of the correlational matrix in order to see if this non-parametric analysis supported the results of the Pearson's r parametric analysis.

The following paragraphs describe the statistically significant correlations that were found using this process of analysis. For each of the relationships, all of the tests that indicated significant correlation are reported. Omission indicates that it was not statistically significant. It must be noted that using Chi Square with this sample size, where there are more than two groups, it becomes difficult to demonstrate statistical significance because the minimum observed frequency is often less than 5. This was the case when correlating variables with stress levels and with method of feeding, each of which were divided into three groups. In order to facilitate analysis, method of feeding was divided into two groups, one which combined the groups which included any amount of breast feeding, and the other which was exclusively bottle feeding. This allowed some trends to emerge. Using Fisher's exact test, a more sensitive test when there are small cell sizes did not produce any more statistically significant relationships.

Demographic Relationships

The demographic data was grouped in order to highlight the most significant aspects. Age was divided into two groups, those 19-27 and 28-37. Income was reported in the data in three groups; $< \$23,000$, $\$23,000-\$43,000$, and $> \$43,000$. Education level was divided into two groups; those who had completed high school or less, and those who had at least some post-secondary education. Parenting experience was divided into two groups, those who had no previous children, and those who had one or more previous children.

Some positive relationships emerged from the demographics. It was found that the higher age group also had higher income at a significance level of $p=.0005$ using Chi Square. Age also was positively correlated with education at a significance level of $p=.04$ using Chi Square. Education was also positively correlated with income at a significance of $p=.0008$ using Chi Square. Number of children was positively correlated with education using Chi Square with a significance level of $p=.02$. This same correlation was not demonstrated with either income or age.

There was a significant relationship between lower birthweight and kangaroo care using Chi Square, at a significance level of $p=.00001$. This indicates that only smaller infants experience kangaroo care, as outlined by the procedure for kangaroo care.

There were no statistically significant relationships demonstrated between marital status and the other variables. The relationships demonstrated were too weak even using Fisher's Exact test which is sensitive to small samples. It is interesting to note however, that among the age group 28-37, all of the subjects were either married ($n=27$) or living common-law ($n=2$), while the younger age group 19-27 was more divided between those who were married ($n=9$), living common law ($n=3$) and single ($n=9$). No relationship was found between marriage and social support. The subjects who were married, were evenly divided, into the group who reported more than average support, ($n=18$) and the group who reported less than average support ($n=18$).

Methods of Feeding

Demographic variables including age, education and number of children, were compared with methods of feeding in basic frequency tables, and then were correlated using Chi Square. The methods of feeding were originally recorded as breast, bottle, or both, for both method of feeding at discharge and method of feeding at present. The initial examinations of relationships were done with these three groups, but the numbers were too small to demonstrate statistically significant relationships. When two of the

feeding groups were combined, to form one group that were doing some or all breastfeeding, and another that was exclusively bottle feeding (or no breastfeeding), more significant relationships emerged. These are described in the next paragraphs.

Method of feeding at time of discharge did not positively correlate with any variables, mainly because the vast majority of subjects ($n=41$) were doing at least some breastfeeding. This includes 16 who were exclusively breastfeeding and 25 who were doing some bottle supplementation. Many mothers were pumping their breasts and feeding expressed breast milk by bottle.

Method of feeding at the time of interview, approximately 4-6 weeks after discharge did indicate some significant relationships. The strongest relationship was between those with higher education, and continued breastfeeding, at a significance level of $p=.003$. This relationship was also evident using the original three groups, with those with higher education being most likely to be doing both breast and bottle, while those with lower education more likely to only bottle feed, at a significance level of $p=.01$. Higher income was also positively correlated with breastfeeding at a significance level of $p=.03$. Those subjects who reported greater than average social support were also more likely to continue breastfeeding, at a significance level of $p=.04$.

Parent Education / Social Support / Self-Efficacy

The main purpose of the quantitative portion of this study was to examine these specific relationships between parent education, social support, and infant care self-efficacy. The relationships already reported help us to understand these key results.

Parent education was examined in two ways, first as a total score from the FSQ, which includes questions about parent education, support and helpfulness of various professionals. It was also reported in the parent education subscore which measured the perception, or satisfaction with the help and information (parent education) that subjects received in the hospital, and their assessment of their preparedness for caring for their

infant. This variable should ideally be referred to as “perceived parent education”, as there is no actual measure of the amount of help and information they received. The two scores, the total FSQ and the parent education subscore were strongly correlated using Pearson’s r at a significance level of $p < .001$.

One significant correlation that emerged was that lower parent education subscores were correlated with hospital of admission. Subjects whose infant was treated at one of the hospitals had significantly lower parent education scores than the other hospital, using Chi Square ($p = .0014$). The two subjects who had experiences at both hospitals were not included in this particular evaluation.

The only other relationship which emerged between the parent education scores and the demographic data was the inverse correlation between income and patient education scores at a significance level of $p = .02$. This may be a result of expectations. Those who have more income and more education, also expect more of their health care providers.

The NSSQ provided scores on: the total functional support, including both emotional and tangible support; total network, which took into account the number of people in the network, the length of time they had provided support, and the frequency of contact; and the total amount of support that had been lost to the subject in the previous year. It was found that the total network and total functional support were strongly correlated using Pearson’s r at a significance level of $p < .001$.

The only demographic variable that demonstrated a significant correlation with social support was number of children. Having one or more previous children was positively correlated with total functional support, using Pearson’s r at a significance level of $p = .05$.

The final variable to be examined is infant care self-efficacy as measured by the ICS. The only demographic variable that had any correlation with the ICS scores was

parenting experience. Using Chi Square, previous parenting experience was strongly correlated with higher scores at a significance level of $p < .001$.

When social support (total functional support), parent education (total FSQ scores) and infant care self-efficacy (total ICS scores) were correlated, significant relationships emerged. The total FSQ scores were positively correlated with ICS scores using Pearson's r , at a significance level of $p = .018$. This relationship held true for the knowledge subscore and the skill subscore of the ICS as well, correlating with the parent education subscore at significance levels of $p = .013$ and $p = .004$ respectively. Social support showed a positive correlation with parent education scores using Chi Square at a significance level of $p = .02$. Parent education sub-scores (on the FSQ) were positively correlated with ICS scores using Pearson's r at a significance level of $p = .006$.

The following table provides the correlational coefficients for the major variables in the study, total ICS score, total FSQ score and total functional support score from the NSSQ, for the entire sample. Multivariate analysis and logistic regression were considered at this point. The relationships are too weak for this to be a useful test.

Table 15
Correlational Matrix (Pearson's r)

	NSSQ	ICS	FSQ
FSQ	.0916 $p = .527$.3334 $*p = .018$	
ICS	.0458 $p = .752$		
NSSQ			

Research Question 3

What is the best predictor of infant care self-efficacy in mothers of high risk infants?

In order to determine the best predictor of infant care self-efficacy it is necessary to sort out the relationships which have previously been identified. Age, income, education, breastfeeding, and parenting experience all demonstrated positive correlations in various combinations. Parenting experience was the only demographic variable significantly correlated with infant care survey scores. This indicates that there are two distinct groups within the data set, those who have previous children, and those who do not. In order to eliminate this potentially confounding variable, the data set was divided into two separate groups based on previous parenting experience. These groups were studied separately. In dividing the two groups a single outlier on the total ICS score was identified. This subject reported a significantly lower ICS score than any other subject, scored below the mean in both parent education and total FSQ scores, while fitting into the higher education, higher age and higher income group. This subject was not included in the statistical analysis on the advice of the statistical advisor. In order for the data to resemble a normal distribution the raw scores were adjusted by using a logarithm. This variable was then used in the correlations.

The two groups were examined separately, using both descriptive statistics and correlations. The numbers were relatively small with the experienced group having only 20 subjects and the inexperienced group having 29 (excluding the outlier), so most of the Chi Square statistics were not significant. The following table indicates how the two groups differed on the different variables when examined separately.

Table 16
Comparison of Groups

Variable (mean scores)	Group 1 (no previous children)	Group 2 (one or more previous children)
Total ICS	186.5	227.5
Total FSQ	52	52
FSQ Patient Education subscore	38.7	40.3
FSQ Feeding subscore	8.8	8.6
Total Functional Support	150	182
Total Follow-up Visits	5.8	4.3

The same statistical correlations were carried out for each of the sub data sets that were done for the whole. The group of subjects with previous experience showed no statistical correlations with any of the other variables using both Chi Square for the grouped data and Pearson's r for the linear data. The small sample size contributed to this result. One result which was not statistically significant but did indicate a strong trend was that the older age group of mothers who had previous children were all ($n=17$) doing at least some breastfeeding. The following correlational matrix shows the differences between the two groups on the three major variables, ICS, NSSQ (total functional support scores) and FSQ scores.

