

***A DESCRIPTIVE STUDY OF THE FORMAL AND INFORMAL  
SUPPORT RECEIVED BY MOTHERS WHO HAVE HAD  
AN INFANT IN INTENSIVE CARE***

*by*

***Kathryn June Hamelin***

***A thesis  
presented to the University of Manitoba  
in fulfillment of the  
thesis requirement for the degree of  
Master of Nursing***

***Winnipeg, Manitoba***

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A thesis submitted to the Faculty of Graduate Studies of  
the University of Manitoba in partial fulfillment of the requirements  
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## ***DEDICATION***

*This thesis is dedicated to the  
memory of my son*

***Michael Anthony***

*September 1972*



## **Abstract**

### **A Descriptive Study of the Formal and Informal Support Received by Mothers who have had an Infant in Intensive Care**

Since the early 1960's, survival rates for high-risk infants have dramatically improved. Although some improvement in survivorship can be attributed to obstetrical management, much is due to advances in neonatal intensive care.

The need of high-risk infants for comprehensive care, however, extends well beyond their stay in neonatal intensive care units. Reports of developmental and physical impairment, increased mortality and morbidity, and parenting disorders indicate the need for continued community followup and support of the high-risk infant and family.

The role of the social network and the support it offers in alleviating the effects of stressful life events has emerged as a major focus in literature concerning family adaptation to the birth of a high-risk infant. Recent research evaluating the effect of formal and informal support on the adaptation and later parenting of high-risk infants is inconclusive. This suggests that intervention and support must be tailored to meet specific individual needs, to ensure continued adaptation to this stressful life event.

The purpose of this descriptive study was to identify the needs and concerns of mothers of high-risk infants following the discharge of their infants from intensive care. Maternal perceptions of the need for and helpfulness of sources of formal and informal support were also explored. Assumptions from family systems

theory, crisis theory, and social support theory guided the study. This combined conceptual framework provided insight into the family disruption that can occur during the crisis of neonatal illness and need for support during this stressful time.

Non-probability sampling was employed to recruit fifty mothers of high-risk infants cared for in two major neonatal centers. Subjects participated in a semi-structured interview that occurred six weeks after their high-risk infants were discharged home. Interviews generated both qualitative and quantitative data. Quantitative data were analyzed with descriptive statistics while qualitative data were subjected to content analysis.

Findings indicated that mothers of high-risk infants experienced a crisis when their infants were discharged from hospital. Respondents reported significant concerns about their infants in the postdischarge period and the need for continuing followup from both formal and informal sources of support. Nurses in hospitals and the community can provide this support if they are available in the postdischarge period and if they are knowledgeable in the care and potential problems of graduates of neonatal intensive care and their families.

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## CHAPTER I: PROBLEM STATEMENT

The survival of newborns with life-threatening illness has increased dramatically over the past twenty years. Improved standards of obstetrical care, earlier referral and transport of mothers at risk for delivering an infant requiring intensive care, advances in biomedical technology, and improved neonatal transport and neonatal care have resulted in improved mortality and morbidity in this high-risk group (Fanaroff & Merkatz, 1977).

The need of high-risk neonates for comprehensive care, however, extends well beyond their stay in neonatal special care units. Infants requiring intensive care at birth are at risk for developmental and/or physical impairment (Turner, 1988). Several reports document a high frequency of illness requiring rehospitalization during the early years of life (Sells, Neff, Bennett & Robinson, 1983; Mitchell & Najak, 1989). Very-low-birth-weight (VLBW, < 1500 grams) infants, in particular, are readmitted to hospital four times as often as normal-birth-weight (NBW, > 2500 grams) infants and their postneonatal death rate is five times as high (McCormick, 1985; Broton, Kumar, Brown, Butts, Finkler, Bakewell-Sachs, Gibbons, & Delivoria-Papadopoulos, 1986).

In addition, it is well documented that mothers separated from their infants at birth are at increased risk of disharmonious mother-child interactions and parenting disorders (Jeffcoate, Humphery & Lloyd, 1979; Boer, 1978). The experience of premature birth and neonatal illness is a crisis for the family and precipitates reactions of grief, fear, and guilt (Caplan, 1960). An equally devastating

crisis may occur at the time of the infant's discharge from hospital. Salitross (1986) describes the discharge of a healthy premature infant as extremely stressful for families. Added responsibilities of caring for a chronically ill infant or an infant who was critically ill at birth can intensify this stress and permanently change the family (Arenson, 1988).

While the majority of research in this field of study concentrates on the emotional reactions and needs of parents of premature infants, it is recognized that parents of all sick, high-risk, or low-birth-weight infants may experience an emotional shock when their infant requires specialized or intensive care at birth. Illness and separation of full-term infants and their parents are just as stressful events as the separation of premature infants and their parents. Both can result in disintegration of the family's physical, emotional, and social health if the crisis is not successfully resolved (Noga, 1982).

A recent trend to early hospital discharge of premature infants has benefits as well as potential problems and may place additional stress on the family. Potential benefits of early discharge include decreased iatrogenic illness and hospital-acquired infection, enhanced parent-infant interaction, and decreased costs for hospital care (Casiro, Becker & McFayden, 1988; Brooten et al., 1986). These benefits may be offset, however, if early discharge imposes highly stressful monitoring and care on unprepared parents. Clearly, to meet the complex, multiple, and long-term needs of all infants who required special care at birth and their families, follow-up care and support after discharge is required.

The availability of social support can influence parental adaptation to the birth of a high-risk infant. The emotional disequilibrium associated with crises such as the hospitalization and subsequent home care of high-risk infants may encourage parents to consider outside resources and influence their receptiveness to formal and informal support (Affleck, Tennen, Rowe, Roscher & Walker, 1989). Family and friends can offer invaluable informal support during family crises while more formal support systems provide information and concrete aid. Recently, however, negative as well as positive effects of formal and informal support on mothers' adaptation to the hospital-to-home transition of high-risk infants have been found (Affleck et al, 1989; Zarling, Hirsch & Landry, 1988).

Parents of high-risk infants experience feelings of inadequacy and helplessness to provide needed care, in addition to worries about their infant's survival and developmental outcomes. These concerns, coupled with the many real and potential problems facing graduates of neonatal intensive care, point to the need for follow-up services for the high-risk infant and their family. Despite the well-known, potential health and psychosocial problems facing families of high-risk infants, however, professional support in the community continues to be limited (Affleck, Tennen, Allen & Gershman, 1986; Crnic, Greenberg & Slough, 1986). While medical and nursing care is routinely provided in the community through a variety of sources, families of high-risk infants often have unique needs that cannot be addressed through standard follow-up care.

Extensive literature is related to the care of high-risk infants in hospital. Very little, however, has been written about specific community nursing needs

following discharge from special care (Turner, 1988). In addition, few studies have explored the concerns of mothers in caring for high-risk infants in the home or examined maternal perceptions of the care provided to them after discharge.

The purpose of this study, therefore, was to identify the needs of mothers of high-risk infants after the discharge of their infant from special care. In addition, maternal perceptions of the support that families of high-risk infants required and received from professional and non-professional sources during transition period from hospital to home were assessed.

Specifically, the following questions were addressed:

1. What are the common worries and problems mothers experience when their high-risk infant is discharged from neonatal special care?
2. Whom do mothers turn to for help and support after their high-risk infant is discharged from special care?
3. Which sources of support are most useful to mothers after their high-risk infant is discharged from special care and why are these sources considered most helpful?

Health care of an ever-increasing population of high-risk premature and full-term infants is a significant and growing concern. Quality perinatal care encompasses not only the sick neonate but the family as well, and must extend beyond the initial period of hospitalization to include follow-up care in the home environment. As increasing numbers of vulnerable infants are discharged home, community care of the high-risk infant becomes a shared nursing responsibility. Maternal perceptions of the support received from professional and non-

professional sources in the community setting were examined in this study and contributed to an understanding of how families cope when a high-risk infant is discharged from special care. An examination of the post-discharge concerns of mothers of high-risk infants presented an opportunity to assess the contribution that community health nurses can make to the continuing care and support of this high-risk population.

## CHAPTER II: CONCEPTUAL FRAMEWORK

### Introduction

The conceptual framework for this research is based on family systems theory. General systems theory, introduced by von Bertalanffy in 1936, has been applied with increasing frequency by health care professionals to the study of the family (Wright & Leahey, 1984). Systems theory provides a comprehensive framework for observing individuals, families, and communities, and for viewing the interrelationships among these systems as they influence health (Helvie, 1981). Systems theory, therefore, can be utilized to examine how health care professionals, including nurses, interact with and influence the health of individuals and the systems to which they belong.

When concepts from systems theory are combined with concepts from crisis theory, family function during crisis events can be examined and described. Since an individual's ability to successfully resolve crises depends to a large extent on the availability of a supportive social context, the concept of social support must be considered as well. This discussion, therefore, will include: 1) an overview of general systems theory, focusing on the family as a system; 2) an examination of a systems theory of crisis intervention; and 3) a review of the concept of social support. The conceptual framework will then be applied to the need for and provision of social support to mothers during the potential crisis period that follows the discharge of their high-risk infant from neonatal special care.

Theoretical Foundations of General Systems Theory  
as Applied to the Family

A system can be defined as a complex of elements in mutual interaction, which endures over time and ensures the survival, growth, and continuity of the system (Wright & Leahey, 1984). When this definition is applied to the family, it permits an appreciation of the relationships existing among family members and a recognition that any significant family event or change will effect family members in varying degrees and ultimately influence the organization and functioning of the family as a whole.

Several useful assumptions from systems theory provide a theoretical foundation for understanding the family as a system and will be highlighted in the following discussion.

Assumption 1: A family system is part of a larger suprasystem and is composed of many subsystems as well (Wright & Leahey, 1984, p.10).

The concept of a hierarchy of systems is useful in understanding family structure and function. The family system as a whole is composed of many subsystems, such as parent-child, marital, and sibling subsystems. These subsystems are in turn composed of subsystems of individuals who are complex systems themselves (be they physical systems such as reproductive or cardiovascular, or psychological systems such as the id, ego and superego). The family at the same

time is nested within larger suprasystems such as neighbourhoods, health care organizations, religious associations, and other groups of individuals affecting the family system (see Figure 1). Interaction among the multiple components of the family system must be considered in understanding the family as a whole.

Systems are arbitrarily defined by boundaries, which aid in specifying what is inside or outside of the system. Family systems, as all living systems, have boundaries that are both permeable and limiting; permeable enough to be open to ideas and input from the outside environment yet sufficiently limiting to maintain family integrity and identity. The family system is able, therefore, to incorporate outside resources into the family unit at times of need. This capacity promotes the maintenance of a family balance in the face of crisis and change, and ensures the survival and growth of the family system (Wright & Leahey, 1984).



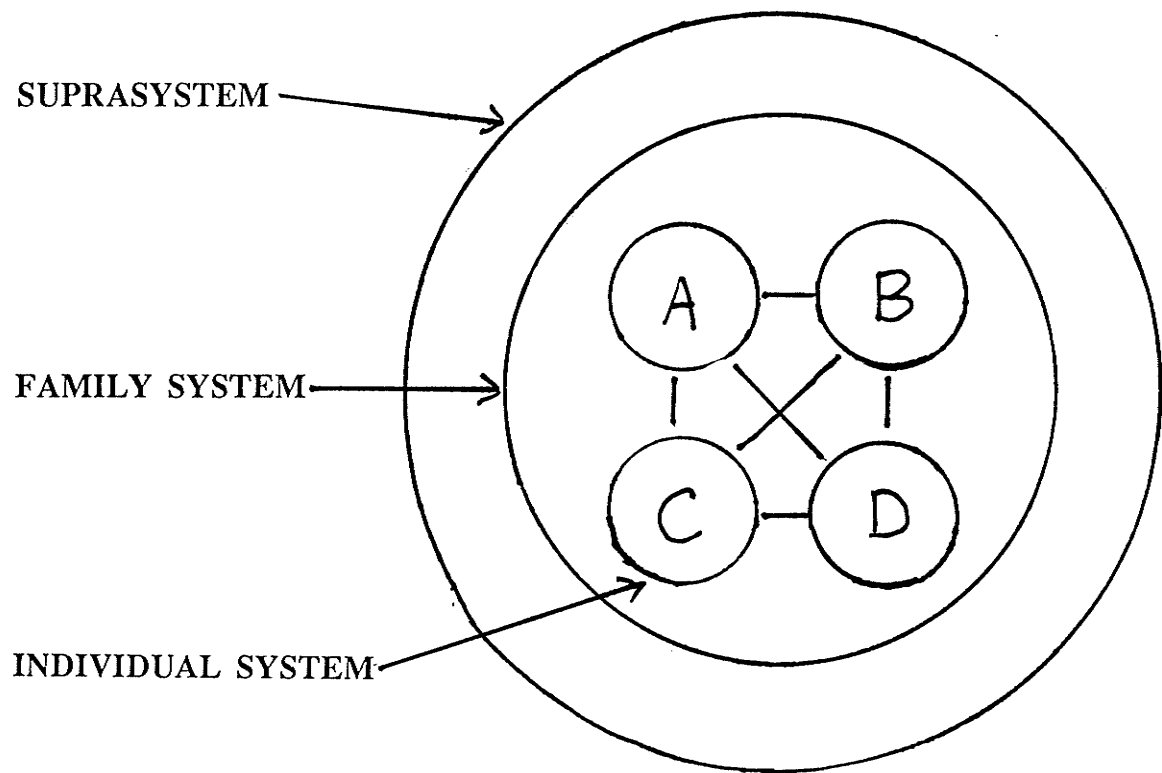


Figure 1. The family as it relates to other systems.  
(Wright & Leahey, 1984, p.11).

Assumption 2: The family as a whole is greater than the sum of its parts  
(Wright & Leahey, 1984, p. 12).

This assumption emphasizes that family wholeness is more than simply the addition of each individual to the family system. It stresses that individuals are best understood within their larger context, which is normally the family, and that the behavior of family members cannot be studied apart from the larger family system to which they belong. Understanding family structure and function includes an appreciation of the relationships existing within the family and a realization of how interaction among family members affects both individuals and the family as a whole.

Assumption 3: A change in one family member affects all family members  
(Wright & Leahey, 1984, p. 13).

This assumption acknowledges that any significant event or change in one family member will affect all family members in varying degrees and ultimately influence the structure and function of the family as a whole. An awareness of this relationship by health care professionals encourages the recognition that illness in one family member invariably affects the entire family system. The assumption also can be applied to understanding the impact of intervening into a family system, and focusing on how a change in the behavior of one family member will have repercussions for the entire family unit (Wright & Leahey, 1984).

Assumption 4: The family is able to create a balance between change and stability (Wright & Leahey, 1984, p. 13).

As a system interacts with its environment, it is capable of developing toward order and organization or disintegration and disorder; disorder is always present to a certain degree since parts of the system must continually adjust to outside input (Helvie, 1971). As the system moves toward disorganization, individual parts of the system do not function efficiently as a whole and the system is less able to fulfil its goals. As the system receives sufficient input of energy and information, however, there is a tendency toward increased order and organization (Helvie, 1981).

Von Bertalanffy (1968) suggested that systems, in this case family systems, are able to achieve a balance among forces operating within them and upon them, and that change and stability can coexist in living systems. There has been a recent shift, however, toward the belief that families exist in a state of constant flux and are always changing (Wright & Leahey, 1984). Since families at certain stages of development or in certain situations tend to return to a fixed point of balance after a disturbance, it is assumed that change and stability can coexist in the family system. Stability at a higher level of functioning may be one positive result of family change, if appropriate support systems are available during crisis. Families experiencing extreme upheaval, however, may "get stuck" in a maladaptive situation. These families may eventually require outside assistance in finding solutions to obtain a more equal balance between the phenomena of stability and change (Wright & Leahey, 1984).

Assumption 5: Family members' behaviors are best understood from a view of circular rather than linear causality (Wright & Leahey, 1984, p. 14).

The major difference between linear and circular causality lies in the structure of the connections between the elements of the pattern. Linear patterns are limited to sequences and are heavily rooted in a continuous progression of time; circular patterns on the other hand form a closed loop, are recursive, and are dependent upon a framework of reciprocal relationships based on meaning (Tomm, 1981).

The assumption is made in family systems theory that family patterns are circular in nature and that each family member mutually contributes to adaptive as well as maladaptive interaction. Each individual's behavior, therefore, influences the behavior of other members of the family system.

#### Application of Systems Theory to the Research Question

There has been a dramatic shift in nursing from a focus on the individual to a focus on the family as the unit of health care. Nurses today recognize that the family is a significant factor in the state of health and well-being of the individual. To foster health care at the family level, nurses consider the impact of illness on the family and the influence of family interaction on the "cause" and "cure" of problems (Wright & Leahey, 1984). The connection between these two factors is more fully understood by conceptualizing the family as a system.

Consequently, application of family systems theory to the research question is beneficial in understanding the impact of neonatal illness on the family. The birth of a high-risk infant influences all members of the family system. Initially, the infant is hospitalized, separated from its parents, and unable to take its place in the family unit. This event disrupts family subsystems, including the parent-infant system, the sibling system, and the marital system. When the infant is finally discharged home, disruption of the family system can abate, continue, or escalate to a point where family function is disorganized and the health of the family unit is threatened. Home-care of a high-risk infant who requires specialized care may represent a period of continuing upheaval for the family; the infant may demand much of the caretaker's time; siblings may feel left out, jealous, and regard the infant negatively; and marital relationships may be adversely affected through a lack of time available to the couple or through fear of giving birth to another high-risk child. Extended family members, neighbours, and friends may be affected at this time as well, through their continuing concern for the infant and family, or through increased demands on their time.

The subsequent disorganization of the family system may result in an inability to fulfil family functions and achieve family goals. The period of disruption may be time-limited and subside as the infant assumes a less demanding role in the family unit. If disorganization persists however, the family may require assistance from outside resources. The provision of professional and non-professional support, in the form of information and concrete aid, may assist the family to return to its previous balance.

Consideration of assumptions derived from crisis theory aid in understanding family behavior during this crisis event and will be examined in the following section.

### Theoretical Foundations of Crisis Theory

Helvie (1981) defines a crisis as a period of disequilibrium which overpowers the system's homeodynamic mechanisms and causes acute change while new coping skills are developed. Eventual crisis resolution may leave the system at a higher, equal, or lower level of coping than before the crisis event.

Crises may be classified as either situational or maturational in nature. Maturational crises occur as a response to the developmental transitions and normal growth which occur in individuals' lives while situational crises arise as a response to situational hazards, challenges, and sudden unexpected events (Caplan, 1964). Regardless of the specific nature of the crisis stimulus, similar patterns of behavior and responses emerge. Kallis (1970) summarizes six basic assumptions of crisis theory which assist in understanding the effects of a crisis event and which provide insight into behavior in a crisis situation. These include:

- 1) the need of the human being to maintain a balanced state;
- 2) the need to try to restore a balanced state if it is disrupted;
- 3) the fact that certain kinds of disruptions can by their characteristics be defined as crisis states;

- 4) that individuals are more open to external influence during crisis;
- 5) that periods of upset are self-limited and will result in a new state of balance or adaptation that may be better or worse than that which preceded the crisis; and
- 6) that balance can be restored by changing the environment, by changing how one copes with it, or by changing both of these factors.

Caplan (1964) outlines four typical phases in the process of crisis resolution which aid in understanding behavior in a crisis situation. In Phase 1, an initial rise in tension provokes habitual problem-solving responses. If these typical responses do not lead to resolution, the individual or family enters Phase 2, characterized by lack of success and the continuation of the problematic stimulus. Increased feelings of tension, distress, and feelings of ineffectuality, characteristic of Phase 3, act as a powerful stimulus to mobilize both internal and external resources. This phase is typically characterized by a reexamination of the problem, utilization of novel problem-solving approaches, a willingness to consider outside assistance, and increased susceptibility to change. In Phase 4, the crisis continues, leading to major disorganization, discontinuity, and imbalance of customary patterns of behavior. According to Caplan, resolution of the crisis, whether it results in a solution of the problem and a return to former levels of effective functioning, or in a movement toward equilibrium at a more dysfunctional level, will occur in approximately six weeks (see Figure 2).

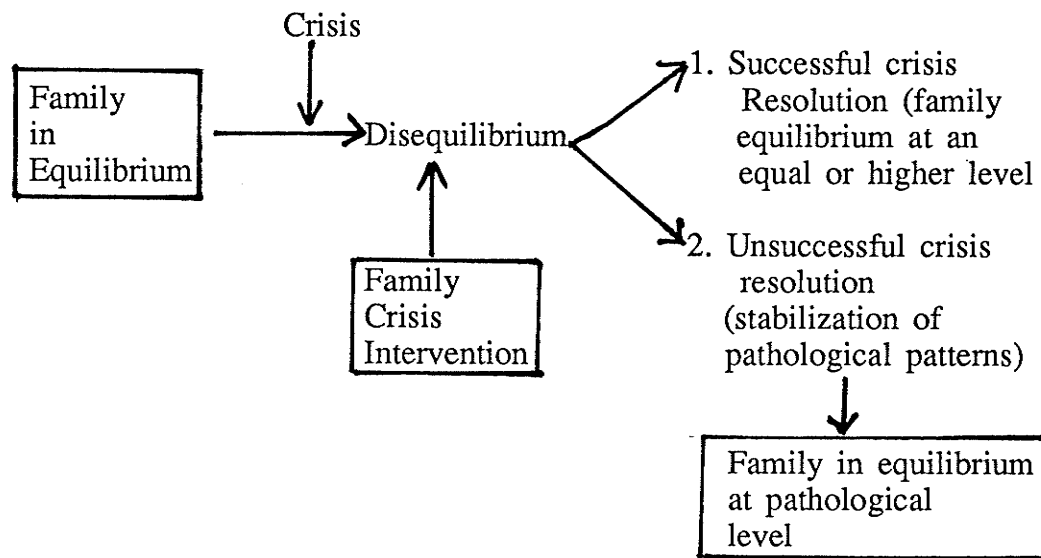


Figure 2. Process of Crisis Resolution  
(Umana, Gross & McConville, 1980, p.4)

### Crisis theory as applied to the family system

Any system may experience crisis at various times throughout its lifespan. As human systems move away from a balanced state, stress and tension arise and may lead to crisis. Assumptions from crisis theory can be applied to understand the effect of crisis upon the family system and can be utilized to plan intervention within the family system at times of family crisis.

A systems model of crisis intervention emphasizes the social context in which the individual and the crisis stimulus come together. Systems adherents view



the social system as the major factor in both the production of the crisis situation and its resolution. Two assumptions of the model that reflect this emphasis are:

- 1) an individual's perception of stressful events depends upon the social context in which they occur; if this context is viewed as non-supportive or if help is unavailable to the individual when the stressful event occurs, the individual is more likely to perceive the event as a crisis; and
- 2) an individual's ability to successfully resolve crises is viewed as dependent upon the availability of a supportive social context; the social system may be the individual's family, work group, or other groups such as the health care community (Umana, Gross & McConville, 1980).

In summary, a systems model of crisis intervention combines key assumptions from family systems theory and crisis theory to assist in understanding the process of crisis within the family system. According to the model, the key variable to a family experiencing crisis is the provision of an effective support system. Proponents of this theory suggest that return to family balance involves offering effective support or correcting ineffective or detrimental interaction patterns within the social system.

Application of a systems model of crisis intervention  
to the Research Question

The birth of a high-risk infant is a crisis event which can be conceptualized as both a situational and maturational in nature; parenthood constitutes the maturational crisis, while the high-risk nature of the event constitutes the situational component of the crisis event (Beaton, 1984).

The birth of a high-risk infant disrupts the family system and disorganizes the roles and relationships within the family unit. Initially, the hospitalized infant is more a part of the neonatal intensive care unit than a member of the family unit. Separation of the infant from its family coupled with the unpredictable nature of the infant's condition precipitates an initial crisis at this time. Recent literature suggests that the discharge of an infant who has required special care at birth presents an additional period of crisis for the family. Parents often feel unprepared to take on the responsibility of caring for a small and fragile infant and are uncertain that they can provide the expert care their infant received in hospital. Repercussions of the crisis event are felt by the entire family system.

A systems model of crisis intervention stresses that resolution of family crisis is often dependent upon the availability of a supportive social network. In this study, the researcher examined whether the availability of formal and informal sources of family support can help to alleviate the stress that accompanies this crisis event (see Figure 3).

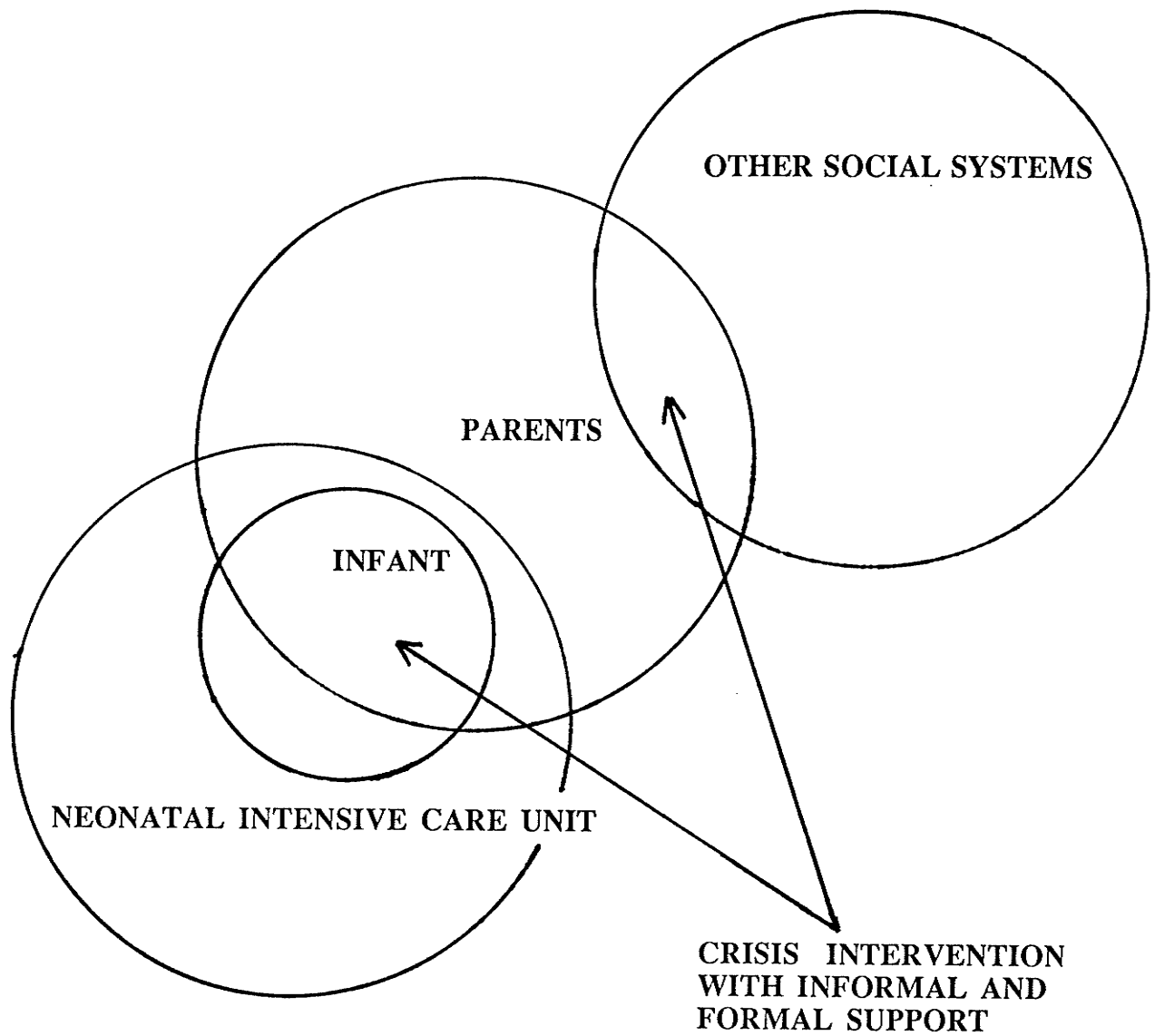


Figure 3. Interaction of the components of the crisis of premature birth.  
(Beaton, 1984).

## A Review of the Concept of Social Support

Social support has been hypothesized to buffer or mediate the effect of stressful life events on psychological distress. Direct effects of social support in improving health also have been reported. This section will provide a brief review of the concept of social support and its implications for the use of social support with individuals, families and communities. A more comprehensive literature review of the application of social support to families experiencing the birth of a high-risk infant is found in Chapter 3.

Many conceptual definitions of social support have been proposed. Early researchers looked at social support in a general manner that was often vague and circular. In these studies, global measures of support were employed that did not clearly distinguish the different facets of this concept. Recent definitions have become more explicit. A variety of types of social support have now been identified, and similarities among categories noted. Most investigators currently regard social support as having at least two major components: emotional support and tangible aid (Norbeck, 1985). House (1981) suggests that social support includes the following components: emotional support (esteem, affect, trust, concern, listening); appraisal support (affirmation, feedback, social comparison); informational support (advice, suggestion, directives, information); and instrumental aid (money, labor, time). His typology is considered the most complete to date.

Recent attention has also been directed toward sources of social support, referred to as the social network. The social network has been defined as the set

of relationships of a particular individual or the specific set of linkages among a defined set of persons (Schaefer, Coyne & Lazarus, 1981, p. 383). Social networks may vary according to: 1) size and range - the number of individuals with whom the individual has direct contact; 2) network density - the extent to which members of the network contact each other; and 3) the degree of connection - the average number of relationships that each member has with other members of the network (Mitchell & Trickett, 1980).

In summary, social support can be best understood as a multidimensional concept. Consideration of the amount, type, and sources of social support are equally important in assessing whether families of high-risk infants are able to rely on and effectively utilize support from social networks to alleviate the stress accompanying this crisis event. In this research project, maternal perceptions of formal and informal support in the postdischarge period were explored. For the purposes of this study, informal support referred to support from family, friends, and neighbours; formal support referred to support from health care professionals, namely physicians, nurses, and social workers.

### Conclusion

A systems theory approach enables an appreciation of the effect of the discharge of a high-risk infant from special care on the family system. When combined with crisis theory, an enhanced understanding of the effect of this

maturational and situational crisis is attained. The availability of social support appears to be a crucial element in the production and resolution of this crisis event.

In summary, this combined conceptual framework enables the researcher to examine the ability of the family of a high-risk infant to cope with the changes that accompany the crisis event, and in particular explore how both internal and external sources of formal and informal support influence family adaptation and ultimately the balance of the family system.

## CHAPTER III: LITERATURE REVIEW

This literature review focuses on the impact of neonatal intensive care on the infant, the family, and on health care professionals involved in caring for the high-risk infant after discharge. It includes a brief examination of the history of neonatal intensive care, the implications of neonatal intensive care on the mortality and morbidity of the high-risk infant, the impact of the high-risk infant on the family, and the need for continuing social support in the postdischarge period. The role of the community health nurse as a source of formal community support also is reviewed.

## The History of Neonatal Intensive Care

Documentation of premature infant care began in the late 1800's when Dr. Martin Couney demonstrated the use of the incubator as a "child hatchery" at numerous exhibitions and world fairs (Harrison, 1984). Although displaying premature infants for profit was morally questionable, the interest and compassion which these infants promoted, coupled with the high survival rate of Couney's premature infants, slowly motivated hospitals to establish premature nurseries within their centers. The first unit of this kind opened at Chicago's Sarah Morris Hospital in 1923 (Harrison, 1984). Since this time, the quality of care offered to premature infants has improved steadily, as has an understanding of the medical and psychosocial needs of the infant and family.

The transition from premature nursery to neonatal intensive care unit occurred around 1960. Statistics pertaining to survival of infants born prematurely in this era are not well documented, however, researchers suggest that on average only 9 to 16% of infants weighing less than 1000 grams and 55% of infants weighing 1000 to 1500 grams at birth survived (Schrechner, 1980).

Treatment innovations during the 1960's resulted in improved survival of premature infants, but often at the expense of increased handicap among survivors. Overuse of oxygen led to blindness; when oxygen administration was restricted, neurological damage increased; and inappropriate delays in feeding led to starvation, hypoglycemia, jaundice and further long-term problems (Harrison, 1984).

McCormick (1989) recently reviewed the past 20 years of neonatal intensive care and provided reassurance that modern neonatal intensive care not only saves lives but that an increasing proportion of ill and premature infants survive free of moderate to severe handicap in the first few years of life. Since survival of many of the tiniest infants is a recent phenomenon, information on long term outcomes for these survivors only now is emerging in the literature.

Today, regionalization and specialization of neonatal care offers high-risk infants every chance to survive. Improvements in obstetrics and the availability of maternal and newborn transport have resulted in earlier referral to tertiary care, and in the opportunity for stabilization of the high-risk and premature infant in the immediate post-natal period.

Admission rates to NICU's have escalated as the acuity of neonatal care continues to increase. In 1976, a major neonatal centre within the province of



Manitoba reported a delivery rate of 2500 infants per year. Fifteen percent of patients who delivered in the center were classified as high-risk. Current statistics illustrate a delivery rate of 4000 per annum at the same centre and a high-risk component of 40% (MacDonald, 1989). In the past 10 years, admissions to NICU in this same facility have increased by approximately 25% to over 600 per year. Census figures confirm an occupancy rate of 80%, with the figure often closer to 100%. Admissions to the province's other NICU facility have similarly increased during this time frame. Admission rates to intermediate care have risen by 33% and to neonatal intensive care by 31% in the past 10 years (MacDonald, 1989).

In examining these findings, it is apparent that an expanding population of high-risk infants is being cared for and ultimately discharged from neonatal intensive care. This high-risk population continues to require care and support in the post-discharge period.

#### Mortality and Morbidity of Infants Who Require Neonatal Intensive Care

Infant survival and handicap rates reflect the quality of health interventions offered in the neonatal period. Accordingly, improvements in the mortality, morbidity and developmental potential of infants requiring neonatal intensive care illustrate the recent progress of this medical specialty.

### Mortality

Recently, McCormick (1989) analyzed a report from the Office of Technology Assessment in Washington, DC, which summarized the published studies on survival of infants treated in NICU's between 1960 and 1985. McCormick's analysis reveals that survival rates for VLBW infants increased from 27% in 1960 to 72% in 1985, while the proportion of these infants who attain relatively good health increased from 7.2% to 56.8% in the same time period. Similar trends are found among extremely low birth weight (ELBW, under 1000 grams) infants. Mortality in this group declined from 92% in 1960 to 48% in 1975 while the proportion without handicap rose from 1.7% to 34.5% during the same interval (OTA, 1987; McCormick, 1989).

Ichord (1988) reports similarly encouraging statistics in the survival of newborns with life-threatening illness, reporting that 50% of newborns weighing 750 grams survive today compared with the same survival rate in infants weighing 1200 grams at birth in 1970.

Researchers conducting a regional perinatal mortality survey in northern England report that survival is becoming increasingly common at 24 to 27 weeks gestation. Physicians now widely accept that the clinical limit of viability is nearer to 24 weeks than 28 weeks, the previously documented limit of viability (Wariyar, Richmond & Hey, 1989). The result of this trend is that a greater number of much smaller infants are surviving the neonatal period and being discharged from NICU.

In a retrospective analysis of changes in mortality in VLBW infants from 1968 to 1972, Mutch, Newdick, Lodwick and Chalmers (1986) report that in 1972, 72% of infants survived the neonatal period. This figure represents a 16% increase in the two-year survival rate of VLBW infants compared to an increase in survival of only 0.3% among NBW infants.

In a comparison of mortality rates of infants weighing 501 to 1000 grams at birth during the periods 1977 to 1980 and 1981 to 1984, Saigai, Rosenbaum, Hattersley and Milner (1989) found that survival rates improved significantly with decreasing birth weights, however, no significant change in the overall survival rate of infants under 1000 grams was found in the two periods. They conclude that health care professionals have reached a plateau in attempts to improve survival rates for infants under 1000 grams and that a high toll in terms of both death and morbidity continues to exist for infants weighing under 800 grams at birth.

Authors of several studies suggest that the decreasing mortality of infants treated in NICU is not necessarily reflected in improved survival among the same group of infants after discharge from intensive care. Kulkarni, Hall, Rhodes and Sheehan (1978) first reported the post neonatal infant mortality rate for apparently well NICU graduates treated between 1971 and 1974 as twice that of the general population. Sudden Infant Death Syndrome (SIDS) and infection contributed to the largest proportion to this mortality.

Sells, Neff, Bennett and Robinson (1983) similarly examined the postdischarge mortality rate of infants cared for at an American neonatal centre, documenting a 3.8% death rate in the first year of life. This figure represents a

sevenfold increase in mortality compared to the general population. Inevitable deaths from congenital anomalies and severe neonatal illness contribute significantly to the high postdischarge mortality in infants requiring intensive care at birth (Kulkarni, Hall, Rhodes & Sheehan, 1978). SIDS and infection influenced the postneonatal death rate in apparently normal infants discharged from intensive care; their mortality rate remains twice that of the general population (Kulkarni, Hall, Rhodes & Sheehan, 1978).

Sells, Neff, Bennett and Robinson (1983) summarized the characteristics of infants who required neonatal intensive care and who later succumbed to SIDS. In a sample of 1,410 infants hospitalized during a three year period in NICU's in Washington, DC, the researchers noted that of 43 identified postdischarge deaths, SIDS accounted for 28% of the deaths and was the most common cause of death in NICU survivors. Although study numbers are small, this postdischarge mortality rate represents an approximately twenty-five fold higher incidence of SIDS in infants discharged from NICU compared to infants who succumb to SIDS in the general population. Mean maternal age, marital status, and parental occupation were not significantly different among these groups. Infants who died of SIDS had nursery courses which were in general less complicated than most infants treated in NICU. Postdischarge deaths appear to be underrepresented in VLBW infants and overrepresented in larger LBW (low birth weight, under 2500 grams) infants.

McLoughlin (1988) also reports that infants requiring intensive care at birth are at increased risk of mortality from SIDS, especially in the first three months of life. She cites shortened gestational periods, low birth weight and admission to

an intensive care setting as risk factors for SIDS. These factors contribute to an increased postdischarge mortality rate in these infants.

In conclusion, it appears clear from recent studies that there has been an improvement in the in-hospital mortality of infants cared for in NICUs. Neonatal intensive care, however, does not appear to alter the incidence of long term mortality. Infants cared for and subsequently discharged from NICU are at increased risk of early death when compared to the general population. Deaths from SIDS and congenital anomalies contribute to a major proportion of this postdischarge mortality. Deaths related to infections, chronic lung disease and trauma also contribute to the higher rate of postdischarge mortality.

### Morbidity

#### General Health

Improved survival rates for ill and very premature infants have raised questions about the postdischarge health status of this population. Abundant medical literature exists concerning follow-up for this vulnerable group, concentrating on neurodevelopmental outcome, physical growth and development, and specialty areas such as pulmonary sequelae. A smaller number of papers describe issues in primary health care. Increased morbidity after discharge has been reported in many of these studies.

The incidence of rehospitalization in infants who require intensive care at birth is a reliable indicator of postdischarge morbidity. McCormick, Shapiro and

Starfield (1980) examined a large random sample (4,989) of one year old infants, stratified to comprise 82 percent who weighed 2500 grams or less at birth, in order to identify factors which determine more serious types of morbidity and the need for hospital use. The researchers collected data from a wide geographical area with diverse ethnic and socioeconomic variables. The sample accounted for approximately 6% of births in the United States. Information on health, medical care utilization, and developmental status was obtained on this random sample of infants born in an eight month period in 1976. A total of 3,179 LBW and 1,777 NBW infants were seen in their homes at one year of age and their mothers were interviewed to obtain the needed information. Results of the study reinforce concerns for the continued vulnerability of LBW infants to serious illness. Overall, 9.1% of infants had been rehospitalized and this rate increased with decreasing birth weight; 32.2% of infants with birth weights of 1500 grams or less experienced at least one hospitalization during the first year of life (McCormick, Shapiro & Starfield, 1980). LBW infants were over twice as likely, and VLBW infants 4.5 times as likely, to be hospitalized as NBW infants in the first year of life. Reasons for admission to hospital included upper respiratory infections, gastrointestinal complaints, accidents/ingestions, congenital anomalies and developmental delay. Increased vulnerability was not entirely explained by the prevalence of congenital anomaly and/or developmental delay in LBW infants, or by interaction with adverse socioeconomic correlates of LBW. The authors suggest that adverse consequences of LBW and neonatal illness may extend beyond the neonatal period for all LBW infants and that these children may require continuing specialized care.

Hack, DeMonterice, Merkatz, Jones and Fanaroff (1981) further described the morbidity of VLBW infants in a prospective follow-up study of 90 survivors with birth weights less than 1500 grams who were admitted to a major neonatal center in Cleveland, Ohio in 1977. Thirty-three percent of the infants required at least one rehospitalization during their first year of life. Reasons for rehospitalization included chronic conditions resulting from complications in the neonatal period (necrotizing enterocolitis, brochopulmonary dysplasia, patent ductus arteriosus), infection (respiratory, gastroenteritis), inguinal herniorrhaphy, and caretaking disorders (potential abuse, failure to thrive). Chronic neonatal complications and neurodevelopmental delay in particular placed the child at risk for continued morbidity in the first few years of life.

Much of the early literature concerning morbidity of VLBW survivors concentrates on the severely disabling conditions of neonatal illness such as blindness and cerebral palsy. Mutch, Newdick, Lodwick and Chalmers (1986) studied changes over time in rehospitalization patterns among VLBW infants to determine patterns of less dramatic morbidity among VLBW survivors. These researchers compared birth cohorts born between 1968 and 1972 and those born between 1974 and 1978. The experience of all VLBW infants in each of these five year periods was compared with random samples of infants drawn from the same cohorts who weighed more than 1500 grams. Data was matched for maternal age, social class, parity, infant sex, birthweight, whether the births were singleton or multiple, and neonatal outcome. Information was extracted on the number of hospital readmissions, age at readmission, duration of hospital stay, diagnosis at

discharge, and operative procedures required. Results indicate that as the survival rate for VLBW infants improved from 35% to 48% between 1968 to 1978, the rehospitalization rate before two years of age increased from 22% to 27%. This figure represents a 24% increase in the rate of rehospitalization of VLBW infants before they are two years of age. In contrast, the rate of rehospitalization in heavier infants declined from 9.8% to 8.9% in the same time period. Diagnosis at discharge was examined to investigate possible reasons for this increased morbidity in VLBW survivors. Nine broad groupings of illness requiring rehospitalization were found. These included congenital anomalies, structural defects associated with prematurity, other anomalies, infections, trauma and poisoning, nutritional deficiencies, convulsions, and a group of other reasons not classified in the above. The researchers suggest that VLBW infants are at increased risk of rehospitalization for a wide variety of reasons compared with their heavier cohorts. In addition, they propose that this enhanced risk may still be increasing as the survival chances of VLBW infants continue to improve. In this study, increased risk of herniation among VLBW survivors stands out as the single most important feature and a recurrent reason for rehospitalization in VLBW infants. Although infants requiring herniorrhaphy were often treated as day patients and therefore, did not contribute significantly to days of hospital stay, these infants did require surgical and anaesthetic facilities. It is possible that increasing use of intermittent positive pressure ventilation contributes to this unique morbidity in VLBW infants after discharge. Studies by Termini, Brooten, Brown, Gennaro and York (1990) support this association. Premature infants who required ventilation experience an increased



incidence of herniation and, in general, a higher rate of postdischarge illness in the first few years of life.

Research by Mitchell and Najak (1989) similarly supports an increased incidence of postdischarge illness in high-risk infants. These researchers carried out a retrospective chart review of 157 infants weighing less than 1500 grams at birth. A twenty-fold increase in the number of rehospitalizations was found in the study group compared to the general pediatric population aged two and under in the state of Georgia in 1978. The population sampled was of lower socioeconomic status, therefore, generalization of results may be limited. However, the hypothesis that premature infants have significant illness during the first few years of life was supported.

Early reports of continued morbidity in LBW and VLBW infants described continued illness in infancy and early childhood. Kitchen, Ford, Doyle, Rickards and Kelly (1989) collected data on a cohort of VLBW children between the ages of two and five years, to assess ongoing health problems and readmissions to hospital in later childhood among this high-risk group. Data were collected from a large neonatal centre in Australia. Eighty-five survivors with a birth weight of under 1000 grams and 123 survivors with a birth weight of 1000 to 1500 grams, born between 1977 and 1982, were assessed at two and five years of age. These children were compared with a NBW cohort of 60 children born contemporaneously. Data on neurodevelopmental abnormalities, health problems, and hospital admissions were systematically collected and compared. Results indicate that VLBW children, compared with NBW children, continue to have significantly

more health problems between two and five years of age. A preponderance of admissions to hospital in the first two years of life confirms previous findings. At five years of age, VLBW children on average had 1.7 hospital admissions and 8.5 days in hospital. These means were significantly higher than the 0.5 admissions and 1.7 days of hospitalization reported for NBW children. Respiratory tract infections and ear, nose, and throat surgery were most common causes for admissions in later childhood years. Malformations and intensive care sequelae rarely caused readmissions to hospital after two years of age. The researchers, therefore, suggest that morbidity of VLBW infants continues into the later childhood years.

Urtis, Clayton and Jay, in a 1988 study, evaluated the severity and occurrence of morbidity experienced by a group of larger premature infants, born between 32 and 36 weeks gestation. Health records of 20 randomly selected premature infants born in 1982 to 1983 were compared with 20 randomly selected full term infants born in the same time period. A severity score was recorded for every illness reported by mothers or seen by health care professionals at each visit to the hospital or clinic during the first year of life. Resulting scores produced an overall measure of severity and occurrence of illness in this time frame. Results illustrate that even though moderately premature infants demonstrate no significant difference in occurrence of illness, they had significantly higher mean scores for severity of illness compared to term infants. The authors suggest that even moderately premature infants may be at risk for more severe illness compared to term infants, especially in the first year of life.

Swanson and Berseth (1987) reviewed predominant causes of morbidity in premature infants in the first few years of life, providing an excellent guideline for the management of these infants following discharge from intensive care. Common problems of the high-risk survivor are similarly discussed by Hurt (1984) and Ichord (1988). The major problems experienced by survivors of neonatal illness are bronchopulmonary dysplasia, apnea, retinopathy of prematurity, hearing loss, alterations in growth, anemia, seizures, and intraventricular hemorrhage.