Table 17
Correlational Matrix - Comparison of Groups (Pearson's r)

	ICS Group 2	ICS Group 1	NSSQ Group 2	NSSQ Group 1
FSQ Group 2	-.0015 p=.995		.1400 p=.556	
FSQ Group 1		.640 *p<.001		-.0063 p=.974
NSSQ Group 2	-.0250 p=.917			
NSSQ Group 1		.0633 p=.744		

Group 1 - no previous children

Group 2 - one or more previous children

The group with no previous experience did show some statistically significant relationships. Using Pearson's r the total FSQ score showed a positive correlation with the total ICS score at a significance level of $p < .001$. This relationship is even stronger than it was using the whole data set, indicating the importance of parenting experience in predicting infant care self-efficacy. This group also showed a strong positive correlation between age and education at a significance level of $p = .004$. Using Chi Square with grouped data, the only statistically significant relationship that emerged was the positive correlation between total FSQ scores and number of contacts with health professionals including physicians and public health nurses since discharge. This makes sense in that those who have more contact are more satisfied with the help and support they received. Those who are less satisfied are less likely to seek more contact.

Regression analysis was carried out in order to determine how strong a predictor formal support is for infant care confidence. The ICS score was used as the response

variable and the FSQ total score was used as the explanatory variable, with number of previous children as an indicator variable. The multiple R was .69444, the adjusted R square of .46022 and $p=.0029$. When the sample was examined in the two separate groups, the group with no previous children had a Multiple R of .64005, adjusted R square of .38779 with $p=.0002$. The group with one or more previous children had a Multiple R of .00102, adjusted R square of $-.05555$, with $p=.9966$. The regression analysis confirms that there is a statistically significant relationship between total FSQ score and total ICS score, and indicates that FSQ score is a moderate predictor of ICS score, in parents with no previous children.

Summary of Results

Results of both the taped interviews and the statistical analysis of the survey tools have provided insight into the experience of parents of high risk infants. The sample consisted of 49 mothers and one father, all primary caregivers of infants who had spent at least ten days in hospital after birth. Eighty two percent were either married or living common-law. Sixty percent of parents had no previous children. They were evenly divided among three income levels. Seventy two percent lived in the city 28 percent in rural areas. Mean age was 27.6 years ranging from 19 to 37 years. Mean years of education was 13.4 ranging from 8 to 24. The infants ranged in birthweight from .729 kg to 3.64 kg with a mean of 1.97 kg. They spent a mean of 37.3 days in hospital. Primary reason for admission was prematurity (82 percent). Seventy two percent had no obvious problems at discharge. Fifty percent of mothers were doing at least some breastfeeding at discharge, 36% were still breastfeeding at the time of contact 4-6 weeks later.

Parents had a wide range of experiences, both positive and negative, and generally experienced a high degree of stress during their infant's hospitalization. There were both stress producers and stress relievers that affected their experience. Two major themes emerged from the interviews, the first was the parent's role in developing a relationship with their infant, and the second was the interpersonal relationships that they had with others in the hospital and as a result of their infant's illness. Parents searched for both information and support during their infant's hospitalization in order to cope with their stress. Both the infant's condition and the hospital environment were common producers of stress for parents. In developing relationships with health care providers there were situations and encounters that both produced and alleviated stress.

The results of the FSQ indicate that there are areas in which parents perceived that they did not receive enough information. These include information about their infant's illness and medications. This is reflected in the ICS scores which were low for areas of

skill and knowledge in treating potential illnesses. FSQ scores indicate parents did receive enough information in general infant care issues and felt quite prepared to take their infant home.

The ICS confidence scores indicate that parents had the most confidence in providing basic infant care at home. Parents also had high confidence in their knowledge of safety issues for their infant. Parents had the least confidence in treating potential illnesses such as croup, ear infections or allergic reactions.

Perceived formal support and parent education is a moderately good predictor of infant care confidence, for parents with no previous children. There was no relationship demonstrated between perceived social support and the either perceived formal support or infant care confidence. How these results impact nursing and other health professionals is discussed in the final chapter of this thesis.

Chapter 6: Discussion and Implications

The parents who participated in this study provided further description of the experience of parents in an intensive care or intermediate care environment. They also provided information regarding the relationships between parent education, formal support, social support, and infant care self-efficacy. Results have helped build nursing knowledge about relevant concepts and this population.

This chapter examines the results of this study looking first at the demographic characteristics of the sample. The results of the qualitative interviews which describe the experience of parents of high risk infants, their needs, and concerns will be discussed. Two particular cases will also be described. This will be followed by a discussion of the results from the three survey tools and the relationships that emerged. The discussion also includes the application to the theoretical framework, the limitations of the study, and the implications for nursing practice.

Demographic Characteristics of the Sample

It is generally understood that high risk birth, prematurity and illness in infants is typically associated with lower socioeconomic status. This study chose \$23,000 to represent the poverty line to compare to previous studies which used Statistics Canada data (Hamelin, 1991). With inflation being near zero for the past number of years this statistic is still relevant and facilitates comparison with those studies.

The sample in this study is not representative of the typical population of parents of high risk infants for one main reason. That is the exclusion of First Nations people. It was determined at the beginning of the study that this population, though it is highly represented among parents of high risk infants, would be difficult to study using this format because a large number of these families live a long distance from the city of

Winnipeg and would thus be excluded on that criteria. The number that would be included from the city would represent a sub-group of the total sample and would probably not be a large enough group, given the numbers in this study, to provide any statistically significant results. To exclude this group means that the results of this study cannot be extrapolated to nursing practice with the First Nations population.

Comparison of demographic characteristics is difficult when studies report different variables in different ways. All of the studies in the table sampled mothers from special care nurseries. Most were convenience samples. The table indicates that the samples of parents of high risk infants varies greatly between studies. The present sample is similar to the others, although the parents are somewhat older and slightly more educated than the majority of other samples. The lower economic group seems appropriately represented in this sample. Only a few studies reported this characteristic, so it is difficult to assess how representative this sample is. With the great variation in sample characteristics, it is difficult to generalize the findings from any of them to the whole population.

The following tables compare the demographic characteristics of this sample with those of other studies. The first table looks at the subjects and the next at infant characteristics from the same studies.

Table 18
Demographic Comparisons of Subjects

Study	N	Age	% Single	% low income	% primip.	years of school
current	50	27.6	18%	34%	60%	13.4
Hamelin (1991)	50	29.3	0%	18%	44%	13.54
Froman & Owen (1990)	183	28.55				
Fowler, Meck, Clafin (1991)	36	26	28%		55%	
Perehudoff (1990)	31	27.9	0		>50%	>12
Goodman & Sauve (1985)	30	24.8	0		67%	13.46
Gennaro et al. (1990)	65	24			46%	12
Brooten et. al (1989)	36	24	69%	77%		<12
Casiro et. al (1993)	100	25	2%	31%		12
McKim (1993)	56	26.85	16.1%		62.5%	

Table 19
Comparisons of Infant Characteristics

Study	Birthweight	Gest. Age (weeks)	Days in Hospital
current	1.97 kg	32.7	37.3
Hamelin (1991)	2.01 kg	32.86	43.9
Fowler, Meck, Claflin (1991)	2 kg	32	37
Perehudoff (1990)	1.37 kg	29.3	
Goodman & Sauve (1985)	2.016 kg	33	40
Genarro et. al (1990)	1.63 kg	32	31
Brooten et. al (1989)	1.187 kg	30	
Casiro et. al (1993)	1.54 kg	31.7	23
McKim (1993)	1.582 kg	31	55.45

A brief examination of the characteristics of the various sample populations indicates that this study is relatively consistent with the others. A few interesting changes which have occurred in the past number of years are evident by comparing samples of studies done in the province of Manitoba. In comparing this sample with Hamelin (1991), the characteristics are fairly similar, although there is a greater number of lower income and single families represented. The mean number of days in hospital has gone from 43.9

to 37.3. Discharge weight went down from 2.71 kg in Hamelin's study to 2.5 in this study. During the time between the two studies Casiro et. al (1993) conducted their study on earlier discharge with community intervention. The length of hospital stay for the intervention group was only 23 days and mean discharge weight was 2.2 kg. Their results indicated that even the control group showed a significant change with mean days in hospital 31.5 days and mean discharge weight 2.275 kg. The program was not continued after the study was complete. It is evident from the results of this particular study that the practices of earlier and smaller infant discharges have not continued, although there has been some overall change in the past five years. The numbers have rebounded in the years since the demonstration project. The sample in this study is not significantly different than those in other similar studies.

Discussion of Results

Experience of Parents of High Risk Infants

Describing the experience of parents of high risk infants was one of the minor objectives of this study. Parents were asked to tell their story in order to analyze the educational and support needs of parents both during and after hospitalization. One of the results of these stories is also a deeper description of the experience that parents had. For many, this was an opportunity for them to talk about what they experienced and felt with an interested observer. Many parents were eager to share their experiences.

The experience of parents has been described, as outlined in the literature review in chapter 3 of this paper. Bass (1991) described the three greatest needs parents identified as: information, attachment/parenting, and staff support. Brown and Ritchie (1991) explored the interaction and role paradox between parents and nurses, and the struggle for control between the two. The reports of parents in this study support these previous

descriptions. The high levels of stress identified by parents are similar to those reported by Graves and Ware (1990).

Parents Needs

In developing a parenting relationship with their infant parents need to be able to get around the barriers presented by the hospital environment. The barriers that parents identified include: distance, lack of privacy, lack of understandable information, personal emotions and grieving, other family stresses, and the inability to care for their own child. Parents identified numerous ways to overcome these barriers. They include: consistent and relevant information, sensitivity to their individual needs, appropriate social support, peers to talk to, opportunity to provide care and to touch their baby, and some control over what is happening to them and their baby. The two themes that emerged from the interviews intersect at this point, because it is the interaction with others in the hospital environment that either helped or hindered parents in developing a parenting relationship with their infant. Parents who had negative experiences with staff did not enjoy coming to the hospital. Others learned about their infant through their positive interactions.

The relationship with nurses was particularly important as parents see them as the gatekeepers for access to the infant. Brown and Ritchie (1991) reported that nurses also see this as part of their role. Policies and procedures of hospitals as they pertain to parents are enforced by nurses. These include, who is allowed to visit the baby and what they are allowed or encouraged to do while they are there. When the nurse was either too busy to help a mother hold her infant, or too unfamiliar with the mother and infant to allow a small infant to be held, this presented a barrier to parenting. Nurses who readily provided information on what the infant had done since the last visit, and who made the parents feel welcome in the hospital unit, facilitated parenting. Although parents need to have some control over the situation, the real control lies with the hospital and the staff. Policies and personnel can either allow or disallow parents to have control. Parents search

for information and support, and they need to have this more readily available to them. They need to have accessible reading material. They need to have an opportunity to talk to other experienced parents, without having to search them out for themselves. The needs that parents identified in this study are similar to those ranked as important by parents in a previous study as well (Bass, 1991).

The results from the FSQ provide further information about the needs of parents of high risk infants. The three items that scored below average, or "moderately helpful" were; clergy, hospital nurse support after discharge, and pamphlets obtained in the hospital. Information about medications and medical problems, as well as the helpfulness of the social worker and Public Health Nurse were rated lower than information regarding basic infant care. General information and preparation, feeding education and support and physician support all scored high. McKim (1993a) also found that mothers of high risk infants received information similar to that given to mothers of healthy term infants.

Parents indicated that they did not receive as much information regarding their infant's specific illness and medications as they would have liked. This finding corresponds with those reported by Sheikh, O'Brien, and McCluskey-Fawcett (1993). They highlighted the discrepancy between parents and nurses regarding which information had been taught. Kenner and Lott (1990) also found this same discrepancy in their examination of parent diaries.

There is presently no formal program for contact between parents and hospital nurses after discharge. Some parents phone the hospital with questions after they have gone home. Other have developed personal relationships with nurses and continue to have contact. Many come for periodic visits after they have gone home. For most it is a social relationship and not particularly helpful for them in caring for their infant at home. Some reach out for this contact with the nurses, who are the ones who understand to some extent what they have experienced. This action tells us something about what parents need. Some degree of formal contact for a short period of time following discharge may

help to alleviate some of the apprehension that parents feel before discharge, and begin to close the gap between parent and nurse perceptions.

The literature supports the effectiveness of home support programs. Afflect, Tennen, Rowe, Roscher and Walker (1989) determined that a program providing information and consultation for mothers who indicated a high level of need had positive effects on personal control, competence, and responsiveness to infants. Barrera, Rosenbaum and Cunningham (1986) also reported an improvement in parent-infant interaction and infant development in the experimental group who received home intervention.

The helpfulness of clergy and social workers may be more of an indication of the lack of proper facilities and adequate personnel in these positions. Only 13 parents had any contact with clergy and 19 had contact with a social worker. Some of these were not hospital staff but were from their own community. Several mothers who had a long hospital experience indicated their need to sit and talk in private to a social worker who was an impartial ear. The hospital did not have appropriate facilities for that to occur, and their meetings were often at the infant's bedside or in the hallway. Public health nurses are not always as helpful when they do not have knowledge or experience with premature or sick infants, that may explain why they scored lower.

The need for adequate written material is also evident by the books that several mothers cited as important for them. The Premature Baby Book, though well written, is becoming out of date. All of the other books are written to an audience of mothers of healthy term infants. Although much of the information can be applied to all new parents, these books do not provide answers to the worries and concerns that parents of high risk infants commonly identify. New resources are needed.

The FSQ scores indicated that general information provided to parents was adequate but specific information about medical conditions and medications did not score very high. Much of this information is provided by professionals other than nurses.

Physicians scored high after discharge, and they are the professionals most frequently contacted by parents. During hospitalization physician contact is limited. There is often confusion in the hospital about which physician should talk to parents about the medical condition of the infant and the results of tests. There are often delays in providing information to parents because of the difficulty with coordinating parents' visits with physician time. This may add to the parents' perception that they are not told everything about their infant. Parents also are not always told about the infant's medications. The medications change, and they are usually not continued after discharge. Some staff may consider this information too complicated for parents to understand.

Parent's Concerns

The concerns of parents also are similar to those noted by other studies. The three most common concerns of parents in this study were feeding, elimination, and the infant's health. Other concerns that were voiced, including apneas and SIDS, were mentioned by other studies as well. Goodman and Sauve (1985) reported feeding as the most common concern. McCain (1990) found that health concerns were frequently cited by parents. What was not found by this study was the concern about growth and development that most other studies report. Only one parent voiced this concern. For parents of very small infants their concern about development may have been too obvious, or too potent for them to mention. These infants are all followed-up by the child development clinic in the hospital. Some may simply not be aware that growth and development should be a concern for premature infants. First time parents do not have previous children to compare their newborn to, and thus may not be as concerned as parents with other children.

What is clear from the parents is that normal infant concerns are also their major concerns. This supports the finding of Butts et. al (1988) in their analysis of parent telephone calls. They reported mothers seeking reassurance. This investigator also found

that during discussions with mothers they looked for reassurance that they were doing the right things for their infant. It was during these discussions that questions about elimination and feeding patterns also came up, rather than when asked what their concerns were.

The concerns surrounding breastfeeding that were raised by many mothers were similar to those expressed by mothers in numerous other studies. Their primary concern focused on adequate consumption, which was also reported by Kavanaugh, Mead, Meier and Mangurten (1995) in their naturalistic inquiry. Meier et al. (1993) reported a 70 percent breastfeeding failure, which is significantly higher than the 44 percent rate found in this study. Fifty six percent of mothers in this study were still doing at least some breastfeeding by four to six weeks.

Formal Support

The results for the Formal Support Questionnaire were encouraging for nurses. The mean individual item score over the parent education questions was 3.9, which correlates with "quite a bit". The scores on the feeding questions were higher. This is also significant when compared to the results of the study by Hamelin (1991) where ninety percent of mothers indicated that more information would have enhanced discharge preparation, and less than half of the mothers who breastfed stated that they received enough instruction concerning breastfeeding. Many parents indicated that the amount of time they had spent caring for their infant in the hospital was a key ingredient to their comfort in doing it at home. Many parents roomed in with their infant. A number said they had declined rooming in because they felt they had already done so much in the hospital that it was not necessary. This was the case more for parents who had other children at home. Results of this study indicate parents are getting opportunities they need to interact with their infants in the hospital.

There are still some gaps in the information that is given to parents regarding their infant's medical problems and the medications used to treat them. The drop-off in breastfeeding by one month after discharge, indicates that although mothers may get enough help in the hospital, this is not sufficient for them to successfully breastfeed at home. Public Health Nurses possess expertise for normal infants but are not always adequate for parents of high risk infants. Formal support drops off dramatically when the infant is discharged. Hamelin (1991) found that mothers felt abandoned by the health care system after discharge of their infant. Community support beyond the pediatricians or family doctors were not evident from the parents responses.

The differences in scores on the FSQ between the two hospitals may be a result of the small sample size. It may also be related to differences in the physical environment of the units and the different approaches taken to parent education.

Social Support

Social support scores are most useful when correlating them with other variables. It is interesting to note however, how scores for this sample compare with those from other studies. This study used the 1995 version of the Norbeck Social Support Questionnaire, which used a 0 to 4 scale. The previous version of the NSSQ used a 1 to 5 scale and thus results in a higher score than the current version. The following table indicates the comparison of this sample with two other samples, with an adjustment made in the functional support scores to adjust for the change in scoring. For each variable the mean score for the sample is listed. The two comparisons are from Norbeck, Lindsey and Carrieri (1981) and (1983).