Bronchopulmonary dysplasia (BPD) is a chronic lung disease that occurs in newborns who have received oxygen or ventilator therapy. The incidence of BPD is inversely related to gestational age and occurs in 6% to 24% of infants treated for respiratory distress. Mortality associated with this disorder ranges from 10% to 40%. Morbidity due to BPD includes recurrent respiratory infections, wheezing, congestive heart failure, and poor growth and development. Approximately 70% of infants with BPD require rehospitalization during the first two years of life (Swanson & Berseth, 1987). Some infants with BPD require oxygen therapy in the home and periodic blood sampling to monitor their respiratory status. With careful management and follow-up, these children gradually improve and are generally free from pulmonary symptoms by two years of age.

Apnea is defined as a respiratory pause that exceeds 20 seconds and commonly occurs in infants born prematurely (Rigatto, 1982). Apnea of prematurity is most likely due to immaturity of receptors and control mechanisms for regulation of respiration and, in infants with persistent apneic episodes, usually resolves by six to nine months of age (Swanson & Berseth, 1987). Evidence shows that infants

dismissed from neonatal intensive care are at greater risk for Sudden Infant Death Syndrome (SIDS) than are other infants. Infants with persistent apneic episodes may be discharged with home apnea monitors until normal respiratory function is ascertained.

Retinopathy of prematurity (ROP) is a disease of prematurity and a complication of life-saving treatment. Incidence is inversely proportional to birth weight and gestational age. Increased survival of VLBW infants and more liberalized use of oxygen have caused an increase in ROP in recent years (Gardner & Hagedorn, 1990; Valentine, Jackson, Kalina & Woodrum, 1989). Of those infants with mild ROP (stage 1 or 2), 70% to 80 % will experience full spontaneous resolution of their disease (Gardner & Hagedorn, 1990). Cryotherapy is currently being used to treat this debilitating complication of premature birth and the possibility of blindness for moderate to severe ROP (stage 3 and 4).

Hearing loss and deafness are reported complications of prematurity and neonatal illness. Salamy, Eldredge and Tooley (1989) performed neurophysical and behavioral assessments of auditory function in 224 VLBW infants born between 1982 and 1987 to determine risk factors for hearing impairment in the neonatal period. Approximately 5% of the sample sustained sensorineural hearing loss of sufficient magnitude to warrant hearing aids in the neonatal period. Chronic lung disease was the only medical condition common to all hearing impaired subjects. Sensorineural hearing loss was statistically associated with furosemide administration in combination with aminoglycoside antibiotic administration and episodes of low pH, hypoxemia, or both (Salamy, Eldredge & Tooley, 1989). Fifty percent of the

newborns tested in the neonatal period, however, continued to develop auditory deficits after discharge. This emphasizes the need for follow-up and hearing evaluation in the first few years of life (Salamy, Eldredge & Tooley, 1989).

Alterations in patterns of growth are relatively common among high-risk neonatal survivors, even though consistent growth and weight gain are prerequisites for discharge from NICU (Hurt, 1984). Abnormal increases in weight can be caused by congestive heart failure while poor weight gain may be secondary to malabsorption or BPD, or may be an early sign of neurologic impairment or poor parenting. Careful measurement of growth is important in the infant discharged from neonatal intensive care.

Anemia, virtually universal in premature infants at discharge, may be iatrogenic, physiologic, secondary to vitamin E deficiency or iron-deficiency, or due to a combination of these factors (Hurt, 1984). Etiology and treatment must be followed closely to ensure the infant optimal opportunity to thrive.

Seizures occur in 0.2% to 0.8% of all live births (Hurt, 1984). Anoxia and/or cerebral ischemia associated with premature birth and neonatal illness make these infants particularly vulnerable to seizure activity in the neonatal period. Infants with a history of neonatal seizures require continued assessment and follow-up after discharge from intensive care to ensure optimal neurological development.

Intraventricular hemorrhage (IVH) occurs in 40% of infants who weigh less than 1500 grams at birth; grades 1 and 2 IVH have not been associated with increased neurological morbidity while grades 3 and 4 IVH are associated with a 40% to 75% risk of neurological and developmental delay (Swanson & Berseth,

1987). A major complication of IVH is progressive ventricular dilatation that may result in obstructive hydrocephalus and the need for a ventriculoperitoneal shunt. Infants diagnosed with any degree of IVH in the neonatal period must be followed closely for head circumference growth and neurological function.

Thus, ongoing medical problems that are sequelae of prematurity and neonatal illness contribute to continuing morbidity in the NICU survivor in the first few years of life. Very recent innovations in the care of extremely low birth weight (ELBW, under 1000 grams) infants, such as the intrapulmonary administration of exogenous surfactant, may further increase the survival rates of the smallest of infants (Lynam, 1990). The probable increase in long-term health problems among these survivors will require even greater commitment from health care professionals to comprehensive follow-up care.

#### Neurological and intellectual status

With the increasing number of VLBW children outliving the neonatal period, a predominant concern among physicians and families is that many are at risk of surviving with persistent neurological deficits that may reduce their potential for normal functioning. Outcomes of VLBW children appear to be improving yet remain highly variable. Although the rate of significant handicap among VLBW survivors has been reduced from the 40% found by Drillien in 1964 to 10% to 20% for VLBW survivors today, these children remain a vulnerable group.

In her 1989 summary of published studies concerning the survival and neurodevelopmental outcome of infants discharged from NICU's between 1960 and

1985, McCormick revealed that while mortality among VLBW infants has progressively declined and the proportion of relatively healthy survivors has increased from 7.2% to 56.8%, the proportion of survivors with moderate to severe handicap has remained relatively stable at 4.5% to 10.1%, (OTA, 1987, cited in McCormick, 1989). A similar trend has been observed among infants of lower birth weight (under 1000 grams). While the mortality rate of these tiny infants declined from 92% to 48% between 1960 and 1985, the proportion of VLBW infants who survived without handicap rose from 1.7% to 34.5% (McCormick, 1989).

The majority of optimistic reports for this vulnerable population deal with rates of major neurodevelopmental sequelae and are based on brief follow-up periods. Rice and Feeg (1985) performed a retrospective chart review of 57 premature infants with a mean gestational age of 32.6 weeks to determine whether postnatal risk factors could predict developmental delay. They conclude that, with the exception of specific neurologic risks such as seizures or IVH, complications in the neonatal period are less predictive of outcome than those occurring after the infant is discharged home. The researchers point to the potential for adaptation, flexibility, and plasticity in the premature infant as factors which facilitate growth and development when the social context in which the child develops is supportive and enriching. The researchers, however, examined only first year outcomes of relatively large premature infants whose outcomes may not be predictive of the smaller premature infants who survive today.

Schraeder (1986) conducted a multivariate study to investigate the developmental progress of VLBW infants during the first year of life. Forty-one

VLBW infants (mean birthweight 1,203 grams) were developmentally assessed and their mothers interviewed when the infants were 6 and 12 months corrected age. The researcher reported that 16% of the sample were inappropriate in development at six months of age. Passage of time, however, had a positive effect on developmental progress during the first year of life and these children scored higher at the 12 month assessment. Findings suggest that environmental factors can assist or sabotage developmental progress in a child who is biologically at risk (Schraeder, 1986).

Saigai, Rosenbaum, Hattersley and Milner (1989) compared the morbidity of infants with birth weights of 501 to 1000 grams in central-west Ontario between 1977 to 1980, and 1981 to 1984. Follow-up included a detailed physical, neurologic, and developmental examination of all infants at 3, 6, 12, 24, and 36 months corrected age. Recorded demographic factors include social class and maternal education level. Survival rates in the 501 to 600 gram range improved while no significant improvement was found in survival in the remaining weight categories in the two time periods. The researchers point to a definite decrease in the proportion of children with disabilities in the second four year period of the study; the proportion of survivors considered normal improved from 50% in 1980 to 73% in 1984. Consequently the chance of having a normal VLBW survivor increased from 1 in 5 births in the first four year period to 1 in 3 births in 1984 (Saigai, Rosenbaum, Hattersley & Milner, 1989). The authors report as well that outcome for infants with a birth weight under 1000 grams appears to be reasonably favorable as a group. Scepticism and pessimism, however, are apparent in the few



studies which have focused on the outcome of the subgroup of infants with birthweights of under 800 grams. Follow-up of these tiny infants illustrates a survival rate of only 20% to 40%. At least one in three of the survivors will have some degree of neurodevelopmental impairment (Hack & Fanaroff, 1986). Thus there continues to be a high toll in terms of both death and morbidity for infants who weigh less than 800 grams at birth.

Since increased survival of very tiny infants is a recent phenomenon, information on longer term outcomes is only now emerging in the literature. Early optimistic reports concerning the developmental outcomes of VLBW infants are now being questioned by reports of learning and behavioral problems in VLBW children at school age. In general, researchers have not found significant differences in general cognitive abilities between non-handicapped VLBW infants and full term controls. Premature infants however, perform less well in tests assessing memory, perception and motor ability. These deficits precipitate a higher incidence of school problems despite a normal IQ. On the other hand, infants included in present long term follow-up studies belong to an earlier era of neonatal intensive care. A great deal concerning the long term developmental status of today's VLBW survivors remains to be determined.

Eilers, Desai, Wilson and Cunningham (1986) followed 33 long term survivors, born between 1974 to 1978 with birthweights of 1250 grams or less, to school age and compared them to school peers and siblings to determine educational levels and needs. Three of the VLBW children (9.1%) were in classes for children with major handicaps, 30 (90%) were found to be comparable to their

classmates by teachers and/or test scores, and 14 (47%) were receiving remedial help to perform at grade level. Overall, 51.5% of these VLBW children required special educational efforts to enable them to compare favorably with their peers.

More recently, Saigai, Szatmari, Rosenbaum, Campbell and King (1990) assessed the intellectual and functional status at school age of a regional cohort of children (n=90) who weighed 501 to 1000 grams at birth, born between 1980 and 1982. In examining the data from this study, the researchers suggest that on average, children born in this VLBW range without neurological impairment scored within one standard deviation of the mean on standard psychometric tests. Scores of children weighing less than 800 grams at birth were similar, except they performed significantly less well on subscales assessing memory and motor ability. At a functional level, two-thirds of the children were performing in the adequate range and the remainder in the moderately low to low range. Eighty-four percent of these children were identified to be at mild to high risk for future learning disabilities.

There seems to be accumulating evidence for an increased prevalence of learning disabilities among premature infants at school age, even when IQ is in the normal range. In Wolverhampton, England, VLBW children were evaluated and compared to their NBW siblings (Lloyd, 1984). Although the two groups exhibit only modest differences on IQ tests, there were substantial differences in their performances in school. Of the VLBW children in this sample, 28% were considered to be doing poorly at school compared with only 3% of the NBW siblings (Lloyd, 1984). Researchers in the Berkeley/San Francisco area found

similar evidence for unusual discrepancies between IQ and achievement (Hunt, Cooper & Tooley, 1988). In a sample of VLBW children born between 1965 and 1978, 16.7% were classified as learning disabled even though the average IQ at eight years of age was 110. Nickel, Bennett and Lamson (1982) found deficits in mathematics, reading comprehension, and in fine and gross motor skills in a cohort of VLBW children at school age. Recent research by Casiro, Moddeman and Thiessen (1989) points to a prevalence of language delay in the VLBW infants they are following; this delay may be one factor that places these children at risk for later learning disability when more complex tasks are demanded.

Sell, Gaines, Gluckman and Williams (1985) undertook a prospective study of children born between 1972 and 1976 who required neonatal intensive care at birth, in order to investigate whether educational problems in this population could be reliably predicted prior to school entry. The study population included 74 children with a mean birth weight of 2,039 grams, a mean gestational age of 33.9 weeks, and a mean hospital stay of 38.5 days. The children were assessed at least once in the preschool period and once at school age, utilizing the McCarthy Scale of Children's Abilities and the Woodstock Johnson Tests of Achievement. All children were enrolled in public school. The authors report that 43.2% of this relatively mature NICU graduate population had either repeated a grade in school or required special resource help. These data are similar to data collected by other investigators who followed smaller and more representative populations of prematurely born infants. In this study, correct prediction of school problems from duration of NICU stay was only in the moderate range. Lack of predictability from

gestational age or birth weight may have been due to the relative maturity of the population sampled for this research. Preschool development from four years of age on was more predictive of school performance than perinatal variables. The researchers report that precursors of school problems in NICU graduates, while not associated with perinatal variables, may be identifiable in the preschool years. Intervention programs at an early age, therefore, may help these children to reach their full potential.

### Intervention

Currently, early intervention programs are being studied to determine if they have a positive effect on cognitive development, behavioral competence, and health status in general of premature infants. Early intervention provides a range of therapeutic and educational services for infants and toddlers with developmental delay or disabilities. Services include physical therapy, occupational therapy, and speech and language services, in conjunction with social services, counselling and family support. Research is in progress to evaluate the effect of early intervention. An increasing data base already suggests measurable benefits for high risk infants relative to the delivery of such services.

Intervention programs for LBW infants have been guided by several theoretical models. First, programs have been aimed at counteracting neonatal sensory deprivation; these involve the provision of visual, auditory, tactile or kinesthetic stimulation to the premature infant while in intensive care (Barnard, 1979). More recent research has concentrated conversely on the detrimental effects

of overstimulation of premature infants in the intensive care setting. Intervention based on this theory advocates modifying noise, light, and tactile stimulation to decrease potentially harmful effects (Als, Lawhon, Brown, Gibes, Duffy, McAnulty, & Blickman, 1986; Weibley, 1989; Thomas, 1989; Tribotti, 1990; Catlett & Holditch-Davis, 1990). Second, intervention programs have been designed to address disturbances in mother-infant bonding. These programs recognize a sensitive period of mother-infant attachment and encourage mother-infant contact and interaction early in the neonatal period (Klaus & Kennell, 1970; Leifer, Leiderman, Barnett & Williams, 1972). Third, intervention programs have been directed at providing compensatory experiences during later infancy to vulnerable infants in culturally disadvantaged environments. These programs emphasize the provision of sensory stimulation and affective interaction to enhance the developmental capacities of survivors of neonatal illness (Beckwith, 1988; Kruskal, Thomasgard & Shonkoff, 1989). Fourth, intervention programs have been directed at helping mothers resolve the emotional crisis of premature birth. These programs originate from the work of Kaplan and Mason (1960), Caplan (1960), and Minde, Shosenberg, Marton, Thompson and Ripley (1980) and suggest that resolution of the crisis of premature birth is vital to successful parenting of the child. And fifth, intervention programs have been directed at recognizing the premature infant's unique characteristics and deficiencies. These programs help mothers to interact more effectively with their infant (Nurcombe, Howell, Rauh, Teti, Ruoff & Brennan, 1984; Secco, 1988).

Researchers in this field suggest that intervention programs which are appropriately designed and implemented early in the neonatal period can facilitate

both child and family adaptation to neonatal morbidity. Today, a wide variety of early intervention programs are available in most parts of North America. Early identification and referral of the high-risk infant is the responsibility of health care professionals caring for the infant in the neonatal period. Identification and referral is crucial to improved outcomes for infants with medical and developmental vulnerabilities and for the families experiencing neonatal crisis.

### The Impact of the High-Risk Infant on the Family

Neonatal illness has the potential to influence the future health and development of the infant. The birth of a sick or premature infant can also profoundly affect family functioning. Coincident with recent improvements in the physiological and developmental care of the high risk infant has been an enhanced appreciation of the psychosocial needs of the family experiencing neonatal crisis.

Our culture views the birth of a baby as an exciting, happy event, surrounded by preparation and joyful anticipation. The birth of a sick newborn throws the family into a tremendous psychological upheaval and crisis for which they are often ill-prepared. Caplan (1960) first described this crisis in his classic study of parental response to the birth of a sick or premature infant. Many studies subsequently have described this unexpected event as a crisis which elicits guilt, sorrow, disappointment, and grief (Mason, 1963; Caplan, Mason & Kaplan, 1965; Benfield, Lieb & Reuter, 1976).

During the crisis of premature birth, parents experience a myriad of intense and confusing emotions. Initially, parents attempt to acquaint themselves with an infant who does not meet their expectations of an ideal baby. In addition, parents must redefine their role to meet the limitations of parenting within an intensive care environment. These experiences may be overwhelming, frightening, and intimidating.

#### Stages of adjustment to neonatal illness

Steele (1987) discusses the major issues which parents of critically ill infants must resolve in order to successfully adapt to this crisis situation. These include the expression of grief, efforts to bond with the infant, attempts to gather adequate information, revision of expectations and roles, utilization of various coping mechanisms and support systems, and attempts to deal with the intense internal and situational stressors which accompany this event.

Parents go through a process of grieving following the birth of a sick infant. This includes grief for the loss of an ideal pregnancy and birth experience, and grief for the possible death or disability of their child (Solnit & Stark, 1961; Benfield, Lieb & Reuter, 1976, Steele, 1987). One of the early tasks of parenting is to resolve the discrepancy between the ideal and actual infant. With a sick or malformed infant this process is more obvious, the grief process more intense, and the consequences of lack of resolution potentially more threatening to the integrity of the family unit (Steele, 1987). Parents of critically ill infants may experience the same intense feelings as parents who are grieving for the actual death of their

child. These feelings include shock, denial, anger, guilt, depression, hopelessness, powerlessness, loss, isolation, confusion, and anxiety (Gennaro, 1988; Brooten et al, 1988; Zachman & Graven, 1972; Gennaro, 1985;). Grief is a necessary stage in the adaptation to neonatal illness. Complete grief resolution is a long-term process; it encompasses plateau periods during which parents feel they are adjusting, followed by exacerbations of grief during rehospitalizations, anniversaries, and other moments of loss, either real or remembered (McCauley & McCauley, 1987; Christensen, 1977; Eikner, 1986; Scharer & Dixon, 1989; Fraley, 1990; Montgomery, 1983). Chronic sorrow refers to the prolonged grief response of parents who have produced a handicapped child. Chronic sorrow is a normal reaction to an abnormal set of circumstances (Lemons & Weaver, 1986). Families must be helped to deal with a birth experience that is a source of stress and anxiety instead of a time of joy. The grief that accompanies this event may last a lifetime.

Parents of premature infants must adjust their expectations for the infant, revise their parenting role, and overcome physical and psychological barriers to bonding in order to be successful in interacting with their infant in NICU. Physical separation at birth and prolonged hospitalization inhibit bonding and attachment (Klaus & Kennell, 1970). Psychological barriers may be less obvious but can inhibit bonding to an even greater extent. Psychological barriers include lack of privacy, the perceived discrepancy between the ideal and real infant, feelings of helplessness and guilt, fears that the child will die, feelings of inadequacy and incompetence, and feelings that the infant belongs more to the staff in NICU than



to the parents (Etzler, 1984; Miles, 1979). Researchers report that parents of premature infants have a higher rate of marital upheaval and demonstrate a greater incidence of child abuse and neglect than parents of full term infants (Boer, 1978; Klaus & Kennell, 1982; Klein & Stern, 1971). These long term effects of neonatal illness have been attributed in part to the physical and psychological barriers that inhibit bonding in NICU. Early and frequent contact between the infant and parents have been advocated to minimize these negative consequences of an infant's illness on the family.

The majority of parents who enter NICU have little or no prior knowledge of neonatal issues. Educational support, therefore, is a crucial component in the ongoing adaptation of parents to their child's critical illness. Parents require adequate information on the current and future needs of their infant. This information lessens anxiety and allows parents to experience greater control. Parents who are well informed knowledgeably participate in caretaking roles and experience greater success in bonding with their infant (Steele, 1987).

Emotional support is helpful in reducing the extent to which parents feel overwhelmed by their intense responses and by the confusion that often results. Minde, Shosenberg, Marton, Thompson, Ripley and Burns (1980) report that parents who participated in support groups visited the NICU, talked, touched, and looked at their infants more often, and rated themselves as more competent in infant caretaking roles. Dilliard, Auerbach and Showalter (1980) developed an intervention program for parents of infants in NICU to decrease the negative effects of neonatal illness on the family. Mothers receiving intervention expressed similar attitudes and

feelings of competence to mothers of healthy full term infants. The researchers suggest that the attitudes and behaviors of the nursing staff in NICU can facilitate or hinder parents' readiness to receive emotional support. Nurses who were available, open, empathic, respectful, and non-judgemental helped parents to feel less overwhelmed by this crisis situation (Steele, 1987).

Several phases of adjustment to the crisis of the birth of a critically ill infant have been outlined in the literature. Steele (1987) describes four phases: an initial passive role immediately following the unexpected birth -- giving in; intense grieving and the forfeiting of parental roles -- letting go; the interminable waiting period while the infant's condition stabilizes -- hanging on; and a final phase which includes the recovery and discharge of the infant -- taking hold. Montgomery (1983) outlines similar phases and tasks for parents of ill or premature infants: the first task is preparation for loss of the infant; the second task involves family acceptance of the infant's prognosis and limitations; the third phase entails a recovery of hope and the beginnings of interaction with the infant; the final task involves parental understanding of how the premature infant differs from a normal term infant in terms of needs and growth.

McHaffie (1990) followed 21 mothers of VLBW infants while in hospital and after discharge home, identifying six distinct stages which mothers of high-risk infants progressed through in resolving the crisis of premature birth. The first stage, anticipatory grief, is dominated by fear of the death of the infant and of other traumatic sequelae to the premature delivery. While mourning for the loss of their "perfect" child, mothers in this stage begin to assimilate facts about their

actual child, while at the same time anticipating the child's death. Mothers are emotionally fragile at this time, and remain emotionally distant from the child to lessen the loss of eventual death.

Once the infant's survival was reasonably assured, mothers move into the second phase of adjustment, characterized by anxious waiting. Emphasis in this stage is on the quality of life that the child can reasonably expect. Gradually, mothers allow themselves to become attached to their infants, perform basic caretaking tasks, and become more confident in their ability to care for their infant.

Phase three, positive anticipation, begins when mothers actively and positively prepare for the infant's homecoming. This phase is characterized by increased pleasure and confidence in handling the infant. Mothers in this stage voice concerns about the infant's perceived vulnerability and their own ability to adequately care for their child at home.

Immediately after the infant is discharged home is a period of anxious adjustment, characterized by a blend of excitement, anxiety, and pride. Mothers experience insecurity and lack of confidence in this stage and express a strong need for professional reassurance. Gradually, this stage gives way to a stage of exhausted accommodation; anxiety, tiredness and extra demands accumulate at the same time that the support mothers receive lessens. Many mothers in this stage express amazement at how much the infant cries, stating that they had not gained a true picture of their child's personality in the hospital environment. Mothers in this stage view their infant as demanding and interfering with family relationships. Gradually as the infant begins to respond, a stage of confident caring is attained. Mothers in

this final stage feel that the rewards they receive from the infant exceed the tiredness and anxiety they experienced in the previous few weeks.