Table 20
Social Support Comparisons

Sample	Total Functional Support	Total Network	Total Loss
parents of high risk infants (n=50)	166	87	1.5
graduate and undergraduate nursing students (n=75)	229	112	1.7
university employees (n=136)	210	108	.78

Each of these samples had regular contact with school or work colleagues. On examination of the data from parents of high risk infants, very few school or work colleagues were included. The majority of support came from family and friends. Health care professionals who were included provided very little tangible support, and the contact was limited. The comparison does highlight the isolation of parents of young infants. They rely on their support to come to them rather than having it around them inherently. Small families or non-supportive families can drastically decrease the total support that parents receive, as was also reported by Mitchell (1992). Lower scores may also be a result of the number of single mothers who do not have the larger extended family to rely on. A number of these mothers also lived by themselves in subsidized housing. Many mothers indicated that their major support came from their spouse. Able-Boone and Steven (1994) looking at parents of NICU graduates, and Burke and Liston (1994) looking at adolescent mothers, reported that the parents also relied the most on the support from their partner. Most mothers welcomed the investigator into their homes indicating that the discussion was a positive experience for them. Some indicated that it was "nice to have another adult to talk to".

Infant Care Self-Efficacy

The best predictor of self-efficacy in this study was previous experience. Those parents with previous children had significantly higher scores on the ICS. In examining the individual items, results highlight some trends. The five items which scored the lowest are: recognizing croup, treating croup, recognizing an allergic response, recognizing an ear infection and treating diarrhea. Five items that scored the highest are: changing a diaper, holding baby, walking while holding baby, using a car seat, and feeding baby. These support the theoretical claim that experience and practice increase self-efficacy (Bandura, 1986). The more opportunity a parent has to perform a task the greater the confidence in doing it. Many parents had never heard of croup, and their children had not yet had an allergic response, ear infection or diarrhea. These received low scores because the information had not yet been needed by most parents. Skill scores on the ICS were generally higher than knowledge scores. In the month since discharge most parents had adequate practice in doing infant care skills and their confidence was high based on the scores.

Results are supported by Froman and Owen (1989) and (1990) in their studies of new mothers. They found that skills performed more often scored higher. However, they found a strong correlation between maternal age and infant care confidence which was not demonstrated in this study. Their study of 200 mothers had a range of mean scores from 2.54 for recognizing croup, to 4.52 for playing with baby. This study, with only 50 parents had a wider range, with 2.38 for recognizing croup and 4.9 for changing diapers. The mean total scores in Froman and Owen's studies are not reported. The smaller number in this study may be the reason for the wider range in mean scores. Results do indicate that parents of high risk infants are not radically different from those in Froman and Owen's studies. They score high and low in similar categories. The lack of correlation with age may also be a result of the smaller number. The mean age in both

Froman and Owen studies was 28 as compared to 27 in this study. The range in age was also similar.

Relationships Between Variables

Overall parents who have no previous experience with children, and who perceive less support and education by health care professionals are less confident in caring for their infant at home.

In examining the relationships that were demonstrated statistically, and the descriptive statistics, a few suppositions may be posed. Generally, parents in this sample who are older, have a higher income, higher education, and more child care experience, are more likely to continue breastfeeding past one month after discharge, perceive greater support and education by health care professionals, have more social support, and are more confident in caring for their infant.

Relationship to Theoretical Framework

The theoretical framework used in this study begins with the assumption that the birth of a high risk infant represents a crisis to the parents. This was supported by the majority of parents, indicating a high level of stress at the time of their infant's birth. Their descriptions of the experience in the hospital also supports the definition of crisis. The diagram in Appendix A highlights the theoretical relationship between social support and parent education, combining to influence infant care self-efficacy. This study demonstrated the correlation between parent education and self-efficacy. The relationship between social support and self-efficacy was not directly demonstrated. There was a correlation between perceived social support and parent education. A larger sample may have provided stronger relationships. The NSSQ may not be sensitive enough to actually

support this relationship. It may have demonstrated a significant relationship if some additional questions had been added to the NSSQ regarding help with infant care.

Results of the ICS and the positive correlation between previous experience and higher self-efficacy strongly support Bandura's theory of self-efficacy. The relationship between involvement with the infant in the hospital as indicated by the Parent Education subscore on the FSQ, and higher ICS scores also supports Bandura's theory. Self-efficacy improves with previous experience, and with practice of the necessary skills. Even parents with no previous children scored higher when they perceived more involvement and information in the hospital.

The qualitative portion of this study also provides some insight into the theoretical framework. In addition to parent education, the parents describe the importance of developing a parenting role, and interpersonal interactions with professionals in assisting them in dealing with their crisis experience. Searching for information was also a way that parents dealt with the crisis of having a high risk infant.

This study has generally supported the conceptual framework. It has also added to understanding of the experience of parents of high risk infants and helped to support the theoretical framework.

Study Limitations

This study is limited by four main factors. They include; the sample size, the method of sampling, the strength of the survey tools, and the reliance on parent perceptions and honesty in reporting.

Convenience sampling may be biased by time of year, or other unknown factors. The size of the population in Winnipeg and the time limitations of the project made a random sample inappropriate. Sample size requires cautious interpretation of results. Using a convenience sample limits the generalizability of the results to the larger population.

The ex post facto approach used in this study precluded any manipulation of variables which may have influenced the relationships that were identified. The important study variables; social support, formal support and infant care self-efficacy, were all “perceived” by the parents. The study relied heavily on the honesty and recollections of the parents. Perception of support and confidence by one parent can vary widely from that of another. A future study might include manipulation of variables such as parent education and social support in a randomized controlled trial.

Survey tools used in this study had not been used with this population before. The FSQ is an untested tool which was modified from a descriptive tool which had been used several times. Reliability and validity remain to be tested. The FSQ was the least tested of the three quantitative survey tools used. This tool showed potential for future and modification for application with other populations of parents. The FSQ could have used more questions focusing on other areas of parent education in order to give a better overall view of the parent’s perspective. There could have been more specific questions about infant care and knowledge about the infant’s illness.

The NSSQ provided good general information about social support. It would have been useful to add some specific questions about emotional support during the infant’s hospitalization and tangible support in caring for the infant at home.

The ICS is a relatively new tool which although it has been tested, has not been widely used. The ICS provides a thorough look at infant care issues. Several of the questions regarding feeding and sleeping schedules were questioned by parents as to their relevance, as parents claimed that they did not set the schedules, but allowed the infant to set them. Some of the questions, which look at potential illnesses relate more to parents of older children and are less useful for parents of young infants. These questions may have caused some confusion for first time parents.

Other studies have identified the reluctance of parents to criticize health care workers (Hamelin, 1991; Saydak, 1991). The investigator in this study was a stranger to

all of the parents, although they were aware that the investigator was a nurse. Some mothers were very open in describing their experiences. Others were brief, and did not provide much depth to their descriptions of the experience. They may have had more insight than they were willing to share with the investigator. Numerous parents, however, provided great depth of insight and contributed in heightening the understanding of their experiences.

Implications for Practice

In spite of the limitations of the study there are some important implications for practice. Most implications apply to nurses working directly with parents of high risk infants, although there are some wider implications as well.

The theoretical framework chosen for this study provides the first practice implications. Recognition of the crisis experience is the first task of the nurse in dealing with parents. More important is the recognition of the individual's response to the crisis. Parents identified a variety of ways they strove to deal with this crisis. The nurse has to recognize this searching process and help the parent find or attain their own goals, whether that is information or support. Recognizing demographic characteristics while not being limited by them is a difficult task of the nurse. Previous experience with caring for infants is a particularly important variable in determining the infant care confidence of a parent. Parents who have no previous children need more information regarding basic infant care and more opportunities to practice caring for their infant in the hospital. All parents need information about their infant's particular medical problems and special care needs, regardless of their previous experience with infant care.

When the initial crisis period is over, parents face their next major task, developing their infant care self-efficacy. Social support, though not directly correlated in this study, is nevertheless an important aspect of the family experience. Assisting parents to identify

and initiate their social support network can facilitate their development of the knowledge and skill necessary to care for their infants at home. Parents may not anticipate the amount of help and support they may need once their infant is home. The nurse can help them to identify it and plan accordingly.

Providing information to parents is an important task of the entire health care team. As the professionals who have the most direct contact with parents, nurses are also the most frequent providers of information. Parents themselves provide the nursing implications in this case. They want information that is “volunteered” and “consistent”. They do not want to ask about everything that is happening. As one mother stated “I didn’t even know what questions to ask”. This same mother also felt that the nurses didn’t know what to tell her. Parents identified the desire to learn about their infant. They wanted to know the correct terms for treatments and conditions. They wanted to hear information more than once, but they wanted consistent answers. As difficult as this may be to provide, it is important for nurses to make the effort.

Parents that perceived more information and assistance, also felt more confident in caring for their infant at home. Communication between professionals is important in ensuring that all necessary information is given to parents. The lower scores in learning about medications and medical conditions of infants indicates that although parents are learning general information about their infants, they are not always learning the details. This is also reflected in the confidence scores. Most of the medical conditions such as croup, allergies and ear infections received low scores. Basic infant care received high scores. Basic infant care is the most important factor in discharging an infant. Parents do not necessarily “need to know” about croup in the first months after discharge. Parents did, however, identify gaps in their knowledge about things such as normal elimination patterns, teething, and development. In some cases, appropriate reading material may fill the gap. Parents cannot be expected to remember all of these things before their infant is

discharged. They did identify a gap in reference material that can also be filled with appropriate planning.

Both providing information, and facilitating social support can be summed up in one phrase, "discharge planning". This was one of the major identified needs to emerge from Hamelin's study in 1991. Changes have been made since then in meeting the needs of parents. The scores on the FSQ reflect a generally high level of perception by the parents of the information and help that they received. There is still work to do however. Written information specific to premature infants is still lacking. Parents from St. Boniface Hospital identified a marked need in this area. Parents from both hospitals claimed that the amount they were "allowed" to do for their infant depended to some degree on which nurse was caring for the infant. Information differed from one shift to the next. This illuminates the need for greater communication between nurses and consistency in what is told to parents.

Nurses are also central to the parent's overall hospital experience. Relationships with hospital staff are important to parents and can influence their perception of the experience. Nurses need to develop a sensitivity to the role they play. Personality conflicts cannot be avoided. Parents who are in a state of crisis can be unpredictable and have a heightened sensitivity to the actions of others. Parents cannot always conform to the expectations of the hospital. Nurses must develop a flexibility and an ability to respond to the parents in a manner that allows parents to feel comfortable in the hospital. Developing close friendships with parents is not necessary, but giving the parents some control and some sense of belonging in the hospital unit is an important aspect of their developing a parenting relationship with their infant. This relationship is an integral part of their infant care self-efficacy and sets the ground work for their future relationship with their child.

Hospital policies and facilities also have a role to play in facilitating the parent's experience. Social support can be inhibited by strict, inflexible visiting policies. Facilities

which do not provide for parent's needs can add stress to an already stressful situation. This includes a lack of parent lounges, poor cafeteria services, and lack of space or privacy in the hospital units. Inadequate staffing for both nursing and other disciplines such as social work and chaplaincy can also inhibit meeting parent's needs for information and support.

There are implications for the health care system as a whole. Although early discharge has been demonstrated to be safe and cost saving (Casiro et. al, 1993; Brooten et. al, 1986), this has not become a trend in Manitoba. There are no specific support programs for these parents, and after a recent demonstration project was over, the trend ended, and hospitalization times and discharge weights demonstrated in this study have again increased. Health care costs have continued to rise. The system also has not kept up in provision of appropriate facilities for hospitals to care for these infants and parents. Although 32% of mothers were discharged fully breastfeeding and another 50% doing some breastfeeding, after a month only 20% were fully breastfeeding and 36% continuing to do some. There is no continued support for these mothers at home. Public Health Nurse contact is infrequent. Mothers who want support must find it for themselves. There is no support system that bridges the gap between hospital and home. A program providing this support, similar to Casiro's demonstration project could be coordinated through the hospital so that not only would parents not feel abandoned by the hospital at discharge, but there would be opportunity for a smoother transition to support from the Public Health Nurse and follow-up programs that are already in place. The transition to home would not be as abrupt as it is presently.

Implications for Future Research

The knowledge and understanding of what parents of high risk infants experience has continued to grow. This study has begun looking at some specific relationships between aspects of that experience. These relationships need to be explored further. Tools need to be tested in order to determine their validity and reliability with this population.

The population of First Nations peoples needs to be studied, as they represent a large percentage of parents of high risk infants. The research method used in this study may not be appropriate for this population. Culturally sensitive research needs to be developed in order to help nurses better understand the unique needs of this group.

Longitudinal research would be useful in order to further understand the long-term implications of the experience. In addition, some manipulation of variables would also provide greater information into the relationships between social support, formal support and infant care self-efficacy. This could be done in conjunction with demonstration projects for discharge education and home support.

Nurses need to become involved in the research of the experiences of this population. It is in the process that understanding evolves. It cannot be expected that nurses attitudes and perceptions change only by reading the research findings of another. The process must be experienced for real change to take place.

Conclusion

There is a significant relationship between the perception of parents of high risk infants regarding the information and formal support that they receive, and their confidence in caring for their infants at home. This relationship is particularly strong for parents who have no previous children. The role of social support in infant care self-efficacy has not been determined. Parents strive to form a relationship with their infant by interacting with them and by searching for information and support during their infant's hospitalization. Nurses play a significant role in facilitating this role for parents. Development of self-efficacy in infant care depends on the parent's receiving adequate information about their infant, care needs, and on the opportunity for them to practice caring for their infant in the hospital.

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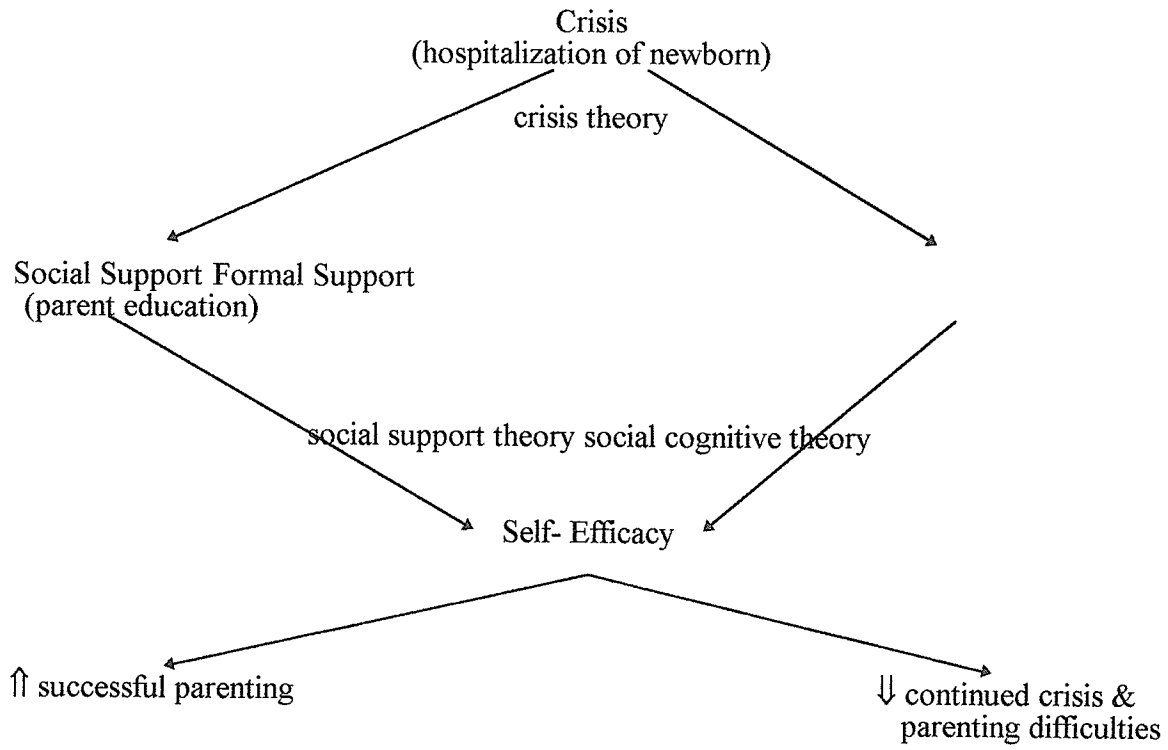
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Appendix A
Theoretical Framework

Theoretical Framework



Appendix B

Norbeck's grid for provision of social support

Norbeck's grid for provision of social support

<i>Duration of support required</i>	<i>Intensity of support required</i>		
	Low	Medium	High
Short Term			acute stressors or illness
Intermediate		life changes and transitions and for facilitating rehabilitation from major illness or surgery	
Long Term or Continuous	day-to-day living/ individual well-being/performance in major social roles		

from Norbeck (1981)

Appendix C
Invitation to Participate

Invitation to Participate in a Research Study

You are invited to participate in a study designed to identify the needs and concerns of mothers of babies who have been in the hospital. All mothers of babies who have been in the hospital for at least 10 days are being invited to participate in this study.