### The impact of neonatal illness on parenting

Early family disruption appears to be an inevitable consequence of the birth of a critically ill or premature infant. These problems do not always end when the infant is discharged home. Caplan's (1960) study strongly suggests that a long-term outcome of premature birth is a disordered mother-infant relationship. Subsequent research indicates that prematurely born infants are poorly parented more frequently than full term infants and are at risk for child abuse and neglect (Klein & Stern, 1971; Boer, 1978; Jeffcoate, Humphrey & Lloyd, 1979; Klaus & Kennell, 1970). More recent research examines the premature infant's behavioural response as a factor which modifies the course of maternal-infant interaction (Minde, Trehub, Corter, Boukydis, Celhoffer & Marton, 1978; DuHamel, Lin, Skelton & Hantke, 1974; Schraeder & Tobey, 1989; Lipitt & Field, 1981). Continuing crises can precipitate and/or perpetuate family upheaval after the high-risk infant is discharged home.

The transition to parenthood that accompanies the birth of a full term, normal child involves personal and marital changes that are often perceived as negative by both partners (Harriman, 1985; Belsky, Lang & Rovine, 1985; Waldron & Routh, 1981). Women, in particular, experience a decrease in marital satisfaction upon the arrival of their first child (Waldron & Routh, 1981). It is not surprising,

therefore, that the birth of a high-risk infant has considerable impact on family solidarity.

White and Dawson (1981) compared family togetherness, family communication, team performance and family ritual in 33 families with normal newborns and 13 families with infants who were ill or premature at birth. Although both groups of families reported coping well since the birth of their infant, parents in the high-risk group reported less agreement on family matters, negative features in their sexual relationships, and less closeness to their high-risk child. The researchers recommend assessment of families of high-risk infants following the infant's birth, and counselling and support of families experiencing negative reactions to their high-risk child.

Gath (1977) followed thirty families of mongoloid infants, matched with thirty families of normal infants for two years following their infant's birth. She found few differences in the mental and physical health of the two groups of parents, but a much greater degree of marital disharmony and breakdown in families with a mongoloid child. Although half of the parents of the mongoloid children stated that the birth of an abnormal child had drawn them closer together and strengthened their marriage, 20% of the families with mongoloid children rated their marriages as poor, compared to none of the control group. The researchers point to the need for family assessment, and early and intensive support for less stable couples during the initial crisis following the birth of an abnormal child.

In assessing the contribution of prematurity and neonatal illness to family problems, Trause and Kramer (1983) asked a sample of parents of high-risk infants

and a sample of parents of normal full term infants to complete the Parental Perception Inventory when their infant was one week old, and again one month and six months after their infant had been discharged home. On the basis of the results, the researchers confirm previous findings, i.e. that parents are extremely distressed immediately following the birth of a high-risk child. However, no long-term difference in adjustment to the birth of these infants was found. Parents of full term and premature infants were coping well and parents of premature infants had comparable feelings about their infants and their own competence as parents of normal full term infants. Limitations of the study include the relatively good health of the high-risk infants, and the economic and social stability of the families involved. An important factor identified in the study was the support mothers received from their husbands in the early post partum period and after their infant was discharged home. The more aware the father was of the mother's needs and feelings, the less difficulty she experienced in adapting to having the infant at home. This was consistent in both groups of parents.

#### Maternal perceptions of the high-risk newborn

It is generally assumed that a mother's perceptions and feelings about her newborn affect her behavior toward her infant and, in turn, the infant's behavior toward her (Broussard, 1970). It is also assumed that the perinatal period is the time when many long lasting maternal perceptions and interaction patterns originate (Broussard & Hartner, 1970). One consequence of neonatal hospitalization is the separation of the mother from her child at a time when she is thought to be most

sensitive and responsive to the infant (Klaus & Kennell, 1970). Separation because of neonatal illness often results in parental perceptions of the premature or ill infant as different or special. These early perceptions may precipitate different maternal behaviors and altered expectations of the child, both in hospital and after discharge home.

Although parents of premature infants often view their infants as special, they frequently do not recognize the specific ways in which a premature or ill infant differs from a full term healthy newborn. Misconceptions about the high-risk infant may lead to negative parental perceptions that outlast the newborn period. In an early study, DuHamel, Lin, Skelton and Hantke (1974) discuss inaccurate parental perceptions of their high-risk newborn and their ensuing feelings of incompetence to care for their infant after discharge home. Many parents of premature or ill infants worry about their infant upon discharge in spite of outwardly good development and health (Minde, 1984). Excessive parental anxiety can precipitate a "vulnerable child syndrome"; overprotection in the first few years of life can lead to behavior problems in the preschool years (Green & Solnit, 1964; Culley, Perrin, & Chaberski, 1989). Jeffcoate, Humphrey and Lloyd (1979) report that parents of VLBW children continue to be anxious and foster a persistent perception of the VLBW child as vulnerable. These long term parental reactions may delay normal adaptation and development of both the parent and child.

Early parental perceptions of premature and ill infants as different however, are not entirely without foundation. Behavioral differences among premature and term infants have been noted in several studies. Boyle, Griffen, and Fithardinge

(1977) assessed 75 VLBW infants at the age of four years and compared them with a control group of matched full-term infants. The researchers visited all families at home, evaluating the child's general health and development, and difficulties in playing, sleeping, and feeding. The authors found significant differences only in the children's general development and play behaviors, although in all other behavioral areas, premature infants did worse, but not significantly so, than normal birth weight children. Parents similarly gave a less favorable evaluation of their VLBW child in the areas of development and play.

More recent studies demonstrate consistent differences between premature and full term infants, with premature infants characterized as more difficult to engage, soothe, and understand, while their mothers work harder with less success and satisfaction during interaction with them (Lipsitt & Field, 1981; Berger & Schaefer, 1985; Crnic, Ragozin, Greenberg, Robinson, & Bashman, 1983; Watt, 1987; Gorski, Davison, & Brazelton, 1980). Parents of VLBW infants followed by McCain (1990) describe the personalities of their VLBW infants as difficult and high-strung. Parents state that these characteristics make it difficult to parent a "premie". Tobey and Schraeder (1990) suggest that the arrhythmicity, low adaptability, and low persistence that characterize VLBW infants persist during the preschool years may have significance for future learning, academic achievement, and behavioral competence.



Implications for child abuse and neglect

Health care professionals must be alert to the impact of the "difficult" temperament of VLBW infants on the interpersonal capabilities of these infants and their families. In 1967, Elmer and Gregg published a paper that linked prematurity with later child abuse. These authors stated that of 50 children who had been seen at the Children's Hospital in Pittsburg between 1949 and 1962 with unexplained bone injuries, an inordinately high number (30%) had been born prematurely. Four years later, Klein and Stern (1971) reported a study in which they had reviewed the charts for all children who had been diagnosed as "battered children" at Montreal Children's Hospital between 1960 and 1969; of the 51 children identified, 12 (23.5%) had been born prematurely.

In an attempt to overcome the limitations of retrospective studies concerning the relationship of major neonatal illness to subsequent child abuse, Hunter, Kilstom, Kraybill, and Loda (1978) prospectively studied high-risk infants hospitalized in 1975 and 1976 in a NICU in North Carolina and their parents, to assess incidence of child abuse and neglect. Of the 255 infants discharged to their families, 10 were subsequently reported as victims of maltreatment during their first year of life. The high incidence of maltreatment (3.9%) in these premature and ill infants supports previous findings of an increased risk of maltreatment in these special infants. The authors listed 13 family characteristics that were significantly associated with later maltreatment, including social isolation, a family history of child abuse and neglect, serious marital problems, inadequate child care arrangements, apathetic and dependent personality styles, and inadequate child

spacing. Maltreated infants were less mature at birth, had more congenital defects, and experienced less family-infant contact during a prolonged hospital stay (Hunter, Kilstrom, Kraybill, & Loda, 1978).

Researchers conclude that prematurely born infants are more likely to be poorly parented than infants born at term. Several factors have been examined to explain this phenomenon. These include deficient parent-infant bonding, specific deficiencies of parents of premature infants, and the interactional deficiencies of the premature infant.

#### Attachment and bonding

Bowlby (1958) introduced the term attachment into the literature as a hypothetical construct reflecting the quality of affectional ties that develops gradually between infants and their parents during the first two years of life. The term describes a reciprocal process that can be influenced by variables such as the quality and timing of parent-infant encounters (Minde, 1984). The term bonding, in contrast, describes a rapid process of mother-to-infant attachment that occurs immediately after birth. Successful bonding implies that the mother feels that a specific baby is "her" baby; it has been suggested that bonding is influenced by close physical contact between the newborn and mother, through fondling, skin-to-skin contact, mutual visual regard, and suckling (Klaus & Kennell, 1982).

Fanaroff, Klaus, and Kennell (1972) and Leifer, Leiderman, Barnett and Williams (1972) provided the first data to suggest that an initial lack of physical contact between parents and infants could result in a comparatively high failure rate

of parental bonding to these infants. Fanaroff and colleagues (1972) compared 105 mothers who visited their hospitalized infants frequently (2 to 3 times a week) with 41 mothers who visited infrequently (less than 3 times every 2 weeks). The researchers reported that nine of the families in the low-visiting group demonstrated disorders of mothering, while only two families that were frequent visitors experienced similar problems. Five of the nine infants in the low-visiting group were described as failure-to-thrive, two as battered, and two as abandoned and fostered. From this data, the authors suggest that a sensitive period exists immediately following birth during which the mother-infant bond is formed. Infrequent visits by parents or lack of opportunity to interact with the infant and develop a bond during this period can precipitate disorders in parenting. Early studies concerning mother-infant bonding had a dramatic impact on maternal-child practice all over the world. Bonding theory and study results must be interpreted with caution however, since early researchers in the field followed-up their subjects in a less than rigorous fashion (Minde, 1984). Evidence contrary to bonding theory has also been found. Leifer, Leiderman, Barnett, and Williams (1972) suggest that providing mothers with the opportunity to make early contact with their infants does not influence mothers' later caretaking behaviors. Mothers followed by the researchers had been separated from their infants at birth due to neonatal illness. While these mothers voiced less confidence in their ability to care for their infants in the initial post-discharge period than mothers who had not been separated from their infants, this difference disappeared after the infant had been home for one month. Crawford (1982) and Easterbrooks (1989) found similar results. With

increasing age, the differences in mothering between separated VLBW infants and non-separated term infants disappeared; separation had little effect on later parenting confidence and parent-infant interaction at 12 months.

In modern neonatal centres, every effort is made to encourage early interaction between the high-risk infant and family; thus deprivation of interaction and resulting deficiencies in parent-infant attachment alone do not contribute to the overrepresentation of parenting problems in families of high-risk infants. It is essential to consider other factors which impinge upon parents' abilities to establish an affectionate mutual bond with their high-risk infant, for example, the characteristics that the parent brings into the parenting situation, and the capacity of the infant to respond to the parent's attachment behaviors.

#### Characteristics of parents of high-risk infants

Traditionally, parents of premature infants have been described as economically and socially disadvantaged. Their poverty has in turn been associated with comparatively inadequate prenatal care and subsequent postnatal problems. In conjunction with a generally low socioeconomic background, it has also been suggested that parents of premature infants possess other characteristics which have implications for their parenting abilities. These include personal deprivation and lack of social support (Hunter, Kilstrom, Kraybill, & Loda, 1978). According to Klaus and Kennell (1976), the attachment process begins even before the birth of the infant and is influenced by many factors. Past experiences in the lives of both the mother and father may influence acceptance of the pregnancy and the infant when

it is born. Several family characteristics which have been associated with parenting problems include isolated social settings, marital maladjustment, financial problems, disappointment over the infant's sex, and consideration of abortion. Personality factors associated with poor parenting include tendencies to be impulsive, apathetic, childish and dependent. Parents with a family history of child abuse or neglect are reported as more likely to abuse their own children (Hunter, Kilstrom, Kraybill & Loda, 1978).

Much work has been done to further isolate characteristics of parents who experience difficulties in caring for their small infants. Minde and his colleagues (1980) attempted to determine how past parental experiences influence present caretaking behaviors by observing how mothers of VLBW infants become involved with their infants during their hospital stay. Consenting mothers of 32 infants admitted to the Hospital for Sick Children in Toronto between 1976 and 1977 were observed during two maternal visits per week and at one, two, and three months after discharge from hospital. The researchers report a clear correspondence between the degree of activity mothers exhibited toward their infants in hospital and after discharge, and previous life events. The mother's relationship with her own mother and her relationship with the baby's father were significantly related to interaction with the infant in hospital and at home. In addition, the researchers report that the amount of interaction between the mother and infant during initial visits to NICU is predictive of the frequency of later interaction with her infant and the sensitivity of her later involvement with the child. The authors suggest that a mother's involvement with her infant is primarily a reflection of her own past and present

interpersonal relationships; the quality of the relationships she has with her mother and husband may predict how she will cope with her premature infant at home.

#### Characteristics of premature infants

Interactional deficiencies of premature infants influence the formation of parent-child relationships. The full term normal infant is considered to be active, capable of organizing information, and selectively attentive to visual and auditory stimuli. Researchers report that infant qualities such as alertness, responsiveness, activity level, personality, fussiness, consolability, and cuddliness may affect the quality of mother-infant interaction (Hoffman, Paris, Hall, & Schell, 1988). Only very recently has there been any attempt to assess specific behavioral patterns in premature infants to compare them to those of full term neonates. Frodi and her colleagues (1978) showed videotapes of crying and calm full term and premature infants to fathers and mothers. Physiological recordings taken from these adults during the videotape indicated that the cry of the premature infant was significantly more arousing to parents than the cry of the full term infant. Frodi speculates that the adverse nature of the premature infant's cry may possibly lead some parents to abuse these infants.

Als and Brazelton (1981) looked at the total behavioral repertoire of premature infants and its effect on their caretakers. By comparing behaviors of 10 full term infants and 10 premature infants for nine months, these researchers documented that premature infants were far less responsive and much more disorganized than full term infants in all their interactions. Despite very striking

parental attempts to interact with their premature infants, parents rarely succeeded in holding their infant's attention for any length of time.

Minde (1984) examined the effects of various degrees of neonatal illness on the behaviors of these small infants and their parents' caretaking practices. Utilizing a "Morbidity Scale of Premature Infants" to rate the degree to which pathophysiological states are life-threatening or physically damaging, a summary of both the severity and duration of an infant's course in NICU was obtained. When applied to over 170 consecutively born VLBW infants, Minde found that infants who were seriously ill showed significantly fewer motor movements than did infants with less complications. Minde suggests that infants who were seriously ill signal to parents through their own markedly decreased motor movements, to decrease interaction with them. Parents of infants who have been seriously ill are often overwhelmed by the precariousness of their infants initial condition; as a result, they continue to interact relatively little with their infants even after they recover. Mutual lack of interaction in the neonatal period may compromise the later parent-child relationship.

In summary, many factors impinge upon the development of parent-infant attachment behaviors. These include characteristics of the parents, such as a readiness for parenthood and resources for coping with stress, as well as characteristics of the infant. Deviations from the expected or normal infant, serious illness in the neonatal period, sequelae of neonatal illness which interfere with interaction, and characteristics of premature infants such as lack of cuddliness and responsiveness enhance the possibility of disruption of the initial parent-infant bond.

At a time when parent and infant stress are at a peak, it is essential for health care professionals to enhance rather than inhibit opportunities for early contact and the formation of a positive and nurturing parent-infant bond.

### The Transition from NICU to Home

When the high-risk infant is discharged from NICU to home, parent's emotions vacillate between joy, excitement, fear, and uncertainty. The discharge of a high-risk infant has been repeatedly documented to be a situational crisis. The stress of premature birth and neonatal illness is compounded by the realization that, at home, parents must care for their infant alone (Censullo, 1986).

Several researchers have studied the concerns of families of high-risk infants during the stressful transition from hospital to home. Goodman and Sauve (1985) interviewed thirty mothers of high-risk infants and thirty mothers of normal infants in their homes at two weeks and six weeks following the infant's discharge from hospital, to determine whether the concerns of these mothers differed. Areas of concern identified by all mothers included feeding, sleeping, crying, and concerns about her family and herself. Mothers of normal infants expressed these concerns but had fewer concerns and a lower degree of concern in general. Mothers of high-risk infants were very concerned about all areas of infant and family functioning. In addition, and in contrast to mothers of normal infants, mothers of high-risk infants were concerned about their infant's appearance; as the head of the premature infant rounded out with maturity, the shaved hair grew, and the scalp



bruises disappeared, this concern was alleviated. Mothers of high-risk infants also expressed concerns about attachment; they felt that their infants did not recognize them as mothers and continued to feel that the infants were not their own. Mothers of high-risk infants in general had more negative perceptions of their infants. This finding may have implications for future development of the relationship between the mother and child. Although the study was limited by a small sample size and a relatively short follow-up period, the researchers suggest that the stress of having a high-risk infant does not end when the infant is discharged home. As mothers take on the full responsibility for a demanding infant, their need for continued support and guidance may be acute.

Butts (1988) examined the major concerns of 36 families of VLBW infants following discharge from intensive care and found similar concerns. Reasons for parent-initiated calls to community health nurses for a period of 18 months following discharge included specific infant health problems and issues of normal infant care.

Arenson (1988) states that quality care and a continuation of services "on the outside" are essential for the survival and well-being of both the infant and family. She reports that parental care and devotion to a chronically ill infant at home consumes energy, time, and financial resources. In addition, it can deprive the family of privacy, create social and emotional isolation, intensify the stress of the high-risk birth, and permanently change the family.

Young, Creighton, and Sauve (1988) assessed the needs, experiences, and resources of 48 infants undergoing continuous oxygen therapy at home. Parents and

20 professionals in contact with these families were interviewed to determine their perceptions of discharge preparation, teaching, relief care, coordination of medical care, and expertise of community professionals regarding high-risk infants on oxygen. Parental interviews conducted after discharge revealed concerns about adequacy of information, the infant's oxygen equipment, and social, environmental, and community support. In particular, both professionals and parents reported a need for improved discharge teaching and community support. The researchers concluded that individual family needs must be considered and interventions arranged to assist parents in caring for an oxygen-dependent infant at home.

Eikner (1986) reported her personal experience as a parent of high-risk twins. In comparing her experiences during their hospitalization in NICU with those as their caretaker in the home, she reported the former to be considerably easier. She identified several needs of parents in similar situations. These included the need for information, the need for support, and the need for health care professionals to realistically prepare parents for the continued problems they are likely to experience after their chronically ill infant is discharged from intensive care.

Wills (1983) examined the concerns and needs of eight mothers providing home care for children with tracheostomies age 15 months or less. Content analysis of the mothers' responses revealed several categories of concern. These include concerns related to the knowledge and skills relevant to the child's care; psychosocial concerns such as alterations in sleeping patterns; and concerns about the need for support, isolation, and limitations on time.

Several studies have addressed concerns of parents providing home care for infants who required apnea monitoring. Dimaggio and Sheetz (1983) studied 29 mothers of apnea monitored infants. Their major concerns included lack of support, concerns about knowledge and skills related to caring for these infants, and a lack of time for personal needs, household tasks, and other family members. Stengel, Echeveste, and Schmidt (1985) report similar concerns of families with apnea-monitored infants who were followed by registered nursing students as part of their educational curriculum. Ariagno and Glotsbach (1987) acknowledge that parents experience similar adverse psychosocial effects from home monitoring of apnea-prone infants. They report, however, that the majority of families cope with the burden imposed by home monitoring, that families view monitoring as worthwhile, and that apnea monitoring ultimately reduces parental anxiety.

In a qualitative study of 20 mothers of infants on home apnea monitoring, Dean (1986) identified similar themes to those found in previous studies of this population. Mothers named lack of rest, time constraints, and financial burdens among their stressors.

Nuttall's (1988) retrospective interviews with 74 mothers of infants who had been monitored for apnea at home revealed nine categories of upset, including fear, problems of monitoring, lack of support, disruption of family life, emotional effects, concerns for the infant, unresolved problems, helpfulness of health care professionals, and the concern that health care professionals appeared sceptical or minimized reports of infant apneic episodes.

Kenner and Lott (1990) interviewed 10 families of high-risk infants in the first and fourth weeks following the infant's discharge, in order to elicit parental concerns during the transition period following the discharge of their infant from NICU. Five categories of responses emerged. Parents expressed the need for more information about their infant's physical needs and the emotional and psychological needs of the family; parents continued to view their infant as "sick" and "different" and as a result their levels of comfort in caring for the infant were undermined; parents expressed a need for more information regarding physical and behavioral differences between their infant and a healthy full term newborn; parents felt they received very little support for their parental role in NICU and even less once they were home; and parents stressed the importance of both formal and informal sources of support after their infant was discharged.

Similar data were found by Sterling (1990) in interviewing the primary caretakers of 19 infants with chronic lung disease who had been cared for at home for a minimum of two weeks. Six themes were identified from thematic analysis of interviews. These included responses related to the parents' ability to care for the child, responses related to time for self and family, responses related to behaviors utilized to relieve stress, responses related to physical and psychological support from family and friends, responses related to health care professionals and the services required to facilitate the child's care, and responses related to finances and equipment needed to care for the infant at home.

The presence of a medically fragile infants at home appears to disrupt normal family routines and has the potential to precipitate family dysfunction.

Home care of a high-risk or chronically ill infant often consumes the lives of primary caretakers and other family members. Parents are asked to acquire sophisticated knowledge and to maintain the demanding level of care required by their infant after discharge. A major problem parents face is how to manage the infant in conjunction with the other responsibilities and tasks necessary to sustain family life. In most of the studies reviewed, parents perceived a large discrepancy between their needs, perceptions, and concerns and the health care professional's perceptions of these same needs and concerns. The potential for ongoing problems after the high-risk infant is discharged home and the lack of confidence that parents experience in caring for these infants after discharge illustrates the need for enhanced discharge preparation and planning, and continued professional support after the infant is discharged home.

#### Learning needs of parents of high-risk infants

Parenthood is a stage of adult development that involves extensive learning. Many adults deliberately prepare themselves by attending structured education classes and through books, film, friends and relatives. The premature birth of an infant often disrupts this learning process. Many parents of premature infants enroll in education classes but do not attend because of the early and unanticipated birth. Parents of premature infants in addition to coping with this crisis situation, must undertake additional learning projects in preparation for care of their infant at home. Teaching and discharge preparation programs for parents of high-risk infants have the potential to increase parental knowledge concerning the differences

between full term and premature infants, enhance parental feelings of competence upon the discharge of their infant from intensive care, and diminish the anxiety and stress parents experience during the transition from hospital to home.

Although several researchers have reported that parents taking an infant home from intensive care want information, instruction, and help to care for their infants at home, relatively little research is available on the teaching and learning needs of parents of VLBW and high-risk infants.

Cagan and Meier (1979) designed a discharge planning tool to minimize the crisis which parents experience during the transition from hospital to home care, and to standardize and document the nursing role in discharge planning. The researchers examined readiness for discharge from the primary caretaker's perspective. Families participating in the pilot testing of the tool demonstrated differences in preparedness for discharge. Two families instructed according to the discharge planning guidelines made only one phone call to NICU to question nursing staff about some aspect of their infant's care after their infants were discharged home; one family which was not prepared for discharge in this manner phoned the NICU eleven times during the first postdischarge week.