Participation involves approximately 30 minutes of your time to complete a three part questionnaire at approximately 6 weeks after your baby goes home. The first part asks questions about the help and teaching that you received from health care professionals. The second part asks questions about the help you receive from your family and friends. The third part asks you how confident you feel in caring for your baby.

If you think that a discussion of your experience would be upsetting to you feel free to refuse to participate.

There are no right or wrong answers to the questions. Your thoughts and experiences will be recorded and compared to those of other mothers in order to help nurses and other professionals better understand your situation, and to plan ways to provide mothers in the future with improved care. The information that you provide will be confidential and you will not be identified in any way. Only Doris Sawatzky-Dickson and Dr. Annette Gupton will have access to the data.

The decision to participate is entirely your own. If you do not wish to participate it will not influence in any way the care you or your infant receives. You may withdraw from the study at any time. If you do choose to participate, the research nurse will contact you by telephone approximately a month after your baby goes home to make an appointment with you.

The investigator is a Master of Nursing student at the University of Manitoba. This study has been approved by the Faculty of Nursing Ethics Committee at the University of Manitoba.

The study results may be published in the form of a journal article in the future, but the identity of the mothers who participated will never be revealed. A summary of results will be provided to those requesting it.

If you have any questions about the study I would be pleased to answer them before you make a decision to participate. You may call me at (204) 774-0779. If you agree to participate please complete the attached form, providing me with your name, phone number and address. If you would like a copy of the summary of the study after it is completed, please indicate that on the form.

Thank you very much for your consideration.

Doris Sawatzky-Dickson

You may keep this invitation and leave the next page for me when you make your decision

Invitation to Participate (page 2)

I agree to allow Doris Sawatzky-Dickson to contact me about participating in her study.

Name:

Address:

Phone Number:

Yes I would like a copy of the summary when the study is completed.

This form can be left with the chart and will be picked up by the investigator

Appendix D
Explanation of Study and Consent Form

Explanation of Study
(given at beginning of meeting with mother)

My name is Doris Sawatzky Dickson. I am a student in the Master of Nursing program at the University of Manitoba. Thank you for agreeing to participate in this study. The purpose of my study is to describe the information and support needs of mothers of infants who have been in the hospital, to find out who mothers turn to for support, what kind of information and support is the most useful, and how confident mothers are in taking care of their infants at home. I will begin by asking you some questions about yourself and your baby, and then I will ask you to fill out a questionnaire. There are three parts to the questionnaire, which should take about a half hour to complete. Your name will not go on any papers, so once our meeting is over there will be no way to link you with the information you give me. I will be the only one who will have access to the information, and I will keep it in a locked container for about 10 years before I destroy it. If you would like a copy of the summary of the results let me know and I will send you one.

Explanations of Interview Schedule(for select mothers only)

There are a number of additional questions that I would like to ask you once you have completed the questionnaire. This interview will take about a half an hour. I will be tape recording the interview. You will not be identified in any way on the tape. The tape will also be kept in locked storage for 10 years and only I will have access to it.

Consent Form

Doris Sawatzky-Dickson RN, a graduate student from the Faculty of Nursing, University of Manitoba, Winnipeg, Manitoba is conducting a research project to describe the education and support needs of mothers of high risk infants. The study will be supervised by Dr. Annette Gupton, Faculty of Nursing, University of Manitoba.

I understand that I will be interviewed by Doris Sawatzky-Dickson once, and asked to complete a three part questionnaire which will take approximately 30 minutes. I understand that I may be asked a few additional questions by the research nurse which may take an additional 30 minutes. The interview will take place in my home or at an alternate agreeable location, approximately 6 weeks after my baby is discharged home.

I understand that I may refuse to participate if I feel that a discussion of my experience is too upsetting for me.

I understand that my name will not be used in the transcribed data, or in any publications that arise from the study. Coded data will be stored on a computer, but will not be identifiable with any individual subjects. Only Doris Sawatzky-Dickson and Dr. Annette Gupton will have access to the data. I may receive a summary of the results if I so desire.

I understand that this study is not expected to have any direct benefits to my infant or myself, but hopefully the knowledge gained from the study will benefit mothers of infants who are in the hospital in the future.

I understand the purpose of the study and my role in the research project. If I have any concerns or questions, I may contact Doris Sawatzky-Dickson by telephone at _____, or Dr. Annette Gupton at _____, or by writing to them at the faculty of Nursing, The University of Manitoba, 246 Bison Building, Winnipeg, Manitoba. R3T 2N2.

I understand that participation in the study is completely voluntary. I am free to refuse to participate, or withdraw from the study at any time, and the health care provided to me and my infant will not be affected.

I have received a copy of this consent form.
My signature below indicates a willingness to participate in the study.

Date _____

(signature of participant)

(signature of researcher)

Appendix E
Demographic Information Collection Tool

Demographic Information

Please place a check mark or fill in the answer of each question.

Marital Status

married _____ common-law _____ separated _____ single _____

Family Income

<\$23,000 _____ \$23,001-\$42,999 _____ >\$43,000 _____

Place of Residence

Winnipeg _____ outside Winnipeg _____

Number of Children

(including baby) _____

Your Occupation _____

Your Age _____

Years of Education completed

last grade completed _____ number of years after high school _____

Method of feeding at discharge

breast _____ bottle _____ breast and bottle _____

Present method of feeding

breast _____ bottle _____ breast and bottle _____

How would you describe your level of stress when your baby was born?

high _____ med _____ low _____

At discharge?

high _____ med _____ low _____

Now?

high _____ med _____ low _____

Demographic Information Part 2
(Investigator to ask questions)

Reason for Hospitalization

prematurity____apnea____cardiac anomaly____other anomaly____
respiratory distress____seizures____asphyxia____sepsis____
other_____

If baby was premature, did you do Kangaroo Care?____Yes____No

Infant Type

single____twin____

Gestational Age of Infant at birth____weeks

Birthweight____grams

Discharge weight____grams

Hospital of Admission

St. Boniface____Health Sciences Centre_____

Units of Admission

NICU only____Intermediate Care only____NICU and Intermediate Care____

Numbers of Days in hospital_____

Number of Days at home_____

Since discharge:

Number of visits by Public Health Nurse_____

Number of visits to Pediatrician_____

Number of visits to Family doctor_____

Has your baby been re-admitted to the hospital? yes____no____

If yes, for what reason

for how long?____days

Significant Diagnoses at Discharge?

Appendix F
Formal Support Questionnaire



THE UNIVERSITY
of LIVERPOOL

21 May 1996

Mrs D Sawatzky Dickson

Winnipeg
Manitoba
Canada

Professor K A Luker,
PhD, RGN, RHV, NDN Cert.
Head of School

Faculty of Medicine

School of Health Sciences
Thompson-Yates/
Johnston Building
Liverpool L69 3BX

Telephone: 0151 794 5799
Facsimile: 0151 794 5796
Email: lukerka@liverpool.ac.uk

Dear Mrs Sawatzky Dickson

Thank you for your letter dated 4 March, which was somewhat delayed in reaching me; since it went to the University of Manchester and I have been at the University of Liverpool for seven years.

I have no difficulty with you using your amended version of the family support questionnaire. I apologise for the delay in my response and wish you well with your work.

Yours sincerely

Professor K A Luker
Head of School

Formal Support Questionnaire

All of the questions are marked on a 5-point scale. Please circle the number that you think is right for you.

0 = not applicable / 1 = not at all / 2 = a little / 3 = moderately / 4 = quite a bit / 5 = a great deal

1) To what extent were you involved with your baby in the hospital?	0	1	2	3	4	5
2) How helpful were the pamphlets that you were given in the hospital?	0	1	2	3	4	5
3) To what extent did you learn about your baby while he/she was in the hospital?	0	1	2	3	4	5
4) To what extent did you learn about your baby's medicines?	0	1	2	3	4	5
5) To what extent did you learn about your baby's medical problems?	0	1	2	3	4	5
6) To what extent did you learn about bathing your baby?	0	1	2	3	4	5
7) While still in the hospital, to what extent did you feel prepared to take your baby home?	0	1	2	3	4	5
8) Once you were home, to what extent were you prepared for looking after your baby when he/she came home?	0	1	2	3	4	5
9 a) Were you given enough help and teaching in breast feeding your baby when he/she was in the hospital?	0	1	2	3	4	5
9 b) Were you given enough help and teaching in bottle feeding your baby when he/she was in the hospital?	0	1	2	3	4	5
10) Overall were you given enough help in learning how to feed your baby in the hospital	0	1	2	3	4	5
11) How helpful has your Public Health Nurse been for you since your baby has been home?	0	1	2	3	4	5
12) How helpful has your Family Doctor been since your baby has been home?	0	1	2	3	4	5
13) How helpful has your Pediatrician been since your baby has been home?	0	1	2	3	4	5
14) How helpful have the hospital nurses been since your baby has been home?	0	1	2	3	4	5
15) How helpful has the social worker been?	0	1	2	3	4	5
16) How helpful has the chaplain or other clergy been?	0	1	2	3	4	5

Appendix G
Interview Schedule

Interview Schedule

- 1) Let's start by talking about what happened when your baby was born.
- 2) How did you feel when your baby first came home?
- 3) What did you find most positive about your experience?
- 4) What did you find most helpful in your experience at the hospital?
- 5) Looking back, do you think that there are ways in which the quality of care and support offered to parents who have had a child in Neonatal Intensive Care or Intermediate Care might be improved?
- 6) What suggestions would you like to make which might improve the way in which parents are prepared for their baby's discharge by the nurses in Neonatal Intensive Care?
- 7) What suggestion would you like to make which might improve the way parents are prepared for their discharge by nurses in Intermediate Care?
- 8) Your baby has now been home from hospital for ___ weeks. What would you say were the main things concerning her/him that worry you now?
- 9) Is there anything else you would like to tell me about your experience of bringing home a baby from Intensive Care or Intermediate Care?
- 10) In what ways do you think the quality of care offered by Community Health Nurses to parents who have brought a child home from Intensive Care or Intermediate Care might be improved?
- 11) If you were asked to give advice to parents who are about to bring a baby home from Intensive Care or Intermediate Care, what would you think they ought to know?
- 12) How are you doing now?
- 13) How would you describe your ability to take care of your baby at home just after he/she was discharged? now?

Appendix H

Norbeck Social Support Questionnaire

Appendix A

Request Form

I request permission to copy the Norbeck Social Support Questionnaire (NSSQ) for use in research in a study entitled:

A descriptive analysis of the support and educational
needs of parents of high risk infants.

Oct 1/95

Signature of Investigator Date

DORIS SAWATZKY-DICKSON

Typed or Printed Name of Investigator

GRADUATE STUDENT

Position

UNIVERSITY OF MANITOBA.

Institution

Address

WINNIPEG, MB CANADA

City, State, (Country), ZIP Code

Permission is hereby granted to copy the NSSQ for use in the research described above.

Jane S. Norbeck
 Jane S. Norbeck

October 10, 1995
 Date

Please send or fax two signed copies of this form to:

Jane S. Norbeck, RN, DNSc
 Professor and Dean
 School of Nursing, Box 0604
 University of California, San Francisco
 501 Parnassus Avenue
 San Francisco, CA 94143-1604
 FAX:

SOCIAL SUPPORT QUESTIONNAIRE

PLEASE READ ALL DIRECTIONS
ON THIS PAGE BEFORE STARTING

Please list each significant person in your life on the right. Consider all the persons who provide personal support for you or who are important to you.

Use only first names or initials, and then indicate the relationship, as in the following example:

Example:

	First Name or Initials	Relationship
1.	<u>MARY T.</u>	<u>FRIEND</u>
2.	<u>BOB</u>	<u>BROTHER</u>
3.	<u>M.T.</u>	<u>MOTHER</u>
4.	<u>SAM</u>	<u>FRIEND</u>
5.	<u>MRS. R.</u>	<u>NEIGHBOR</u>

etc.

Use the following list to help you think of the people important to you, and list as many people as apply in your case.

- spouse or partner
- family members or relatives
- friends
- work or school associates
- neighbors
- health care providers
- counselor or therapist
- minister/priest/rabbi
- other

You do not have to use all 24 spaces. Use as many spaces as you have important persons in your life.

WHEN YOU HAVE FINISHED YOUR LIST, PLEASE TURN TO PAGE 2.

Note: Before use, pages 1-4 should be cut along the dashed center line to allow the response lines for Questions 1-6 to align with the Personal Network list on page 5.

For each person you listed, please circle the number that applies.

- 0 = not at all
- 1 = a little
- 2 = moderately
- 3 = quite a bit
- 4 = a great deal

Question 1:

How much does this person make you feel liked or loved?

- 1. _____
- 2. _____
- 3. _____
- 4. _____
- 5. _____
- 6. _____
- 7. _____
- 8. _____
- 9. _____
- 10. _____
- 11. _____
- 12. _____
- 13. _____
- 14. _____
- 15. _____
- 16. _____
- 17. _____
- 18. _____
- 19. _____
- 20. _____
- 21. _____
- 22. _____
- 23. _____
- 24. _____

[EMO1]

Question 2:

How much does this person make you feel respected or admired?

- 1. _____
- 2. _____
- 3. _____
- 4. _____
- 5. _____
- 6. _____
- 7. _____
- 8. _____
- 9. _____
- 10. _____
- 11. _____
- 12. _____
- 13. _____
- 14. _____
- 15. _____
- 16. _____
- 17. _____
- 18. _____
- 19. _____
- 20. _____
- 21. _____
- 22. _____
- 23. _____
- 24. _____

[EMO2]

GO ON TO NEXT PAGE

Note: Before use, pages 1-4 should be cut along the dashed center line to allow the response lines for Questions 1-6 to align with the Personal Network list on page 5.

- 0 = not at all
- 1 = a little
- 2 = moderately
- 3 = quite a bit
- 4 = a great deal

Question 3:

How much can you confide in this person?

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____
11. _____
12. _____
13. _____
14. _____
15. _____
16. _____
17. _____
18. _____
19. _____
20. _____
21. _____
22. _____
23. _____
24. _____

[EMO3]

Question 4:

How much does this person agree with or support your actions or thoughts?

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____
11. _____
12. _____
13. _____
14. _____
15. _____
16. _____
17. _____
18. _____
19. _____
20. _____
21. _____
22. _____
23. _____
24. _____

[EMO4]

Note: Before use, pages 1-4 should be cut along the dashed center line to allow the response lines for Questions 1-6 to align with the Personal Network list on page 5.

- 0 = not at all
- 1 = a little
- 2 = moderately
- 3 = quite a bit
- 4 = a great deal

Question 5:

If you needed to borrow \$10, a ride to the doctor, or some other immediate help, how much could this person usually help?

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____
11. _____
12. _____
13. _____
14. _____
15. _____
16. _____
17. _____
18. _____
19. _____
20. _____
21. _____
22. _____
23. _____
24. _____

[AID5]

Question 6:

If you were confined to bed for several weeks, how much could this person help you?

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____
11. _____
12. _____
13. _____
14. _____
15. _____
16. _____
17. _____
18. _____
19. _____
20. _____
21. _____
22. _____
23. _____
24. _____

[AID6]

Note: Before use, pages 1-4 should be cut along the dashed center line to allow the response lines for Questions 1-6 to align with the Personal Network list on page 5.

Question 7:

How long have you known this person?

- 1 = less than 6 months
- 2 = 6 to 12 months
- 3 = 1 to 2 years
- 4 = 2 to 5 years
- 5 = more than 5 years

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____
11. _____
12. _____
13. _____
14. _____
15. _____
16. _____
17. _____
18. _____
19. _____
20. _____
21. _____
22. _____
23. _____
24. _____

[DURATION]

Question 8:

How frequently do you usually have contact with this person? (Phone calls, visits, or letters)

- 5 = daily
- 4 = weekly
- 3 = monthly
- 2 = a few times a year
- 1 = once a year or less

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____
11. _____
12. _____
13. _____
14. _____
15. _____
16. _____
17. _____
18. _____
19. _____
20. _____
21. _____
22. _____
23. _____
24. _____

[FREQCON]

PERSONAL NETWORK

First Name or Initials	Relationship
1. _____	_____ [SOU1]
2. _____	_____ [SOU2]
3. _____	_____ [SOU3]
4. _____	_____ [SOU4]
5. _____	_____ [SOU5]
6. _____	_____ [SOU6]
7. _____	_____ [SOU7]
8. _____	_____ [SOU8]
9. _____	_____ [SOU9]
10. _____	_____ [SOU10]
11. _____	_____ [SOU11]
12. _____	_____ [SOU12]
13. _____	_____ [SOU13]
14. _____	_____ [SOU14]
15. _____	_____ [SOU15]
16. _____	_____ [SOU16]
17. _____	_____ [SOU17]
18. _____	_____ [SOU18]
19. _____	_____ [SOU19]
20. _____	_____ [SOU20]
21. _____	_____ [SOU21]
22. _____	_____ [SOU22]
23. _____	_____ [SOU23]
24. _____	_____ [SOU24]

PLEASE BE SURE YOU HAVE RATED EACH PERSON ON EVERY QUESTIONS. GO ON TO THE LAST PAGE.

9. During the past year, have you lost any important relationships due to moving, a job change, divorce or separation, death, or some other reason?

- _____ 0. No
_____ 1. Yes

[LOSS]

IF YES:

9a. Please indicate the number of persons from each category who are *no longer available* to you.