Cagan and Meier subsequently evaluated their discharge planning tool in a more controlled follow-up study, using a larger sample (Cagan & Meier, 1983). Subjects in the study were parents of high-risk neonates for whom survival was no longer an immediate threat. Parents of 35 infants were prepared for their infants' discharge in the traditional manner, while the discharge of 40 infants was coordinated by use of the discharge planning tool. The two methods of discharge

preparation were compared by employing a questionnaire to measure parents' perceptions of their readiness to care for their high-risk newborn in the home. The researchers report that parents using the discharge tool to prepare for their infant's homecoming were less anxious at discharge and perceived themselves as more capable of caring for their high-risk infant at home.

Consolvo (1986) looked at "care-by-parent" units to enhance discharge teaching by providing parents with hands-on experience with their infants before discharge. She reports that parents who actively participate in all aspects of their infant's care are more prepared and less anxious when the infant is discharged home. Other researchers advocate a "rooming-in" type of preparation where infants and parents can interact in a home-like environment close to the NICU. This atmosphere encourages parents to bond with their infants at the same time as they learn the infants' needs, in a setting in which registered nurses are available to problem solve if necessary (Salitross, 1986). Both approaches have been effective in reducing parental anxiety in the transition from hospital to home; neither has been evaluated, however, for long-term impact on patient outcomes.

Recent research on pre- and postdischarge teaching of mothers of VLBW infants has focused on the timing of the teaching, the use of teaching tools, and on some of the specific learning needs of this population (Brooten, Gennaro, Knapp, Brown, & York, 1988). This study was conducted as part of a larger study on early hospital discharge and nurse specialist follow-up of VLBW infants. One group of VLBW infants received routine care and hospital discharge; parents of a second group of VLBW infants discharged earlier from hospital received discharge

planning, teaching, and home follow-up for 18 months following hospital discharge by a perinatal clinical nurse specialist. Content analysis of the parent teaching carried out by clinical nurse specialists revealed that the majority of teaching occurred in the postdischarge period (this is not surprising given the 18 month follow-up period). Five major categories of teaching were found: teaching regarding the infant, the mother, the family, the home environment, and available resources. Although the study was limited to fairly healthy premature infants who met the criteria for early discharge, researchers stress that several factors pose potential problems for families with a high-risk infant at home. These include the need for a variety of follow-up services, the complexity of the health care system, the postdischarge problems of these infants, and the stress placed on these parents; all demonstrate a clear need for teaching in the pre- and postdischarge period.

Culp, Culp, and Harmon (1989) examined the effectiveness of intervening with parents of premature infants by showing them examples of their newborn's sensory, perceptual, and social capabilities. Fourteen couples and their premature infants were divided into an intervention group and a non-intervention group. Parents in the intervention group observed an assessment of their premature infant's behavior (APIB) and received feedback from the examiner prior to completing measures assessing their anxiety, perception, and awareness of neonatal behavior. The non-intervention group did not observe the APIB until after measures were assessed. Comparison between the two groups revealed that the intervention group had significantly less anxiety, more realistic perceptions of their newborn, and a significantly more accurate awareness of their newborn's abilities. The researchers



suggest that having parents of premature infants observe an APIB may be an effective way to educate them relative to their infant's behavioral capabilities.

Consolvo and Wade (1990) suggest that videotapes for home use by parents of high-risk infants can reinforce what parents learn in the hospital about the special care their infant requires. These authors recognize that learning under stress is difficult, but discharge teaching is, nevertheless, often completed at the stressful time of discharge. They suggest that learning videos at home can increase comprehension and permit parents to learn at their own pace. Suggested topics for parent videos include oxygen administration, apnea monitoring, medication administration, gavage feeding, and recognition of newborn illness.

Several other studies suggest that short-term hospital-based education programs for parents of premature infants do not enhance infant development or parent-infant interaction. Brown and colleagues (1980) evaluated a program in which nurses taught mothers how to stimulate their infants and respond appropriately to infant cues. Follow-up assessments at three and nine months after discharge failed to demonstrate differences between the intervention and comparison groups. The relatively minor nature of the intervention program, the low socioeconomic status and multiple problems experienced by most of the mothers, and the nursing support provided to both groups may have obliterated any differences arising from the intervention. Harrison and Twardosz (1986) evaluated the effects of a structured teaching program on 30 mothers' perceptions of, and interaction with, their premature infants at two, four, and eight weeks after the infants were discharged home. Mothers in the control group received routine care

while mothers in the instruction group received instruction relative to the unique physical and behavioral characteristics of premature infants, in addition to routine care. No significant differences were found on measures of maternal perceptions and behaviors obtained during any of the home visits. Study limitations help to explain these results. The inclusion of only married mothers into the sample may have excluded mothers who might have benefitted most from the teaching program, and the small sample size may have precluded identification of group differences. The authors conclude that the structured teaching program did not significantly enhance support currently provided by nursing staff.

Researchers have documented that families of high-risk infants have unique needs that are often not met by standard hospital procedures. Flexible and comprehensive teaching programs for parents of high-risk infants assist health care professionals to discharge the high-risk infant to a knowledgeable, competent, and well-integrated family unit. To ensure the successful transition from NICU to home however, supportive follow-up after discharge from intensive care is required.

### Social Support

Social support has been hypothesized to buffer or mediate the effect of stressful life events and to have beneficial effects on health in general. This segment of the literature review will provide an brief overview of the conceptualization and operationalization of social support by examining definitions

provided by several authors. It will be followed by a review of the research which examines the implications of social support for parents experiencing neonatal crisis.

### Definition and Operationalization of Social Support

Many definitions of social support have been proposed. Early researchers looked at social support in a general manner; their definitions were vague and circular. Hogue (1985), House (1981), and Wilcox and Vernberg (1985) defined social support as behavior which is supportive. Cobb (1976) defined social support as information which leads individuals to believe they are cared for, loved and esteemed. Kaplan, Cassell and Gore (1977) concluded that social support was derived from either the gratification of a person's basic social needs or the presence of psychosocial support from significant others. Lin, Simeone, Ensel, and Kuo (1979) defined social support as support accessible to an individual through social ties to other individuals, groups, or a larger community. These early definitions did not clearly distinguish the different facets of the social support, and led to difficulties in operationalizing the concept.

Later definitions became more explicit and focused on the types and key elements in social support. Schaefer, Coyne and Lazarus (1981) identified emotional support, tangible support, and informational support as three types of perceived social support, and emphasized the importance of distinguishing among these sources. Kahn (1979) proposed that social support be defined as interpersonal transactions which include affect, affirmation, and aid. House (1981) was the first researcher to include all four previously described types of supportive behaviors in

his definition. He identified the following as components of social support: emotional support (esteem, affect, trust, concern, listening); appraisal support (affirmation, feedback, social comparison); informational support (advice, suggestion, directives, information); and instrumental support (aid in money, labor, time). House also proposed that social support be viewed as a matrix vis-a-vis the source (informal, such as family and friends, and formal, such as professional and self-groups), and the direction of perception (objective versus subjective) (Heaman, 1987). House's typology is considered the most complete to date.

Attention has been directed in the literature to sources of social support, or the social network. Schaefer, Coyne, and Lazarus (1981) define social network as the set of relationships that a particular individual has, or the specific set of linkages among these relationships. Mitchell and Trickett (1980) identify several characteristics of social networks. These include structural characteristics (the number of individuals with whom the individual has direct contact), network density (the extent to which members of a individual's social network contact each other independent of the focal person), and the degree of connection (the average number of relationships that each member has with other members of the social network). Social support is presently considered a multidimensional concept; the amount, type, and source are equally important in the consideration of this concept.

Operationalization of social support has been difficult due to the absence of well-developed measures and the variety of different approaches used to assess the concept. House and Kahn (1985) reviewed the approaches available to measure the concept of social support. They included: a social integration approach to measuring

social support, which assesses the individual's connection to others; measurement of the structure of a person's social relationships for size and density to assess an individual's social support; and assessment of the functional content of an individual's relationships through asking persons about their perceptions of the quality and adequacy of the support provided to them by others. The majority of instruments utilized in nursing research measure the relational and structural dimensions of social support (Norbeck, Lindsey, & Carrieri, 1981; Brandt & Weinert, 1981).

#### Effects of social support

Social support has been hypothesized to have both buffering and direct effects on health. Heaman (1987) illustrates the ways in which social support can affect stress and health (Figure 4). Social support can directly enhance health and wellbeing (arrow c) or it can directly reduce levels of stress (arrow a), and hence indirectly improve health (via arrow d). These are direct effects of social support. Social support may also have the potential to buffer or mediate the impact of stress on health (arrow b).

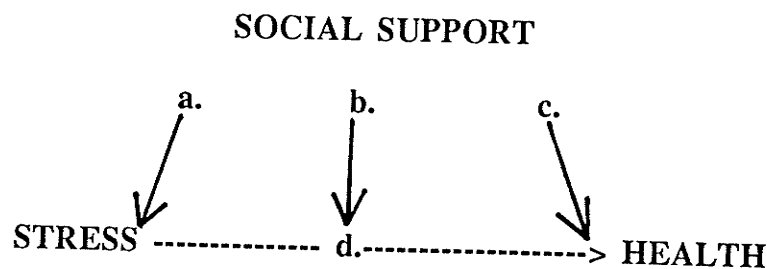


Figure 4: Potential effects of social support on stress and health, (Heaman, 1987, p. 33).

According to the buffering hypothesis, social support buffers the individual from the adverse effects of stressful life events on health (Gottlieb, 1983). Under conditions of high life change or chronic exposure to stressors, social support buffers the individual from potential adverse effects on mood and functioning, and facilitates coping and adaptation, reducing the likelihood of illness (Gottlieb, 1983).

In contrast, hypotheses regarding the direct effects of social support on health state that social support has a positive influence of people's health regardless of their levels of stress. Social support is thought to insulate people from exposure to stressors and enhance good health (Gottlieb, 1983). Research provides a great deal of evidence to support both hypotheses; i.e. that social support can reduce stress and buffer the impact of stress on health (Hogue, 1985).

#### Effects of social support on adaptation to neonatal illness

The role of the social network and the support it offers in alleviating the effects of stressful life events has emerged as a major focus in literature concerning adaptation to the birth of a high-risk infant. Health related benefits of social support have recently been studied. Social support variables during and after the hospitalization of a high-risk infant have been positively and negatively associated with maternal-infant attachment and bonding, and adaptation to parenthood. Researchers have found social support to be beneficial to maternal adaptation to the care of a high-risk infant at home. Others researchers have found that social support can inhibit adaptation to this crisis event.

Researchers have examined the effect of supportive networks during the time an infant is hospitalized in intensive care. As a result, various types of support groups have been established for parents of infants in NICU. Support group organizers utilize crisis intervention techniques to ameliorate the effects of neonatal illness on parents, and to promote parent-infant attachment and caretaking behaviors. Programs range from professional crisis intervention on an individual basis (Dillard, Auerbach, & Showalter, 1980), to "buddying" parents with veteran parents for visiting and support (Eager & Exoo, 1980), to hospital-based parent support groups (Boukydis, 1982; Minde, Shosenberg, Marton, Thompson, Ripley & Burns, 1980; Boer, 1978; Erdman, 1977). Studies emphasize the enormous relief which parents express when sharing their experience with empathic others. Researchers also suggest that support groups may have positive implications for later parenting behaviors (Zarling, Hirsch & Landry, 1988; Minde, Shosenberg, Marton, Thompson, Ripley & Burns, 1980). Since this research concentrates on the provision of social support after the high-risk infant is discharged from intensive care, studies exploring this phenomena will be examined more closely.

The homecoming of infants treated in NICUs poses a challenge to parents' resources and well-being. The availability of social support has been shown to play a role in how well parents adapt to problems associated with caring for high-risk infants and young children with special needs. Crnic, Greenberg, Ragozin, Robinson and Basham (1983) found that with mothers of full-term and premature infants, both social support and maternal stress significantly predicted maternal attitudes at one month and interactive behavior at four months infant age. In

addition, mothers with more support, especially intimate support, were more positive in their attitudes and behaviors. Social support appears to have equal benefit for mothers of full-term and premature infants, but this similarity may be attributed to the relatively healthy status of the premature infants in the study.

Affleck, Tennen, Allen and Gershman (1986) studied perceived social support and the functions of support for 42 mothers whose infants were considered to be at high risk for developmental disorders or further medical problems. Mothers were interviewed approximately two months after their infants were discharge from intensive care. The researchers found that mothers' satisfaction with emotional, informational, and tangible support was associated with more positive adaptation to a high-risk infant after discharge. These findings were especially applicable to mothers of infants whose postdischarge status was more severe, compared to mothers of infants with a more reasonable prognosis.

Philipp (1984) investigated the relationship between parental recollections of social support during and following their high-risk infant's hospitalization and the subsequent adjustment they made to their child. Utilizing a questionnaire developed for the study, Philipp rated the parent's overall adjustment to their child, the availability of supports, and the parents' ability to use the support available. The author suggests that the ability of parents to use support in hospital, during the stressful homecoming period, and thereafter (when the hospital support system is no longer available) plays an essential role in facilitating adaptation to their child. Philipp states that it is important for health care professionals to determine whether parents rely more heavily on formal supports in the community, professionals or



paraprofessionals, or informal sources of support, family and friends. She suggests a detailed support inventory could provide parents with information concerning types of supports available in the community.

Beckman, Pokorni, Maza, and Balzer-Martin (1986) interviewed 17 mothers of premature infants and 17 mothers of full term infants at 3, 6, and 12 months after their infant's birth. Over this time period, the researchers compared sources of stress and support in families of healthy full term infants and families of infants at risk of handicap due to low birthweight and prematurity. From the data, the authors report mothers of premature infants experience significantly more parent and family problems than mothers of full term infants and these problems do not decrease significantly over time. In addition, parents of premature infants report significantly more formal and informal support than parents of full term infants. For families of premature infants, stress is significantly and negatively related to the amount of formal support reported at the preceding age. The researchers report the relationship between stress and informal support was less consistent. They make the following suggestions from the study: families of premature infants require and receive more informal and formal support during the infant's first year of life; differences in formal support can be attributed to increased contact with follow-up support programs premature infants participate in during the newborn period; differences in informal support may result from the situational crisis of premature birth which mobilizes certain aspects of the informal support network which then become dormant when the source of stress is over. Families of premature infants rely on this informal support system as a method of coping, while families of full-

term infants have no need to rely as heavily on the system. The authors suggest for families of premature infants, formal support may be an important mediator against later stress and lack of informal support may influence family utilization of formal support systems. The study is limited as participants were predominantly white middle-class families. The results, however, do have implications for families in adverse socioeconomic conditions with fewer sources of support.

Research with families of high-risk infants has concentrated on support available from traditional sources, such as spouse, extended family, friends, and neighbours. Crnic, Greenberg and Slough (1986) investigated whether support from professional sources influence positive outcomes over and above those effects of more proximal network members. In the study, measures of maternal stress and support were collected from 52 mothers of premature infants one month after the infants were discharged home. These measures were compared to measures of parenting, mother-infant interaction, infant social and developmental competence, and infant attachment at 8 and 12 months corrected infant age. The researchers report that stress and support from various sources are related to parent and infant outcomes at both measurement occasions. In addition, stress and support measures gathered at 1 month postdischarge are predictive of mother and infant functioning 7 and 11 months later. Among informal sources of support, the marital relationship is a critical determinant of parenting competence and subsequent child development. The authors suggest that support from professionals contributes significantly to maternal parenting and infant health status, above and beyond contributions of other more proximal sources of support. Implications for the potential of early

intervention and availability of formal sources of professional support following discharge from intensive care can be drawn.

Beckman and Pokorni (1988) investigated whether amount of stress reported by parents of premature infants decreases over time, and whether stress is significantly associated with social support. Through the study of 44 families of premature infants at 3, 6, 12, and 24 months postnatal age, the researchers report that family stress does change, but not necessarily decrease over time, and that family needs vary depending on child-related problems confronted at a given time. The researchers also report that stress is significantly and negatively associated with informal support at all ages, but not significantly associated with formal support at any age. The authors advocate the need to identify changes in family needs, and therefore support, over time.

Research by Zarling, Hirsch and Landry (1988) contradicts the buffering effect of informal support in a crisis situation. In comparing the birth of a 34 premature infants and 20 full-term infants, the authors suggest that the birth of a premature infant leaves family and friends unsure of their roles and how to respond. In the study, a higher density of friends and family was related to less maternal sensitivity in the premature group but to greater sensitivity in the full-term group. The researchers suggest that sources of informal support who react with pity and fear for the premature child may increase the mother's distress and inadvertently exacerbate her fears and sense of failure.

Findings concerning the effect of formal support in alleviating stress in families of high-risk infants are contradictory as well. While Beckman, Pokorni,

Maza and Balzer-Martin (1986) and Crnic, Greenberg, and Slough (1986) similarly report positive correlations between professional support and maternal functioning, and negative correlations between formal support and stress, more recent studies fail to find this relationship. Affleck, Tennen, Rowe, Roscher and Walker (1989) followed 94 mothers of high-risk infants who were randomly assigned to a control group or to a group who received a formal support program designed to aid their adaptation to the transition from hospital to home. The researchers report that mothers' pre-discharge need for support and severity of the infants' pre-discharge medical problems moderated program effects, which were assessed six months after NICU discharge. Positive effects of the program on mothers' sense of competence, perceived control, and responsiveness were evident for mothers who needed the most support. At low levels of need for support, participation in the program had negative effects on outcomes. The authors suggest that mothers needing support may benefit from formal support after discharge from NICU, while mothers who have little need for support may experience temporary disruption in adaptation from a formal support program.

Continued longitudinal research is necessary to evaluate effects of formal and informal support on adaptation to birth and later parenting of a high-risk infant. Researchers suggest intervention strategies and support should be tailored to meet specific individual needs, to ensure continued adaptation to this crisis event.

Community-Based Nursing as a Source of Formal Support

Parents of high-risk infants often feel overserved while their infant is in hospital. Many, however, feel abandoned in the postdischarge period, when their need for support and education may be most acute. Timely and appropriate nursing intervention during this period can provide needed support, and promote growth and development of the family system and the individuals within it. Community health nurses, however, appear to be a neglected part of the neonatal team, even though they are available professional community health workers who can assist parents of high-risk infants in their transition to home care (Boer, 1978). The dearth of literature concerning community nursing care of infants discharged from NICU presents difficulties for critical assessment in this area.

Censullo (1986) suggests community health nurses engage in three important stages to assess the family of the high-risk infant upon discharge from intensive care. Stages include assessment of individual needs of the family, diagnoses of more specific needs and intervention strategies, and identification of mutual goals that both the nurse and family wish to accomplish over the course of the relationship. During this stressful transition period, community health nurses counsel to resolve grief and facilitate crisis resolution, provide education relative to the special characteristics and needs of the high-risk infant, refer infants for developmental programs and parents for support, and are generally available to solve practical problems which arise after the infant is discharged home.

Jacknik, Gumerman and Parker (1983) evaluated the quality of nursing follow-up for high-risk infants and their families in an area of southern Illinois.

Families with high-risk infants were asked to complete a questionnaire about their perceived need for community nursing follow-up and usefulness of the nursing follow-up. The majority of parents stated they appreciated having a knowledgeable and interested person to listen to their concerns following the discharge of their infants from intensive care. One-fourth of parents, however, stated that the nurse's visit was an imposition and they felt their parenting skills were being evaluated. The researchers report that a major limitation of community nursing service is the physical assessment skills of the nurses. Parents reported infants being weighed and undergoing developmental screening but elaborated very little concerning the skilled nursing services received. Another deficiency revealed was lack of coordination between hospital nurses and community health workers. Periodic meetings and predischARGE assessments of infant and family are recommended to overcome this deficiency.

Couriel and Davis (1988) discuss the benefits of community neonatal nurses for a population of high-risk infants enrolled in an early discharge program. Evaluation of the program reveals advantages for infants and families in terms of continued health monitoring and formal support, more efficient use of limited hospital resources, and savings in terms of costs for hospital care.

Brooten, Gennaro, Knapp, Brown and York (1989) examined the pre- and postdischarge teaching required by parents of VLBW infants. Content analysis yielded five major teaching categories, infant, mother, family, home, and resources. Sixty-two percent of the teaching occurred in the postdischarge period. Follow-up revealed that parents require education and support to manage high-risk infants after

discharge. These authors and others (Turner, 1988; Couriel & Davis, 1988)) suggest that follow-up by nurses who specialize in the care of high-risk infants and their families, is needed to provide continuing care and support to this vulnerable population.

Marshall (1987) interviewed 20 mothers of infants who had received surgical intensive care within the previous 18 months, in order to examine their perceptions of the discharge process and support received after their infant was discharged from intensive care. The researcher reports discharge preparation was disjointed and incomplete while support in the community was inconsistent. Mothers report having to teach the community health nurse the specialized knowledge required to care for high-risk infants at home, and in general having "muddled through" postdischarge problems by themselves. The author recommends a framework for discharge which includes both physical and psychological preparation of parents, and improved community nursing support.

Samson (1989) recognizes the need to educate community health nurses to meet the complex needs of NICU graduates in the home. She states that community health nurses historically have functioned as generalists, providing home care to patients across the life span. This broad scope of practice often precludes the expertise necessary for recognition of problems in the recovering neonate. Samson suggests an outreach educator is necessary to plan and implement an educational program for community health nurses. Outreach education may prepare community health nurses to meet the needs of this patient population and thereby improve survival and quality of life for these vulnerable infants and their families.

Noga (1982) describes and evaluates a similar program addressing educational needs of community health nurses caring for high-risk infants at home. Evaluation indicates the educational program helped nurses provide consistent comprehensive care to families, who were in turn very grateful for home visits by a community health nurse. Ritchie and Mertens (1987) replicated these findings in a survey which asked parents of high-risk infants to rate care they received from community health nurses after their infants were discharged home. Sixty percent of respondents rated visits as helpful or very helpful, indicating mothers had a positive attitude toward the formal support provided by nursing in the community.

In summary, community health nurses, properly trained, can provide an important source of formal support to families whose infants have recently been discharged from NICU. To date, this source of support in the community appears to be under-utilized.

### Summary

Infants who require intensive care at birth are a vulnerable population. They risk considerable mortality and morbidity in the first few years of life. Many high-risk infants experience physical, developmental, and learning sequelae as a result of their neonatal illness. Long-term effects may persist to school age or later.

Families of high-risk infants also experience continuing crises after their infants are discharged from intensive care. Parents separated from their infants at



birth due to neonatal illness risk disruption in maternal-infant bonding. This has been associated with disorders in parenting, including child abuse and neglect.

Sources of formal and informal social support can influence family adaptation to the birth and continuing care of a high-risk infant. Community health nurses can offer educational, emotional, and tangible support, and assist parents in coping after the infant is discharged home.

In this research project, the concerns and needs of mothers during the six week period following the discharge of their high-risk infant from hospital were explored. Maternal perceptions of the need for formal and informal support during this stressful period were examined, and in particular, maternal perceptions of formal support received from community health nurses.

## CHAPTER IV: METHODOLOGY

## Study Design

Postdischarge experiences of mothers whose high-risk infants were recently discharged from intensive care were examined in this descriptive exploratory study. Little has been written about the concerns of mothers following the discharge of their high-risk infant from hospital. A descriptive approach, therefore, was selected to enable the investigator to observe, describe, and document this situation. This method provided insight into the needs, concerns, and requirements for social support mothers of high-risk infants experience in this stressful situation.

Data were collected through semi-structured or focused interviews. Semi-structured interviews offer the researcher opportunity to move from content area to content area, to follow-up on cues suggested by the respondent, and to spend varying amounts of time interviewing subjects (Polit & Hungler, 1987). The interview guide successfully encouraged respondents to express themselves freely, and to introduce thoughts and observations which were particularly relevant to their personal experiences and perspectives. Face-to-face interviews invited responses and permitted clarification by the interviewer and the respondent.

### Setting

The setting for this study was the city of Winnipeg, Manitoba, Canada and the rural area within a 160 kilometer radius of the city of Winnipeg. The Health Sciences Centre and the St. Boniface General Hospital are the only two neonatal tertiary care centers in Winnipeg. High-risk infants from Manitoba and North-Western Ontario are transported to these centers for neonatal intensive care.

### Subjects

A convenience sample of fifty subjects was drawn consecutively from mothers of infants admitted to the Neonatal Intensive Care Unit (NICU) or the Intermediate Care Nursery (ICN) at St. Boniface General Hospital or the Health Sciences Centre, Winnipeg. Infants were inborn or transferred to these centres after birth. Subjects who met the criteria for inclusion in the study were:

1. mothers of infants admitted to NICU or ICN immediately after birth;
2. mothers of newborn infants who were cared for in NICU, ICN, or both units for at least 10 days before discharge home;
3. 18 years or older;
4. able to understand English verbally and in written form; and
5. living within a 160 kilometer radius of Winnipeg city.

Mothers of infants enrolled in an ongoing demonstration project, "Shortened Hospital Stay for Low Birth Weight Infants" (Casiro, Becker, McFayden, 1988)

were excluded from the study. These mothers received supplementary teaching, discharge preparation, and support which would have confounded study results. No restrictions were placed on the infants' gestational age or the ethnic or socioeconomic backgrounds of the respondents. Subjects from rural and urban centres in Manitoba were approached to participate in the study. A boundary of 160 kilometers around Winnipeg was chosen based on the geographical limit of ground transport for the Neonatal Transport Team to transport high-risk infants born in rural Manitoba to a high-risk neonatal centre.

Five mothers who were approached opted not to participate in the study. One was the mother of an infant with extensive congenital anomalies. One was the mother of a full-term infant with sepsis. The others were mothers of relatively healthy premature infants. These mothers did not give their phone number to the researcher; therefore reasons for their unwillingness to participate were not explored.

### Procedure to Recruit Subjects

This research project was the second phase of a collaborative research study. Another graduate nursing student conducted phase 1 of the project. Phase 1 and phase 2 collectively represent replication of an ongoing study conducted by Dr. Karen Luker, in Manchester, England. In Phase 1 of the study, maternal perceptions of the experience of having an infant in intensive care were examined. This phase entailed an interview with mothers of high-risk infants prior to the discharge of

their infant from hospital. In this research project, Phase 2, perceptions of the event of neonatal illness which mothers have six weeks after the high-risk infants are discharged home were examined, and the need for continued support in the postdischarge period were explored. On completion of both phases of this project, data collected in phase 1 will be compared with data collected in phase 2 of the project. Maternal perceptions of the adequacy of discharge preparation and the need for continuing help and support will be examined. A long-term goal is comparison of collective data from this study with data collected in the concurrent British study. International differences in preparation for discharge and continued community support may then be assessed. These long-term goals, however, are beyond the scope of this individual research project.

Since access to subjects for the research project occurred in Phase 1 of the study, both researchers were jointly involved in the process. Once ethical approval was received, permission for access to potential subjects was obtained from the Health Sciences Centre, The Children's Centre, and the St. Boniface General Hospital (Appendices A, B, and C). This gave the researcher permission to approach potential subjects in the NICUs at Children's Hospital and St. Boniface General Hospital, and the Intermediate Care Nurseries (ICNs) at Women's Centre (Health Sciences Centre) and the St. Boniface General Hospital. Through discussions with the Directors of Nursing and the Head Nurses in these areas, the Assistant Head Nurses (AHNs) in each respective unit were designated as the intermediaries between the researcher and the potential subjects.

The researcher explained the project to the AHNs and addressed their questions and concerns. The researcher then met with the AHNs on a regular basis to discuss which potential subjects were eligible for inclusion in the research project. After determining that a potential subject met the criteria, the researcher requested the AHN approach the potential subject, offer a brief verbal description of the study, and request permission to give the subject's phone number to the researcher (Appendix D). Potential subjects were then contacted by telephone and the research project was explained in detail (Appendix E). If subjects verbally agreed to participate in the study, arrangements were made to meet with both researchers at the subject's convenience. Potential subjects were provided with a written description of the research project at that time (Appendix F), given time to consider participating, and opportunity to ask questions concerning the research project. Subjects were advised that participation in the research project was strictly voluntary, that refusal to participate would in no way affect the care their infant received, and that they could withdraw from the study at any time. After subjects agreed to participate, consent forms for Phase 1 and Phase 2 (Appendix G) of the research project were examined and signed. Consent forms for Phase 2 included permission for the researcher to have access to the demographic data collected in Phase 1 of the research project. Before Phase 1 was conducted, the researcher thanked subjects for their cooperation and advised that they would be contacted by phone approximately six weeks after their infants were discharged from hospital.

It was considered important for both researchers to meet with potential subjects at first contact, even though only Phase 1 of the research project was

conducted at this time. Introduction of the researcher and explanation of Phase 2 of the project enlightened potential subjects fully concerning the entire research project. In addition, it facilitated the development of rapport that was meaningful for data collection in Phase 2 of the research project. Initial approach to potential subjects did not occur until the infants were progressing well and mothers were being prepared for their infant's discharge home.

Six weeks after the infants were discharged from NICU or ICN, subjects were contacted by phone and asked if they were still interested in participating in Phase 2 of the research project (Appendix H). The researcher then made arrangements for administration of Phase 2 of the study.

On all occasions except one, data collection occurred in the respondents' homes. This facilitated comfort of the respondents and their infants, and encouraged free expression of thoughts and feelings. The interviews varied in length from 40 minutes to 2 1/2 hours. The mean time for Phase 2 of the research project was 1 hour and 15 minutes. Participants willingly shared their thoughts and time with the researcher. After data collection was complete, subjects were thanked for their time and cooperation, encouraged to contact the researcher with questions or concerns they might subsequently have, and advised that a summary of the study would be mailed to those who wished to receive one.

Data collection occurred over the period June 1, 1990 to November 15, 1990.

## Ethical Issues

The research project was approved by the Nursing Ethical Review Committee, School of Nursing, University of Manitoba, Winnipeg, Manitoba (Appendix I). All potential study subjects were provided with a verbal and written description of the study, informed that they were under no obligation to participate in the study, and advised that they were free to withdraw from the study at any time. If subjects chose to participate, they were asked to sign a consent form and were given a copy of the consent form. All subjects were given opportunity to request a summary of study results.

Subjects were asked to participate in a semi-structured interview. This was arranged at a time and place convenient for the respondent. To assure anonymity and confidentiality, the questionnaires used in the interviews were coded with a subject number and only the researchers involved in the study had access to this name-number combination. Completed questionnaires were stored in a locked container and destroyed following data analysis. Data were stored in the computer as part of a collaborative data bank to be used for further analysis. This data is not identifiable with individual subjects. No experimental conditions were imposed on the subjects or their infants. There were no perceived harmful effects of the study. Benefits of the study, while minimal to the respondents, may benefit mothers of future high-risk infants.

Sensitivity of the information elicited from respondents had the potential to trigger unpleasant memories and feelings of anger, depression, or despair. Although



three mothers became distressed recalling neonatal experiences, the researcher offered support and ensured these subjects had regained their composure before leaving. Respondents expressed their appreciation to the researcher for the opportunity to talk about their experiences as mothers of high-risk infants. The researcher answered many questions respondents had concerning the care of high-risk infants in the home and was helpful to respondents in this manner.

### Data Collection Instrument

A semi-structured interview schedule (Appendix J) was administered to consenting mothers of high-risk infants. The intention of the questionnaire was to elicit descriptive information concerning mothers' perceptions of care provided to themselves and their infants after discharge from NICU or ICN, and to identify common problems mothers of high-risk infants experienced at that time. Subjects were asked if the care they and their infants received matched their expectations and how they thought care could be improved; what worries they had at discharge and during the six week postdischarge period; which sources of formal and informal support had been most beneficial; and their opinion on the effect of a high-risk infant on family life.

The questionnaire utilized in the research project was developed by Dr. Karen Luker, The University of Manchester, England, and is currently being employed in Manchester in a similar research study. Format and wording of the interview schedule were devised to acquire valid and reliable information

concerning this neonatal crisis without upsetting or offending the respondent. Questions were worded in an informal, clear, and simple manner. Attempts were made to avoid biased, loaded, or leading questions. The interview schedule included topics suggested by the literature and these topics were arranged in logical order. The questionnaire was piloted in England by mothers of infants who had required intensive care at birth and was found to be acceptable and non-threatening to respondents.

The questionnaire was modified for this study to reflect changes which were necessary to enable the researcher to carry out the study in this locale. Dr. Luker restricted her sample to VLBW infants while this research project included mothers of all infants admitted to NICU or ICN at birth. In addition, some of the wording was changed to reflect differences between Canadian and British health care systems and language differences between the two countries. The revised questionnaire was piloted prior to use. Four mothers who were acquaintances of the researcher and who had recently experienced the birth and illness of a high-risk infant were asked to review the questionnaire. Feedback from the pilot procedure determined that respondents understood the questions and did not find the information requested objectionable or upsetting. The questionnaire was an acceptable length, measured what it intended to measure, and addressed the purpose of the study. Feedback was positive; there was no need to modify the questionnaire as a result of the pilot procedure.

Psychometric testing of the tool has not been carried out. Continued use of the questionnaire in collaborative, intersite research will contribute to testing and refinement of the interview guide.

### Data Analysis

Quantitative and qualitative data were generated from the interview questions. J. Sloane, Statistical Consultant for the Manitoba Nursing Research Institute, provided statistical consultation in the analysis of data collected from the sample.

Quantitative responses indicated how involved mothers felt in the care of their infants in hospital, whether this involvement prepared them to care for their infants at home, what worries mothers had at discharge and during the six weeks after their infant was discharged home, how mothers perceived their high-risk infants, and how the infant had affected family life. Quantitative responses rated the helpfulness of informal support and formal support during the six weeks following discharge. Several responses directly rated the helpfulness of community health nurses as a source of formal support.

Simple descriptive measures were applied to summarize and describe the quantitative data. These included frequency distributions, measures of central tendency, and measures of variance. Quantitative data were analyzed using the Number Cruncher Statistical System (Hintze, 1987).

Content analysis was used to analyze qualitative data. Qualitative responses were organized manually according to major themes that emerged in the data.

These themes were summarized and systematically described. Responses were then quantified to determine the frequency of each category of maternal concern. Qualitative responses indicated how mothers felt discharge preparation could be improved, how mothers felt when their infants were discharged from hospital, concerns mothers had at discharge and six weeks after discharge, and the effect of the high-risk infant on family life. In addition, qualitative data revealed how mothers felt the care provided to them after discharge could be improved, and in particular, how community health nurses could address the needs of mothers of high-risk infants. Qualitative data provided insight into quantitative responses which rated maternal perceptions of postdischarge care, help, and support.

Analysis of quantitative and qualitative data indicated how well prepared mothers felt to care for their high-risk infants after discharge, and identified which sources of formal and informal support were most helpful in the postdischarge period. This included an analysis of the formal support provided by community health nurses.

Demographic data collected in Phase 1 of the research project were examined to describe the participants in the research project. These data provided insight into characteristics of mothers participating in the study and information concerning their high-risk infants as well.

## CHAPTER V - RESULTS

The purpose of this study was to describe common problems that mothers of high-risk infants experienced after their infants were discharged from intensive care. In addition, maternal perceptions of sources of support that mothers found most useful during the six week period following the infants' discharge home were elicited. Data for the study were collected over a five month period from June 1990 to November 1990. Instruments were hand scored by the investigator and all data were coded and transferred to a computer file. A statistical program, Number Cruncher Statistical System (Hintze, 1987), was used to calculate results. Demographic data and quantitative instrument scores were summarized using descriptive statistics. Qualitative data derived from interviews were subjected to content analysis and themes emerging from the data were identified.

The results of the data analysis are described in this chapter. First, the sample is described. Second, data from the interviews are divided into three major themes: 1) concerns of mothers in the postdischarge period, 2) the effect of a high-risk infant on family life, and 3) maternal perceptions of the usefulness of sources of formal and informal support. Results from quantitative data are presented for each theme and qualitative data emerging from interview questions pertaining to the same theme are presented concurrently. Finally, additional results are summarized. These include maternal perceptions of the experience of expressing breast milk for ill or premature infants, maternal perceptions of communication with

health care professionals in hospital, and advice given by respondents to future parents of high-risk infants.

### Demographic Data

During the five month period of data collection, a total of fifty-five mothers of high-risk infants were approached and invited to participate in the research project. Fifty mothers, or ninety-one percent of the women contacted, agreed to participate in the study. Five mothers declined to participate, including a mother of an infant with extensive congenital anomalies, a mother of a full term infant with sepsis, and three mothers of premature infants. Characteristics of respondents and high-risk infants are summarized in Tables 1 to 4.

**TABLE 1**  
**DEMOGRAPHIC CHARACTERISTICS OF RESPONDENTS**

Variable	Class	N (%)
MARITAL STATUS	MARRIED/COMMON LAW SINGLE	50 (100%) 0
RACE	CAUCASIAN NATIVE NORTH AMERICAN	49 (98%) 1 ( 2%)
FAMILY INCOME	< \$ 23,000 \$23,000 - \$43,000 > \$ 43,000	9 (18%) 21 (42%) 20 (40%)
PLACE OF RESIDENCE	URBAN (WINNIPEG) RURAL (OUTSIDE WINNIPEG)	32 (64%) 18 (36%)
NUMBER OF CHILDREN	PRIMIPAROUS MULTIPAROUS	22 (44%) 28 (56%)
EMPLOYMENT STATUS BEFORE BIRTH	EMPLOYED UNEMPLOYED	40 (80%) 10 (20%)
PLANS FOR WORK AFTER MATERNITY LEAVE	PLAN TO WORK PLAN NOT TO WORK UNSURE	23 (46%) 16 (32%) 11 (22%)
OCCUPATIONAL STATUS (BLISHEN SCALE)	PROFESSIONAL/ SEMI-PROFESSIONAL SKILLED/UNSKILLED OCCUPATION NOT LISTED ON SCALE UNEMPLOYED	24 (48%) 12 (24%) 4 ( 8%) 10 (20%)

**TABLE 2**  
**AGE AND EDUCATION OF RESPONDENTS**

Variable	Mean	S.D.	Range	
			Min.	Max.
AGE IN YEARS	29.3	3.58	22	37
YEARS OF EDUCATION	13.54	2.62	10	22

Note: S.D. = Standard Deviation  
Min. = Minimum  
Max. = Maximum



**TABLE 3**  
**GESTATIONAL AGE AND WEIGHT OF INFANTS**  
**DAYS HOSPITALIZED AND DAYS HOME**

Variable	Mean	S.D.	Range	
			Min.	Max.
GESTATIONAL AGE IN WEEKS	32.86	3.75	24	42
BIRTHWEIGHT IN GRAMS	2018	788	600	3880
DISCHARGE WEIGHT IN GRAMS	2712	650	1928	4235
DAYS HOSPITALIZED	43.88	29.15	10	143
DAYS HOME	44.44	5.6	32	63

Notes: S.D. = Standard Deviation  
 Min. = Minimum  
 Max. = Maximum

**TABLE 4**  
**CHARACTERISTICS OF INFANTS RELATED TO HOSPITAL STAY**

Variable	Class	N (%)
HOSPITAL OF ADMISSION	HEALTH SCIENCES CENTRE	29 (58%)
	ST. BONIFACE HOSPITAL	21 (42%)
UNIT(S) OF ADMISSION	NICU ONLY	4 ( 8%)
	ICN ONLY	2 ( 4%)
	NICU and ICN	3 ( 6%)
	ICN and ANNEX	8 (16%)
	NICU, ICN, and ANNEX	33 (66%)
INFANT TYPE	SINGLETON	47 (94%)
	TWIN	3 ( 6%)
REASON FOR ADMISSION	PREMATURITY	42 (84%)
	APNEA	1 ( 2%)
	CARDIAC ANOMALY	1 ( 2%)
	RESPIRATORY DISTRESS	2 ( 4%)
	SEIZURES	2 ( 4%)
	ASPHYXIA	1 ( 2%)
	SEPSIS	1 ( 2%)
COMPLICATIONS DURING NEONATAL PERIOD (OTHER THAN PREMATURITY)	NONE	11 (22%)
	APNEA	10 (20%)
	NECROTIZING ENTEROCOLITIS	1 ( 2%)
	RENAL FAILURE	1 ( 2%)
	ERB'S PALSY	1 ( 2%)
	MULTIPLE COMPLICATIONS	26 (52%)
CONDITION AT DISCHARGE	NO OBVIOUS PROBLEMS	42 (84%)
	APNEA MONITORING	1 ( 2%)
	REQUIRED MEDICATION	4 ( 8%)
	REQUIRED SURGERY	2 ( 4%)
	RETINOPATHY OF PREMATURITY	1 ( 2%)

Note: NICU = Neonatal Intensive Care Unit  
 ICN = Intermediate Care Nursery  
 Annex = Convalescent Nursery

## Interview Data

Theme 1Concerns of Mothers in the Postdischarge PeriodDischarge Preparation

In the preliminary portion of the interview, the researcher asked mothers to rate involvement with infant care in hospital and to assess whether this involvement helped prepare mothers to care for the infants at home. The majority of respondents reported that they were encouraged to be as involved as they wanted to be in caring for their infants. Seventy-seven percent of mothers whose infants were cared for in NICU and 76% of mothers whose infants were cared for in ICN stated that nursing staff encouraged mothers to be involved with infant care. Only eight mothers in NICU and 10 mothers in ICN indicated that they were less involved than they wanted to be while their infants were in cared for in these units.

At the time the infants were discharged from hospital, the majority of mothers (n=42, 84%) reported that they felt prepared to care for their infants at home. Only 10% (n=5) stated they were not prepared for the discharge of the infant. Mothers were asked whether involvement in infant care in hospital contributed to discharge preparation. Forty percent of mothers (n=20) stated that this involvement made them feel very well prepared, 36% (n=18) that involvement with their infants prepared them fairly well, and 16% (n=8) that they were only adequately prepared as a result of participating in infant care. One mother (2%) stated that she had received only some preparation, one mother (2%) did not

require preparation to care for her infant at home, and two mothers (4%) stated that they felt poorly prepared for the infants discharge from hospital.

Preparation for breast or bottle feeding prior to discharge was specifically assessed. While the majority of mothers who bottle fed their infants (60%) stated they were given enough instruction in bottle feeding before discharge, less than one-half of mothers who breast fed their infants (48%) received enough instruction concerning breast feeding.

Respondents were asked for suggestions to improve discharge preparation from neonatal special care. Qualitative analysis of data resulted in recurrent themes that were categorized into the need for more information, the need for practical experience with infant care, and other concerns.

#### The need for information.

The need for more information was a predominant concern of parents who were caring for a high-risk infant at home. Ninety percent of mothers (n=45) stated that more information, and information that was realistic and consistent would have enhanced discharge preparation. Examples of comments include:

"We needed more information from nurses as to what to expect."

"We needed more information about her lung condition. Someone should have fully explained what was wrong with her, how to manage it, and what to expect when we got her home."

"Parents need more formal classes to teach them how to look after their premature infants at home. These classes should be run every 2 weeks to teach parents about premature infants."

"We needed more teaching about reflux and more teaching about our baby's feedings at home -- what cereal to use and that cut nipples are available."

"I expected a similar pattern when he came home but I was naive to expect him to just eat and sleep --he was not like a newborn and we not prepared for that."

Eight mothers stated that information sheets prepared by nurses when infants were discharged home were a useful and available guide in the first few weeks after discharge. Ten mothers commented that consistency among nurses would be helpful in preparing parents for their infants' discharge.

"Comments, opinions, and suggestions from nurses about breast feeding were very different and very strong."

"The nurses have to get together and coordinate the information they give to parents so it does not conflict."

"There was contradictions in the teaching from nurses so we didn't know what to believe."

"Every nurse is different and her style is different so you get taught that different things are right and wrong -- and you hear contradictory advice, for example you shouldn't hold her when she is sleeping or that that's okay . It's hard to know what to do."

"We needed a library of books or sheets of information."

"There was no real discharge plan that I could take home with information on it."

#### The need for practical experience with the infant.

Sixty-eight percent of respondents (n=34) commented that they did not "know" their infants when they took them home. Mothers stated that inadequate

knowledge of infant habits and personalities hampered adjustment in the postdischarge period.

"We didn't really know D. before he came home. We didn't know what went on when we weren't there. We couldn't sit with him all day so we didn't know what he did between feedings."

"We were prepared for her physical needs but not for the fact that she was not going to be like a newborn baby. We didn't really know what to expect."

"The nurses told us about her routine and what to do with her. They said to treat her like a normal baby but that's just not enough -- because she's different and the difference shows up when she gets home."

"He cried all day and night when he got home. There were just so many things I didn't know about him."

Mothers stated that parents must be allowed to participate in infant care to learn about their infants before discharge. Several mothers who had "roomed-in" with their infants before discharge commented that this was a valuable learning experience. The researcher asked mothers if they had been given the opportunity to "room-in" with their infants. Ninety-two percent of mothers ( $n=46$ ) had not been given this opportunity. Of these mothers, 80% ( $n=37$ ) would have considered "rooming-in" with their infants for 24 to 48 hours before they took their infants home.

"You need to room-in with the baby to get experience with her and her equipment." (This infant was discharged with a home apnea monitor.)

"Rooming-in would help you to get to know the baby as a person. We never heard him cry until we got him home."

"I think parents should be strongly encouraged to stay overnight and room-in with their baby before discharge. I was given the opportunity but didn't

take advantage of it -- and I should have because I didn't really know all about J. even though I spent so much time there with him."

"I roomed-in with C. and D. before discharge and fed them both all night. It was great."

"I spent two days with S. -- there in the hospital before I took her home. It was fantastic to spend the nights there with her beside me -- I really learned a lot about her in those two days."

"Rooming-in was only casually mentioned once but I took advantage of it. I think the nurses should stress how valuable it is."

#### Others concerns and suggestions.

Mothers commented on the inadequacies of the physical environments in which their infants received care. Lack of space and lack of privacy inhibited visiting and interaction with infants. Three mothers specifically commented that overcrowded conditions precipitated early discharges for their infants. The suddenness of the infants' release from hospital heightened anxieties at discharge.

"It was a last minute discharge and he had only gone 3 days without a brady. Did they run out of space?"

"We knew he wasn't quite ready to come home. His oxygen saturation was only borderline with feedings. But they needed the beds so he had to go home -- he really could have used a couple more days in hospital."

"The suddenness of his discharge caught us unaware. Do babies just suddenly turn the corner or do the staff just want to get rid of them?"

Infants in this study were cared for in the Neonatal Intensive Care Unit, the Intermediate Care Nursery, and/or a convalescent nursery called the "Annex". Sixty percent of the infants were cared for in all three of these units before they were

discharged home. Transition from unit to unit was a frightening experience for mothers who had to adjust to a new area and new staff.