- | | |
|-----------------------------------|---------|
| _____ spouse or partner | [LOSS1] |
| _____ family members or relatives | [LOSS2] |
| _____ friends | [LOSS3] |
| _____ work or school associates | [LOSS4] |
| _____ neighbors | [LOSS5] |
| _____ health care providers | [LOSS6] |
| _____ counselor or therapist | [LOSS7] |
| _____ minister/priest/rabbi | [LOSS8] |
| _____ other (specify) _____ | [LOSS9] |

[LOSSNO]

9b. Overall, how much of your support was provided by these people who are no longer available to you?

[LOSSAMT]

- _____ 0. none at all
_____ 1. a little
_____ 2. a moderate amount
_____ 3. quite a bit
_____ 4. a great deal

Appendix I
Infant Care Survey

U N I V E R S I T Y O F

CONNECTICUT

THE SCHOOL OF NURSING

Doris Sawatzky-Dickson
Winnipeg, Manitoba, Canada

Oct. 9, 1995

Dear Ms. Sawatzky-Dickson:

I'm delighted the Infant Care Self-Efficacy Scale (ICS) can be of use to you. Feel free to use it in your research. A copy is enclosed.

Scoring is relatively simple. Visually inspect item 8. That is the lie item. If a score of "C" or more confidence is noted, the rest of the scale responses become suspect, unless the respondent has given some reason for the response on item 8 (i.e. "I'm a nurse"). In any case, item 8 is not included in calculating a score. The most commonly used ICS score is the mean item response across all items answered. In other words, sum up all the responses (except item 8) using A=5, B=4, C=3, D=2, and E=1. Then divide the total by the number of items answered. The total ICS score then ranges from 1 to 5, commonly used with a two place decimal. Others have used the same mean score system to construct subscale scores for Knowledge self-efficacy (use all the knowledge items), Skill self-efficacy (use the skill item responses), and the three separate groupings of Health, Diet, and Safety. In all cases using the 1 to 5 metric allows comparison between subscale scores and total score and translates easily back to the A through E original response format with verbal anchors of "Quite a Lot" (5) and "Very Little" (1) confidence.

Good luck with your research.

Sincerely,

Robin D. Froman, RN, Phd, FAAN
Professor and Director
Center for Nursing Research



Infant Care Survey

How much confidence do you have about doing each of the behaviors listed below?

1 = very little

2 = some

3 = moderate

4 = mostly

5 = quite a lot

1. Knowing immunization schedules	1	2	3	4	5
2. Knowing schedule for physical exam	1	2	3	4	5
3. Recognizing signs of a ear infection	1	2	3	4	5
4. Identifying diaper rash	1	2	3	4	5
5. Knowing when to get help from the clinic, emergency room or doctor	1	2	3	4	5
6. Recognizing teething	1	2	3	4	5
7. Knowing regular breathing sounds of babies	1	2	3	4	5
8. Recognizing congestion	1	2	3	4	5
9. Recognizing an allergic response	1	2	3	4	5
10. Recognizing croup	1	2	3	4	5
11. Knowing expected weight gain patterns for an infant	1	2	3	4	5
12. Recognizing constipation	1	2	3	4	5
13. Recognizing diarrhea	1	2	3	4	5
14. Recognizing gas pains	1	2	3	4	5
15. Knowing normal growth and development patterns	1	2	3	4	5
16. Know how much to feed your baby	1	2	3	4	5
17. Selecting the best formula	1	2	3	4	5
18. Selecting baby foods	1	2	3	4	5

19. Planning a balanced diet for your baby	1	2	3	4	5
20. Knowing how to use a baby bottle.	1	2	3	4	5
21. Identifying safety hazards in the house.	1	2	3	4	5
22. Choosing safe baby toys.	1	2	3	4	5
23. Choosing safe baby furniture	1	2	3	4	5
24. Choosing safe baby clothes	1	2	3	4	5
25. Knowing which medications are dangerous	1	2	3	4	5
26. Knowing safe positions for a baby after feeding	1	2	3	4	5
27. Knowing what articles are safe to leave with your baby in the crib or baby seat	1	2	3	4	5
28. Treating diaper rash	1	2	3	4	5
29. Burping your baby	1	2	3	4	5
30. Weighing your baby	1	2	3	4	5
31. Taking your baby's temperature	1	2	3	4	5
32. Changing a diaper	1	2	3	4	5
33. Relieving pain from teething	1	2	3	4	5
34. Relieving congestion	1	2	3	4	5
35. Giving your baby a liquid medication	1	2	3	4	5
36. Relieving croup	1	2	3	4	5
37. Treating constipation	1	2	3	4	5
38. Treating diarrhea	1	2	3	4	5
39. Relieving gas pains	1	2	3	4	5
40. Establishing a sensible sleeping schedule	1	2	3	4	5
41. Soothing your crying baby	1	2	3	4	5

42. Breast or bottle feeding your baby (whichever way your baby is fed)	1	2	3	4	5
43. Spoon feeding your baby	1	2	3	4	5
44. Preparing baby food	1	2	3	4	5
45. Introducing new food into baby's diet	1	2	3	4	5
46. Establishing a sensible feeding schedule	1	2	3	4	5
47. Holding your baby	1	2	3	4	5
48. Demonstrating a tonic neck reflex	1	2	3	4	5
49. Bathing your baby	1	2	3	4	5
50. Using a car seat	1	2	3	4	5
51. Walking while holding your baby	1	2	3	4	5
52. Playing with your baby	1	2	3	4	5

Appendix J
Ethical and Facility Approval

The University of Manitoba
FACULTY OF NURSING
ETHICAL REVIEW COMMITTEE

APPROVAL FORM

Proposal Number N#95/51

Proposal Title: "A CORRELATIONAL STUDY OF THE EDUCATIONAL AND SUPPORT NEEDS
OF MOTHERS OF HIGH RISK INFANTS."

Name and Title of
Researcher(s):

DORIS SAWATZKY-DICKSON, RN, BN
MASTER OF NURSING GRADUATE STUDENT
UNIVERSITY OF MANITOBA FACULTY OF NURSING

Date of Review: DECEMBER 04, 1995.

APPROVED BY THE COMMITTEE: DECEMBER 04, 1995.

Comments: APPROVED WITH SUBMITTED CHANGES AND CLARIFICATIONS OF
DECEMBER 07, 1995.

Date: DECEMBER 07, 1995.

Linda J. Kristjanson, PhD, RN
Associate Professor
University of Manitoba Faculty of Nursing

Chairperson

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.

Revised: 92/05/08/se



Pediatric Research
Coordinating Committee
820 Sherbrook Street
Winnipeg, Manitoba R3A 1R9
Dial Direct (204) - 787-2455
Facsimile#: (204) 787-5040

November 6, 1995

Doris Sawatzky-Dickson

Winnipeg, Manitoba

RE: *"A Correlation Study of the Educational and Support Needs of Mothers of High Risk Infants"*

Dear Mrs. Sawatzky-Dickson,

Your study was reviewed by the PRCC on November 6, 1995. It was **approved**. Though we have the following minor concerns:

1. Various grammatical/spelling errors.
2. Most of the impact will be on the parents and on the nurses in NICU and TI nursery.

Thank you for your submission.

Sincerely yours,

Wade T.A. Watson, MD, FRCPC
Chair, Pediatric Research Coordinating Committee
Children's Hospital of Winnipeg

WTAW:ck





Hôpital général **St-Boniface** General Hospital

December 13, 1995

Doris Sawatzky-Dickson

Winnipeg, Manitoba

**Re: Access to SBGH for Study Entitled:
A CORRELATIONAL STUDY OF THE EDUCATIONAL
AND SUPPORT NEEDS OF PARENTS OF HIGH RISK INFANTS**

Dear Doris Sawatzky-Dickson:

I am pleased to inform you that your research access request has been approved. You may proceed with your study on the understanding that:

- 1) any significant changes in your proposal will be submitted to my attention prior to implementation;
- 2) you review the enclosed policy on confidential information and then sign and return the enclosed Pledge of Confidentiality;
- 3) you inform us when your data collection is complete. This information helps us coordinate research access requests and minimize competing demands of research study protocols on patients and nursing staff time;
- 4) you inform us of the funding status of your study.

We may call you to make presentations to hospital staff about your research at our Brown Bag Research Luncheons held monthly. Upon completion of your study, we request that you provide us with a brief summary of your final report.

Thank you for selecting St. Boniface as the site for recruiting participants for your study. Please feel free to contact me with your questions or concerns. Should you encounter any site-related difficulties during the course of your study, I would appreciate being notified of these.

All the best with the completion of your study.

Sincerely,

Katherine Stansfield, R.N., M.N.
Nursing Program Development
and Evaluation Specialist
Tel.

KS/mj

Encl: Confidential Policy & Pledge

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