"We were nervous about the moves from NICU, to ICN, to the Annex, to home. It was hard to take the transitions -- it takes time to get comfortable again."

"The transition from unit to unit was hard on the baby -- she had to get to know a whole new set of nurses. She was transferred both times when she was sleeping and woke up in a new environment. She really felt it -- you could tell."

"The transitions from NICU to ICN to the Annex were encouraging and a rite of passage for B., but they were frightening for us."

Another suggestion for discharge included policy changes that enhance the family-centered experience of having a new baby. Differences in visiting restrictions and guidelines concerning holding and feeding infants at specific weights caused confusion and resentment among parents used to more flexible rules. Suggestions were made to improve parking facilities and accommodations for parents who are from outside of Winnipeg. Mothers stated these considerations encourage visiting and preparation for discharge home.

#### Feelings and Concerns at Discharge

Mothers were asked to describe their feelings when their infants were discharged home. Seventy-eight percent of respondents (n=39) commented they were happy and excited. This response was associated with comments of anxiety, fear and apprehension in 74% of mothers (n=37).



"We were happy to have him home but a little apprehensive as well."

"Excited but apprehensive because she had been so little and so sick."

"Excited but nervous and scared."

"Happy that he was well enough to be home but nervous because I couldn't duplicate the care he received in hospital."

"I was a nervous wreck. When they finally told me I could take her home, I was shaking like a leaf."

"Thrilled and very frightened."

Another predominant response was one of relief. Thirty-two percent of mothers (n=16) commented on the relief they felt when they realized they would not have to travel to the hospital on a daily basis and that they could return to a normal family routine. Four mothers stated that they felt rushed and hassled at discharge, eight that they felt unsure of infant care, and six mothers that they had not bonded with their infants at this point and were apprehensive to care for them at home. Two mothers stated they finally felt like a "real mom" when they were able to take their infant home.

Mothers were asked if they worried about their infants at discharge. The majority of mothers (n=40, 80%) had significant worries when they took their infants home. Qualitative responses highlighted the specific worries and concerns mothers of high-risk infants experienced in the immediate postdischarge period. The predominant concern was that high-risk infants would continue to experience apneic and bradycardic episodes after discharge. Eight mothers expressed

the fear of their child dying from Sudden Infant Death Syndrome (SIDS).

Comments included:

"...his breathing, apnea and bradycardia after feedings."

"Another couple had a premature infant who stopped breathing after she got home so I worried that it would happen to P."

"...about not being on a monitor -- what if his heart rate stopped?"

"...his breathing and his lungs -- even though his lungs were mature I felt something might still go wrong."

"He had stopped breathing once in the hospital and I was afraid he might do it again."

"...his breathing. I checked to see if he was breathing every 10 minutes."

"...afraid of bradys -- they took him off his medication without monitoring him for very long -- I was afraid he might have a brady at home."

"...apneas and bradys -- I didn't sleep for two days."

"SIDS was a concern so we read up on it and made sure we didn't do anything that they say might cause it to happen --like give her antihistamines or keep her too warm."

"My mother worried about crib death but I didn't want to think about it so I tried not to -- but the worry was always there."

Mothers expressed other concerns in the immediate postdischarge period.

These are summarized in Table 5.

**TABLE 5**  
**MATERNAL CONCERNS AT DISCHARGE**

Variable	Class	N (%)
FREQUENCY OF WORRY AT DISCHARGE	WORRIED ALL THE TIME	13 (26%)
	WORRIED SOMETIMES	27 (54%)
	RARELY WORRIED	5 (10%)
	HAD NO WORRIES	5 (10%)
SPECIFIC WORRIES AT DISCHARGE	APNEA AND BRADYCARDIA	32 (64%)
	SUDDEN INFANT DEATH SYNDROME	8 (16%)
	WEIGHT GAIN	18 (36%)
	ILLNESS	6 (12%)
	TEMPERATURE CONTROL	2 (4%)
	DEVELOPMENTAL PROGRESS	7 (14%)
	MONITOR MALFUNCTION	1 (2%)
	SEIZURES	1 (2%)
	INGUINAL HERNIA	1 (2%)

#### Concerns at Six Weeks After Discharge

Mothers expressed continuing concerns six weeks after the infants were discharged from hospital. Only 12% of mothers (n=6) stated they had no worries and concerns at this time. Several categories emerged as predominant concerns. These are outlined in Table 6.

**TABLE 6**  
**MATERNAL CONCERNS SIX WEEKS AFTER DISCHARGE**

Variable	Class	N (%)
FREQUENCY OF WORRY SIX WEEKS AFTER DISCHARGE	FREQUENT CONCERN	44 (88%)
	NO CONCERNS	6 (12%)
SPECIFIC CONCERNS SIX WEEKS AFTER DISCHARGE	GENERAL INFANT CARE	15 (30%)
	IRRITABILITY/SLEEPING	12 (24%)
	ILLNESS	7 (14%)
	DEVELOPMENT CONCERNS	11 (22%)
	APNEA AND BRADYCARDIA	2 ( 4%)
	SEIZURES	1 ( 2%)
	INGUINAL HERNIA	1 ( 2%)
	TALIPES VARUS	1 ( 2%)

In spite of a multitude of worries at discharge and continuing concerns six weeks after the infants were discharged home, only one respondent (a mother of high-risk twins) stated that she was not coping in caring for her infants and needed help, and one mother reported that she was "just about coping". Ninety-six percent of respondents (n=48) stated that they had coped since their infants were discharged home; 62% (n=31) reported coping very well, and 34% (n=17) reporting coping fairly well six weeks after their infants were discharged from hospital.

Theme 2The Effect of a High-Risk Infant on Family Life

Several questions in the interview addressed the impact of a high-risk infant on the family (Table 7). Respondents reported that the experience of having a high-risk infant affected relationships with spouses. More than one-half of the respondents (n=28, 56%) stated this experience resulted in improved relationships with spouses. Twelve percent (n=6) stated that relationships with partners had suffered, and 32% of respondents (n=16) felt that the birth of a high-risk infant had made no difference to these relationships. The following comments provide insight into these findings:

"We feel much closer to each other because of what we've been through."

"It stressed our relationship to the hilt but in the long run made it better."

"You don't realize how much you rely on someone until you have to support each other. We made a pact that if I needed the help he would be strong for me and if he needed the help I would be strong for him. It worked and we were able to support each other."

"Going through different experiences together really bonds you closer together -- it made our marriage better."

"I always thought that my mother was the most important person to me - but now I know that it's my husband."

"Better at first -- but the long time he was in hospital really strained our relationship. It's back to normal now."

"It made our relationship worse. He wants to leave me and the babies -- he says he can't stand the crying anymore. I can't leave -- but he just might."

"It really changed our lives together. We had 14 happy years and now that's all changed -- we have no time for each other and we aren't happy anymore."

The majority of mothers (n=42, 84%) stated fathers reacted positively to the high-risk infants after discharge, and that the majority of fathers (n=48, 96%) confidently and willingly participated in infant care.

Respondents stated that the birth of a high-risk infant had both positive and negative effects on plans for future pregnancies. While 38% of mothers (n=19) stated they planned to have another child, 38% (n=19) did not plan more children, and 24% (n=12) were unsure.

Only 17 mothers (34%) stated that the infants "fit easily into the family routine". The majority of mothers felt this transition process took a few days to few weeks (Table 7).

**TABLE 7**  
**EFFECT OF HIGH-RISK INFANT ON FAMILY**

Variable	Class	N (%)
EFFECT ON MARRIAGE RELATIONSHIP	RELATIONSHIP IMPROVED	28 (56%)
	RELATIONSHIP DETERIORATED	6 (12%)
	NO DIFFERENCE NOTED	16 (32%)
IMPACT ON FAMILY PLANNING	IMPACT ON PLANS FOR FUTURE PREGNANCIES	20 (40%)
	NO IMPACT ON PLANS FOR FUTURE PREGNANCIES	27 (54%)
	UNSURE OF IMPACT	3 ( 6%)
HOW INFANT FIT INTO FAMILY ROUTINE	FIT IN EASILY	17 (34%)
	TOOK A FEW DAYS	19 (38%)
	TOOK A FEW WEEKS	13 (26%)
	STILL HAS NOT FITTED IN	1 ( 2%)

Twenty-eight respondents with other children at home were asked how the other children felt about the new baby. Twelve of these mothers (43%) reported that other children expressed positive feelings about the new addition to the family. These feelings included love, pride, and a protective attitude toward the infant. Four of these mothers (14%) reported their children had mixed feelings about the infants. These feelings included love and resentment because the infants required so much of their mothers' time. Four of these mothers (14%) reported that the other children were jealous of their sibling, and two mothers (7%) reported that the

other children had been afraid when the infants were ill and were now relieved to have their sibling at home.

Respondents were asked if the birth of a high-risk infant affected how they felt about themselves as a woman. Twenty-two mothers (44%) acknowledged that the birth of the infant had affected how they felt about themselves. Eight mothers stated they were afraid to have more children for fear of having another high-risk child. Nine mothers felt inadequate, guilty, and blamed themselves for giving birth to a high-risk infant. One mother commented she felt "gypped" when she lost her pregnancy at such an early stage, and that early delivery represented a real loss. Additional insight can be gained from these comments:

"I believed I was inadequate and still do to a certain extent. My body did something to her and she was born with problems."

"She was born at 42 weeks and I felt guilty that I hadn't pushed for her to be born sooner."

"I felt a lot of guilt about the baby's condition. I felt it was my fault."

"I felt bad because I didn't do it right -- I didn't have him like I was supposed to. We were all hyped up on a natural delivery and breastfeeding for 9 months -- but everything went wrong instead."

"I felt that it was my fault -- he was my second premature baby."

Finally, mothers were asked how they felt about their infants and whether they considered the infants to have more problems than other infants the same age. The majority of mothers (80%) did not feel their infants were at risk of developing more problems than infants who had not been premature or ill at birth. Sixty-two



percent of mothers, however, compared the health, development, and behaviors of their infants to other infants the same age. The majority of mothers whose infants were premature (89%) considered the infants' prematurity when comparing the infants to others infants the same age. Sixty-six percent of these mothers, however, felt others did not considered the infants' prematurity when these comparisons were made. These findings are summarized in Table 8.

**TABLE 8**  
**MATERNAL PERCEPTIONS OF THEIR HIGH-RISK INFANTS**

Variable	Class	N (%)
HEALTH STATUS OF INFANT	PROBLEMATIC	10 (20%)
	NOT PROBLEMATIC	40 (80%)
COMPARE INFANT TO OTHER INFANTS	ALL THE TIME	7 (14%)
	SOMETIMES	17 (34%)
	SELDOM	7 (14%)
	NEVER	19 (38%)
CRITERIA FOR COMPARISON	SIZE	31 (62%)
	DEVELOPMENT	19 (38%)
	FEEDING/SLEEPING	7 (14%)
	RESPIRATORY STATUS	1 ( 2%)
	PERSONALITY/BEHAVIOR	5 (10%)
CONSIDER PREMATUREITY (44 INFANTS)	YES	39 (80%)
	NO	5 (11%)
OTHERS CONSIDER PREMATUREITY (44 INFANTS)	YES	14 (32%)
	NO	30 (68%)

### Theme 3

#### Maternal Perceptions of Formal and Informal Support

The interview generated quantitative and qualitative data regarding maternal perceptions of the usefulness and availability of sources of formal and informal support following the discharge of an infant from special care. Quantitative data provided a rating as to which sources of support were considered most useful to mothers. Qualitative data provided insight into why these sources were considered useful and in which circumstances.

#### Informal Support

Several questions were directed at assessing how supportive family and friends had been since the high-risk infants were discharged home. The majority of respondents reported receiving the support they required and had expected to receive from family and friends. Spouses were identified as most supportive by 66% of respondents. These data are summarized in Table 9.

**TABLE 9**  
**MATERNAL PERCEPTIONS OF INFORMAL SUPPORT**

Variable	Class	N (%)
SUPPORT RECEIVED FROM FAMILY AND FRIENDS	RECEIVED MORE SUPPORT THAN REQUIRED	11 (22%)
	RECEIVED THE SUPPORT REQUIRED	34 (68%)
	RECEIVED LESS SUPPORT THAN REQUIRED	5 (10%)
RATE SUPPORT RECEIVED	THE SUPPORT EXPECTED MORE SUPPORT THAN EXPECTED	29 (58%)
	LESS SUPPORT THAN EXPECTED	18 (36%)
		3 ( 6%)
MOST SUPPORTIVE INDIVIDUAL	SPOUSE	33 (66%)
	CLOSE RELATIVE	15 (30%)
	FRIEND	1 ( 2%)
	NEIGHBOUR	1 ( 2%)

Mothers were asked if they had received help and support to care for other children since the high-risk infants were discharged home. Of the 28 respondents with other children at home, the majority (n=17, 60%) reported receiving some help to considerable help in caring for other children. Fourteen of these mothers (50%) identified their spouse, while four mothers (14%) identified a close relative as most helpful in caring for other children after high-risk infants were discharged home. One mother identified a friend and one mother identified a neighbour as

most helpful in this regard. Mothers identified two predominant ways in which they were helped with other children. Fifteen mothers (75% of the mothers who required help) identified that spending time with other children and giving them attention was most helpful at this time. In addition, four mothers appreciated help with practical tasks such as bedtime, baths, and carpooling.

Respondents were asked whom they talked to among family and friends concerning worries they had about the infants after discharge. Many respondents identified more than one source of help. Thirty-nine mothers (78%) talked to their spouse, 30 mothers (60%) talked to a close relative, and 29 mothers (58%) talked to a friend or neighbour concerning worries they had about the infants. Sixty-two percent of mothers (n=31) found their spouses to be helpful while 56% of mothers (n=28) found close relatives to be useful persons from whom to seek help and advice. Twenty-one mothers (42%) identified friends and six mothers (12%) identified neighbours as helpful to them in the postdischarge period.

### Formal Support

Respondents identified sources of formal support they found helpful and supportive since their high-risk infants were discharged home. Mothers reported approaching health care professionals on a regular basis and receiving adequate help and support. Pediatricians and community health nurses were identified as the most supportive sources of formal support during the transition from hospital to home care (Table 10).

Analysis of qualitative data indicated why health care professional whom mothers identified as most helpful were considered helpful and supportive at this time. The predominant reason mothers considered health care professionals to be most helpful was their availability. Twenty-six mothers (52%) reported most helpful health care professionals were available on a constant basis.

"I can phone her on the spur of the moment -- she's always available."

"She says to call any time just to chat."

"I am able to call her if I need help -- she's available if I have any questions."

"He's always available and that's comforting to me. He says to call him any time and he makes a point of getting me in to see him right away if I'm concerned about D."

"If I have concerns, I can phone his office and he calls me right back."

Mothers considered health care professionals helpful for other reasons. These included information about the infants, reassurance that the infants were progressing well, empathy and concern for the family, and emotional support (Table 10). The majority of mothers (n=37, 74%) rated the care they had received from health care professionals since the birth of their high-risk infants as very good. Only one mother rated the care as poor (Table 10).

**TABLE 10**  
**MATERNAL PERCEPTIONS OF FORMAL SUPPORT**

Variable	Class	N (%)
SOURCES OF FORMAL SUPPORT UTILIZED	PEDIATRICIAN	36 (72%)
	GENERAL PRACTITIONER	15 (30%)
	COMMUNITY HEALTH NURSE	29 (58%)
	ICN NURSING STAFF	20 (40%)
	NICU NURSING	1 ( 2%)
	SOCIAL WORKER	2 ( 4%)
	OTHER SOURCES	3 ( 6%)
MOST HELPFUL SOURCE OF FORMAL SUPPORT	PEDIATRICIAN	22 (44%)
	GENERAL PRACTITIONER	9 (18%)
	COMMUNITY HEALTH NURSE	14 (28%)
	HOSPITAL NURSING STAFF	3 ( 6%)
	OTHER SOURCES	2 ( 4%)
WHY FORMAL SUPPORT MOST HELPFUL	AVAILABILITY	26 (52%)
	INFORMATION	14 (28%)
	REASSURANCE	13 (26%)
	EMPATHY	7 (14%)
	EMOTIONAL SUPPORT	8 (16%)
	PHYSICAL ASSESSMENT	6 (12%)
	APPROACHABLE	3 ( 6%)
RATE HEALTH CARE	VERY GOOD	37 (74%)
	GOOD	9 (18%)
	FAIR	3 ( 6%)
	POOR	1 ( 2%)

Note: NICU = Neonatal Intensive Care Unit  
 ICN = Intermediate Care Nursery

Community Health Nurses

Mothers of high-risk infants were asked whether they viewed community health nurses as helpful sources of formal support. The majority of mothers reported community health nurses had visited at least once since their high-risk infants were discharged from hospital and that the visit was useful to them. Eighteen percent of mothers (n=9), however, reported community health nurses had not visited during this time (Table 11).

When asked to describe how community health nurses had helped during this time, several themes emerged. Twenty-five of the forty-one mothers who had been visited by community health nurses (61%) stated that community health nurses were helpful because they gave information, advice, and suggestions for care.

"She gave me information about the baby and suggestions about gas. I didn't have to use them but it was nice to have them."

"She gave me lots of advice and things to try for P.'s colic. She suggested that I try stopping the iron and it worked."

"She gave us literature about B6 and told us how to watch for signs of seizures."

"She gave me a really good book on premature babies."

"She gave me pamphlets and sent me information about premature babies - their sleeping and feedings habits etcetera."

"She gave me information that I needed and told me who to contact in Ottawa when we move there."

"She talked about birth control and breast feeding."

"She helped me to get him on the breast and offered suggestions for breastfeeding that worked."

"She told me some things that I didn't know."

Sixteen of these mothers (39%) stated that community health nurses were helpful because they weighed and checked the infants when they visited. Twelve of these mothers (29%) felt this hands-on care provided reassurance that their infants were progressing well.

"She weighed the baby to see if he was gaining weight."

"She weighs her and charts her growth. She does a developmental test which I watch and find reassuring because it shows she's well beyond her corrected age."

"She came by after J. had been home a week and weighed him -- that really settled my worries about whether he was gaining and whether I had enough milk."

"When they had colds, she came right away and listened to their chests and reassured me that they were fine -- I felt relieved after she came."

Thirteen mothers (32%) stated that community health nurses were most helpful for the emotional support they offered.

"I enjoy her supportive phone calls. At first I thought they were a nuisance but now I rely on contact with her."

"She stayed for a few hours and was helpful and supportive."

"She's easy to talk to and discuss things with."

"She called me when J. was still in the hospital and gave me emotional support."



"She talked to me for hours and was really supportive when C. was still in the hospital -- she has become a really good friend."

"She was good support because I knew there was someone out there locally who could help."

"She gave me so much support -- a different kind of support than I get from my husband. When he ran out of support and got a little frustrated with my constant crying she was always there."

Seven of these mothers (17%) reported community health nurses were helpful because they were available. These mothers felt that they could phone community health nurses if they were experiencing problems, if they had questions about their infants, and if they needed the community health nurse to visit again.

Finally, mothers were asked how support from community health nurses could be improved. The predominant response to this question was that community health nurses required more knowledge and expertise concerning the care of premature and high-risk infants.

"They need to be able to trouble shoot with the apnea monitor -- they need more knowledge about apnea, bradycardia, SIDS, and home monitoring. I felt like I was teaching the nurse."

"I knew more about A.'s condition than she did."

"She was a new community health nurse and didn't have experience with premature babies. She asked me about premature babies but did understand what I told her."

"She looked her over but I don't think she knew a lot about premature babies."

"She should read up on the case before she comes to visit. If she didn't know about his condition, she shouldn't have bothered to come and visit him."

"She didn't have the same knowledge as the neonatal nurses."

"She was trained to deal with the average baby and mother -- she got more from me than I got from her."

Mothers also suggested that community health nurses should visit immediately after the high-risk infants were discharged home and that a second visit should be a regular pattern.

**TABLE 11**  
**MATERNAL PERCEPTIONS OF CARE RECEIVED FROM**  
**COMMUNITY HEALTH NURSES**

Variable	Class	N (%)
FREQUENCY OF VISITS FROM COMMUNITY HEALTH NURSES	WEEKLY	4 ( 8%)
	EVERY 2 WEEKS	4 ( 8%)
	LONGER INTERVALS	9 (18%)
	VISITED ONCE	24 (48%)
	DID NOT VISIT	9 (18%)
RATE USEFULNESS OF VISIT (41 mothers)	VERY USEFUL	18 (44%)
	SOMETIMES USEFUL	16 (39%)
	NOT USEFUL	7 (17%)
HOW COMMUNITY HEALTH NURSE USEFUL (41 mothers)	INFORMATION, ADVICE	25 (61%)
	PHYSICAL ASSESSMENT	16 (39%)
	EMOTIONAL SUPPORT	13 (32%)
	AVAILABILITY	7 (17%)
HOW COMMUNITY HEALTH NURSES CAN IMPROVE SUPPORT (41 mothers)	MORE KNOWLEDGE ABOUT HIGH-RISK INFANTS	16 (39%)
	IMPROVED TIMING OF VISITS	3 ( 7%)

### Additional Findings

Several other areas of interest were explored in the interviews and will be outlined in this section. These include mothers' perceptions of the experience of expressing breast milk for their premature infants, maternal perceptions of communication with health care professionals, and advice given by mothers participating in the study to future parents of high-risk infants.

#### The Experience of Expressing Breast Milk for a High-Risk Infant.

Of the 50 mothers participating in the study, 44 (88%) expressed breast milk for their high-risk infants while the infants were in hospital. Mothers expressed their milk from 5 to 143 days; the mean length of time mothers expressed breast milk was  $35.88 \pm 29.4$  days.

Data concerning infant feeding practices at discharge and six weeks after the infants were discharged home are summarized in Table 12. Mothers reported lack of success in breast feeding their high-risk infants in hospital and after discharge. Although 58% of mothers breast fed their infants when they took them home, only 38% continued to breast feed six weeks after discharge. One-half of these mothers felt they received enough help and support to breast feed their high-risk infants in hospital while one-half reported receiving only some help or no help at all.

**TABLE 12**  
**INFANT FEEDING IN HOSPITAL AND AFTER DISCHARGE**

Variable	Class	N (%)
MOTHERS EXPRESSING BREAST MILK	YES NO	44 (88%) 6 (12%)
ROUTE OF FEEDING AT DISCHARGE	BREAST BOTTLE BREAST AND BOTTLE	12 (24%) 21 (42%) 17 (34%)
ROUTE OF FEEDING SIX WEEKS AFTER DISCHARGE	BREAST BOTTLE BREAST AND BOTTLE BREAST AND CEREAL BOTTLE AND CEREAL	13 (26%) 27 (54%) 4 ( 8%) 2 ( 4%) 4 ( 8%)
SUPPORT TO BREAST FEED IN HOSPITAL (OF 29 BREAST- FEEDING MOTHERS)	RECEIVED ENOUGH HELP RECEIVED SOME HELP RECEIVED NO HELP DID NOT NEED HELP	14 (48%) 8 (28%) 2 ( 7%) 5 (17%)

Mothers were asked what factors influenced their decisions to express breast milk for their infants and to eventually breast feed. Six mothers stated they felt obligated to express their breast milk and pressured to produce enough milk for the infants. Sixteen mothers stated that expressing breast milk was physically demanding and difficult, and nine mothers felt that the experience was not a positive one. Fourteen mothers stated they stopped expressing milk because their milk supply diminished and they were not producing enough milk to feed their infants. Comments include:

"The time commitment is heavy. I had trouble getting enough milk."

"Eventually I wasn't getting enough so I just stopped."

"It was just not the same as nursing your baby -- it's so much easier when the baby goes right to breast -- you don't feel the same when you're pumping."

"It's hard on a woman to pump -- it's just not womanly."

"It's hard to pump every three hours. You set your alarm and sit and pump for 20 minutes. If the baby is crying you get up -- it's hard to get up to the pump."

"I stopped because I just couldn't handle it anymore. I felt like a cow machine -- it was just awful."

"I knew how important it was for her but it was just so awful to do. It was worse than having the baby -- it was so painful for me to pump milk for her."

Ten mothers stated that after pumping their milk for several weeks, their infants would not breast feed.

"The baby just wouldn't nurse. The LaLeche league tried to help but they're not tuned in to premature babies."

"I stopped because he wasn't feeding well at home and wasn't gaining weight after one month."

"D. wouldn't feed and C. just fooled around so I decided that bottle feeding would be much easier."

"It was scary not being able to breast feed her after all those months of pumping. I really wanted to breast feed her but she just couldn't do it and I felt bad."

"It was disappointing not to be able to breast feed T. I wonder how many other mothers are unable to breast feed their premature infants."

Several mothers (n=5) suggested that improved support for breast feeding while in hospital would have made a difference. Conflicting information about breastfeeding was cited as one problem. Mothers suggested that a nurse with expertise in breast feeding would be helpful to start mothers breast feeding immediately and to continue to support mothers through this process.

#### Communication With Health Care Professionals

Respondents were asked to rate their communication with doctors and nurses in NICU and ICN, and to comment on how well informed they felt while their infants were in hospital. The majority of mothers commented that communication with nurses was good while communication with physicians was fair to poor. These results are summarized in Table 13.

**TABLE 13**  
**COMMUNICATION WITH HEALTH CARE PROFESSIONALS**

Variable	Class	N (%)
COMMUNICATION WITH NURSES IN NICU	GOOD	34 (87%)
	FAIR	5 (13%)
	POOR	0 ( 0%)
	NA	11
COMMUNICATION WITH NURSES IN ICN	GOOD	32 (70%)
	FAIR	14 (30%)
	POOR	0 ( 0%)
	NA	4
COMMUNICATION WITH DOCTORS IN NICU	GOOD	19 (49%)
	FAIR	9 (23%)
	POOR	11 (28%)
	NA	11
COMMUNICATION WITH DOCTORS IN ICN	GOOD	9 (20%)
	FAIR	18 (39%)
	POOR	19 (41%)
	NA	4

Note: NICU = Neonatal Intensive Care  
 ICN = Intermediate Care

Themes that emerged from qualitative data give insight into these ratings. Mothers commented that in general they were well informed about their infants, and in particular found nurses approachable and communicative. They reported:

"We were kept well-informed."

"If the nurses didn't know the answers they found it out. We always felt well-informed."

"We were told what we wanted to know."

"It was great -- a little too technical at times, but things were explained when we asked."

"I had all my questions answered and was well-informed."

"I was kept well informed by the nurses. I didn't see the doctors very often but the nurses kept me well informed about the babies."

Thirty mothers commented that communication was inadequate, particularly from doctors.

"It was frustrating to get information in NICU -- we wanted the story behind the story and didn't get the information we wanted."

"We didn't talk to a doctor until our baby was ready for discharge -- we would have liked to meet with a doctor periodically."

"No effort was made on the part of the doctors to communicate with parents."

"Before discharge she had an eye examination and the doctors made arrangements for eye surgery without our knowledge -- we were told later and hadn't even been aware there was anything wrong with her eyes."

"We had zilch information and communication from the doctors -- the resident doctors never talked to the parents -- they went through the nurses to give information to the parents."

"The doctors tell you nothing -- they are very disparaging. If I asked a question they told me to call my pediatrician -- do you know how long it takes to get hold of your pediatrician?"

Mothers reported that information was not given voluntarily and that they had to know what to ask to get the information they wanted.



"We had to ask the nurses for information -- they didn't volunteer it."

"When you could track down the doctors they told you what you wanted to know."

"Some of the nurses kept us well informed -- others we had to ask for information -- they didn't volunteer it."

"You have to push for information -- not be passive about it."

Six mothers commented that they wished access to the baby's chart and resented not being permitted to look at it.

#### Advice to Future Parents of High-Risk Infants

Mothers unanimously reported that having a high-risk infant was a stressful experience for the whole family and that the stress continued after the infant was discharged home.

"Having a premature baby is such a major thing. The baby receives so much care and attention in the hospital -- you have to gown and take such precautions -- then bingo, he's home and that's it -- you're like anyone else with a new baby. It's really scary to take him home -- the lack of care and attention he got at home was the hardest transition of all."

"It was a very stressful experience for us all. We learned that neonatology is such a new science with no set guidelines."

"It was a difficult experience -- a terrible experience -- but it was balanced by the wonderful NICU staff."

"The whole experience was an ordeal. It was a time of incredible stress. When we took him home the stress continued -- because we weren't sure he was really ready to come home. The competent and wonderful nursing staff made it bearable for us though."

Mothers suggested that adequate information is necessary to cope with a high-risk infant in hospital and after discharge. They advised future mothers to learn all they can about their infants before they take them home.

"Don't hesitate to ask questions -- do everything you can to learn about your infant."

"Try to spend the whole day with your infant before you take him home. Sit in ICN and get to know your baby -- it might be boring but it's how to learn all about your baby before you take him home."

"Be prepared that your baby is no longer a newborn and will have different sleep patterns and eating patterns and will want to be awake more."

"Ask a lot of questions in the hospital before discharge -- because there's so many things you don't know about your baby and you'll have to learn them by yourself at home."

"Read everything you can to learn about your baby. Be stubborn and keep asking questions. The knowledge will give you confidence to care for him when you get home."

Mothers suggested a variety of resources that were helpful in caring for their infants at home. These included the pamphlets left by community health nurses, films about premature babies which they watched while their infants were still in hospital, parent information books given to them when their infants were admitted to a high-risk nursery, and specific books about premature infants. The most commonly cited book was "The Premature Baby Book" by Helen Harrison.

Mothers advised utilizing the supports that are available to parents and organizing additional support before the infant is discharged home.

"Contact a parent support group -- even verbal support is great during this stressful time."

"You need support at home -- it's even more stressful after discharge."

"It would be helpful to talk to someone who's been through it."

"It's nice to know support is close by if you need it."

"Get supports into place -- be aware of what's available and have it organized for when you come home with twins -- it's better to have it there and find you don't need it than to need it and not have it there."

"Don't feel guilty about needing the extra support. Admit you need it and get help before you fall apart."

"Parents need to support each other . It's not fair for the father to have to support the mother all the time -- the father is just as vulnerable at this time."

"A support group of parents who have been through this would be helpful -  
- but it's such a rare thing that it's not very feasible."

"Someone to talk to with the same problem would be helpful -- we could use a group of parents to support each other."

"The coffee party we had in NICU was great. It was a real break and the first time I had thought about things other than L. since he was born. It was really helpful to talk to another mom going through the same thing. We supported each other."

"We talked to other parents and it was very helpful -- we supported each other."

### Summary

Interview data were analyzed to describe concerns of mothers of high-risk infants in the postdischarge period, the effect of a high-risk infant on family life, and maternal perceptions of the help received from formal and informal sources of support. Data revealed that mothers of infants who required intensive

care had significant and continuing concerns after their infants were discharged home. Data also suggested that birth of a high-risk infant is a stressful experience for the family and that this crisis can continue in the postdischarge period.

These findings are addressed in the final chapter of this thesis. Implications for nurses who care for high-risk infants and their families in hospital and after discharge are discussed. In addition, educational programs and future research considerations are explored.

## CHAPTER VI - DISCUSSION AND IMPLICATIONS

Mothers of high-risk infants who participated in this study contributed to nursing knowledge concerning the common problems mothers experience when their high-risk infants are discharged home. In addition, respondents identified the persons to whom mothers of high-risk infants turn to for help and support during the transition from hospital to home care. Thus, the study contributed to an understanding of how mothers cope during this stressful time.

This chapter begins with an examination of the sample of mothers who participated in the research project and their high-risk infants. This is followed by discussion of the specific concerns mothers experienced during the transition from hospital to home, the effect of a high-risk infant on the family, and who mothers perceive as most supportive at this time. Implications for discharge planning and continued comprehensive community support are drawn.

## Sample Characteristics

As reported in the literature review (Chapter 3), parents of high-risk infants traditionally have been described as economically and socially disadvantaged. Their low socioeconomic status in turn has been associated with inadequate prenatal care and subsequent postnatal problems.

Schraeder (1986) reviews characteristics of mothers of low-birth-weight (LBW) infants and reports that LBW tends to occur in groups at high social risk -

- the poor, teenagers, racial minorities, and those with low educational achievement. The risk of premature birth in the United States is fifty percent higher among women in the lowest social classes than women in the highest, black women are twice as likely to have LBW children as white women, and LBW children are more likely to be born to very young mothers. Mothers who have less than high school education have higher rates of LBW infants. That is, LBW and neonatal illness are health-related expressions of economic, cultural, and racial inequalities in society.

Canadian statistics reflect American data concerning maternal variables associated with LBW infants. Doucet, Baumgarten and Infante-Rivard (1989) analyzed characteristics of mothers of LBW infants born in Montreal in 1987. Covariables associated with LBW include maternal age, education, and marital status. The authors report that mothers living alone have an increased risk of bearing a LBW infant.

Mothers who participated in this research project did not reflect characteristics typically associated with increased risk of LBW and/or neonatal illness. The mean age of mothers in the study was  $29.3 \pm 3.58$  years, mean educational level attained was  $13.54 \pm 2.62$  years, and all respondents were married or living common-law. Only nine families earned less than \$23,000 per year, twenty-one families earned between \$23,000 and \$43,000 per year, and twenty families reported income of over \$43,000 per year. The poverty line for families with one, two, and three children in Manitoba in 1989 was \$16,270, \$21,440, and \$24,706 per annum respectively (Statistics Canada, 1989). The majority of families

in this study, therefore, were able to provide food, shelter, and clothing for family members. All respondents were Caucasian with the exception of one mother who was a Native North American. The sample, therefore, in contrast to expected characteristics of mothers of LBW or ill newborns, consisted of women who were predominantly Caucasian, middle-aged, well-educated, and of middle to upper socioeconomic class.

The sample represented 91% of eligible mothers who met the criteria for inclusion in the study and who considered participating in the research project. However, mothers of infants who died during this time period, and mothers who lived outside of the 160 kilometer radius of Winnipeg city were not included in the sample. These criteria excluded a population of Native North American mothers living outside of Winnipeg whose high-risk infants required neonatal intensive care. The mothers who participated in the research project appear to be atypical of the socially and economically disadvantaged populations usually associated with LBW and neonatal problems. Further data concerning characteristics of contemporary high-risk Canadian mothers are required to determine if the sample was biased by the selection criteria and/or if mothers of high-risk infants today are typically older, well-educated, and socially and economically established.

Infants of mothers in the study were comparable to populations of high-risk infants admitted to neonatal special care, as described in previous Canadian and American research. The sample was characterized by a mean gestational age of  $32.86 \pm 3.75$  weeks, a mean birth weight of  $2018 \pm 788$  grams, and an average length of hospital stay of  $43.88 \pm 29.15$  days. The predominant reason for

admission to neonatal special care was prematurity. Infants experienced complications during the neonatal period that are typical of infants admitted to neonatal special care. Complications included respiratory distress, apnea, intraventricular hemorrhage, bronchopulmonary dysplasia and feeding intolerance. Eighty-four percent of the infants were discharged home in good condition with no problems apparent at the time of discharge.

Thus while high-risk infants involved in the study were comparable to populations of high-risk infants today, mothers in the study differed from populations of mothers traditionally associated with LBW and neonatal illness. Economic and social characteristics of respondents and the favorable condition of the majority of infants at discharge presuppose one to expect that mothers in the study might cope with the crisis of home care with less difficulty than socially and economically disadvantaged groups.

#### Transition After Discharge From Neonatal Special Care

Mothers experienced a renewed crisis when their high-risk infants were discharged home. Numerous studies have documented the stress and concerns of mothers during the transition period from hospital to home care (Censullo, 1986; Goodman & Sauve, 1985; Eikner, 1986; Kenner & Lott, 1990). The present study supports these findings.

Although 84% of mothers participating in the study stated they felt prepared to care for their high-risk infants at home, 74% expressed feelings of apprehension,



fear, and anxiety in the immediate postdischarge period. Mothers of normal term infants report concerns about general infant care and stressful life changes that occur when their infants are discharged home (Belsky, 1985; Harriman, 1985). Mothers of high-risk infants in this study, however, reported several specific concerns that were predominant at this time, in addition to concerns about infant care and family reorganization. These included concerns for the infants' respiratory status, continued growth, and developmental progress. Other studies suggest that these are realistic and valid concerns for high-risk infants in the postdischarge period, and that high-risk infants remain vulnerable to recurrent illness and developmental delay in the first few years of life (Sells, Neff, Bennett & Robinson, 1983; Turner, 1988; Mitchell & Najak, 1989).

Ninety percent of mothers felt they needed more information concerning the unique characteristics and needs of their infants in order to care confidently for the infants at home. Mothers stated that provision of comprehensive, consistent, and realistic information would have enhanced discharge preparation. This need is documented in previous research and through personal accounts of the experience of neonatal illness and the long-term problems which may arise in the first few years of life (Cagan & Meier, 1979; Cagan & Meier, 1983; Brooten, Gennaro, Knapp, Brown, & York, 1988; Arensen, 1988; Eikner, 1986).

Four percent of the high-risk infants in the sample were rehospitalized in the first six weeks after discharge. This incidence of rehospitalization supports findings concerning the increased risk of rehospitalization for infants who were ill or premature at birth (Sells, Neff, Bennett & Robinson, 1983; Mitchell & Najak,

1989). Arenson (1988) reports that infants who require special care at birth are at even greater risk for rehospitalization if discharge teaching is absent or incomplete. Unstructured, unsystematic, and undocumented teaching is common in many neonatal special care units, and this teaching is frequently carried out on the day the infant is discharged home. In addition, discharge planning often centers on the healthy premature infant. Few centers have structured teaching plans to prepare parents to care for chronically ill infants at home.

Mothers of high-risk infants in this study experienced inconsistent and unstructured discharge planning. While one neonatal centre utilized a "discharge plan" and encouraged some mothers to "room-in" and participate in infant care, the other centre had no structured or formal plan for discharge teaching. Mothers who "roomed-in" and participated in infant care felt more prepared to care for their high-risk infant at home than mothers who were not given these opportunities. Guidelines for discharge planning are presently being developed and improved in both neonatal centres.

Discharge planning guidelines are essential to prepare parents to adequately care for their high-risk infants at home. These guidelines should include knowledge of general infant care as well as the unique and special care needs of the infant, knowledge of infant feeding, preparation for medication administration when necessary, advice regarding preparation of the home environment, and knowledge of follow-up care. Discharge planning should be designed to standardize the information presented to parents, to prepare parents realistically concerning

expectations for the infant and family, and to minimize the crisis that parents experience during the transition from hospital to home care.

Miles (1989) recently found that inadequate communication between parents and health care professionals was one of the most stressful aspects of the parental experience of having an infant in intensive care. Parents indicated they were not told enough about the infant's condition, tests, treatments, and the various complications of prematurity and neonatal illness. Mothers participating in this study revealed similar difficulties in receiving adequate information concerning their infants during the hospital stay. Although communication with nursing staff was favorable in general, 28% of mothers in NICU and 41% of mothers in ICN rated communication with physicians as poor. These mothers stated that physicians were unavailable and/or unwilling to converse with parents and that communication with physicians often was disparaging and frustrating. Parents expressed the need to know "the story behind the story" and resorted to seeking out and reading articles and books on prematurity and neonatal illness to meet this need.

Respondents suggested that information and discharge planning must be realistic. Mothers felt they should not be advised to treat their infants "like a normal baby" when in reality they were not. Eikner (1986) states that it is inappropriate to continue reassuring all parents of high-risk infants that "over 80% of premature infants will be normal". This represents false hope when infants have suffered certain events (grade IV intraventricular hemorrhage or seizures for example) which change their course in hospital and after discharge. False hope and overly optimistic prognoses are cruel in several ways. They may delay family

efforts to deal with the child's situation and to make adjustments in their lives, as well as delay efforts in seeking early intervention and appropriate therapy for the child.

From responses of mothers in the study, it is evident that health care professionals must recognize the need to communicate honestly and openly with parents of high-risk infants. They must acknowledge that parents are partners in the infant's care and the individuals who must deal with long-term problems after discharge. Increased respect for parents and their right to be involved in decisions concerning their infants may result in improved communication among members of the health care team, reduction in parental stress, and enhanced preparation for the infants' discharge home.

The key to successful transition from hospital to home care is for parents to take over all aspects of the care of their infants comfortably while in hospital. This provides opportunity for parents to learn the care which their infants require and to become acquainted with their infants' unique personality and behavioral traits. Mothers participating in the study commented that they "did not know" their infants prior to discharge and that they were unprepared for the personalities and behaviors of the infants at home. Many mothers, for example, had never heard their infants cry. This lack of knowledge hampered adjustment in the postdischarge period.

Mothers reported that participation in infant care helped them learn about their infants. Bathing and feeding infants in hospital provided hands-on experience and a more intimate knowledge of the child. Several mothers "roomed-in" with

their infants for 24 to 48 hours before the infants were discharged home. These mothers considered this to be a most valuable learning experience and suggested that all mothers of high-risk infants be encouraged to do the same. Ninety-two percent of mothers however, had not been given opportunity to spend an extended period of time with their infants prior to discharge. Eighty percent of mothers who had not "roomed-in" would have considered "rooming-in" before discharge had the opportunity been presented.

Salitross (1986) reports that units that encourage "care-by-parents" increase parental confidence and ability to care for the infants at home. Environments that accommodate "rooming-in" provide a unique opportunity for mothers to learn about their infants' distinctive needs with professional reassurance close by. Unfortunately, limited resources and restricted space preclude "rooming-in" in some neonatal centers. Every attempt should be made to encourage this valuable learning experience whenever possible.

Maternal worries about feeding premature and sick infants are reported in several research studies which document maternal concerns after discharge. For example, Brooten and colleagues (1989) reported that breast feeding was a particular problem for mothers of high-risk infants, partially because the mothers had little opportunity to breast feed their infants regularly while the infants were in hospital. Mothers in this study reported similar concerns. Eighty-eight percent of mothers expressed their breast milk for their sick and premature infants for an average of  $35.88 \pm 29.4$  days. At the time of discharge, 58% percent of mothers were feeding their infants by breast or by a combination of bottle and breast. Six

weeks after discharge, however, only 66% of mothers who breast fed at discharge, and only 43% of mothers who expressed their milk in the neonatal period continued to successfully breast feed. Respondents provided insight into this lack of success.

Fifty percent of mothers who expressed their milk for their infants stated that the experience was not positive and that the regime necessary to provide expressed milk for the infants was physically demanding and difficult. Predominant reasons why mothers stopped expressing milk or breast feeding their infants included the demands of expressing milk, a diminishing milk supply, and the fact that the infants were unable to successfully breast feed. Mothers reported feelings of failure when they were unable to nurse their infants after months of expressing their milk. Several respondents suggested that early and consistent instruction and support from an "expert" would have made a positive difference. Broton and colleagues (1989) report that mothers of high-risk infants required concentrated teaching to breast feed their infants in hospital and after the infants were discharged home. The neonatal centers involved in the research project do not employ breast feeding specialists or coordinators. Employment of such a person may be one way to improve the success of breast feeding for mothers of premature infants.

### The Effect of a High-Risk Infant on the Family

The discharge of a healthy premature infant is extremely stressful for the family. Added demands of caring for a chronically ill infant can intensify this stress

and permanently change the family (Arenson, 1988). Researchers suggest that home care of an infant who was premature or ill results in dramatic life style changes which inevitably affect the family adversely (Salitross, 1986; Arenson, 1988). The sick infant becomes the center of family life. Siblings are often left out during the infant's hospitalization and find that their isolation continues when the infant comes home. Families become socially and emotionally isolated through the demands of caring for the infants at home. Marriages often suffer and many dissolve due to the effect of long-term stress. The effect of the birth and home care of a high-risk infant on family life was examined in this study. Respondents reported that spouses, siblings, and members of the extended family were affected by the infant's birth and that family routines were altered when the high-risk infant was discharged home.

While the majority of respondents stated that the experience of having a high-risk infant had improved relationships with their spouses and drawn them closer together as a couple, 12% of respondents felt their marriages had been adversely affected by the infant's birth. Mothers stated that the demands of caring for the high-risk infants left no time for their spouse, and that spouses were negatively affected by the stress of an irritable and sick infant in the home. Maternal responses are consistent with reactions of parents of high-risk infants reported in previous research studies. Couples of high-risk infants report fewer occasions to go out together, less frequent sexual activity, and less agreement on family matters (White & Dawson, 1981). Fathers of high-risk infants acknowledge having their patience tested by their infants, even though they assumed the least

responsibility for infant care (White & Dawson, 1981). Similar data were found among study respondents within six weeks of the infants' discharge home. This supports the assumption that birth of a high-risk infant may be disruptive to the marriage relationship.

The majority of mothers reported other children were coping well with their new sibling at home. Forty-three percent of mothers with other children reported siblings expressed love, pride, and protectiveness towards the infant, while fourteen percent reported a mixture of love and jealousy from other children. Twenty-one percent of mothers reported negative reactions from other children to the birth and illness of this sibling. Reactions included jealousy and fear that the new baby would not survive. Mothers reported they did not have substantial time for other children once the high-risk infants were home. Spouses and close relatives were helpful when they volunteered to spend time with other children and assisted with babysitting, carpooling, and bedtime routines.

Schum (1989) suggests that siblings often experience the most deleterious effects of childhood and neonatal illness. Siblings' lives are disrupted by the absence of their mothers during their frequent visits to the hospitalized infant or child. As a result, siblings are often left with babysitters or relatives, and their sleeping, eating and napping routines are disturbed. Major changes in the environments in which siblings are cared for, and changes in caretakers responsible for these children, precipitate normal developmental reactions to unusual stress. These reactions include crying, clinging and regression, and may last three to six months after the stressful event has resolved. Although the majority of mothers in



this sample reported that other children had adjusted to the stress of a sick sibling, latent reactions to this stressful situation may continue to develop over time.

Blackburn and Lowen (1986) call grandparents the "forgotten grievers" in the event of neonatal illness. They report that when a grandchild is critically ill, grandparents may feel helpless and frustrated, and in need of support. The authors state grandparents often experience a triple grief as they grieve for the grandchild, the infant's parents, and themselves. Unfortunately, this grief often goes unrecognized. Respondents in the study report grandparents expressed considerable concern about their sick grandchildren. Visiting restrictions, however, kept them from becoming more involved. Other extended family members felt excluded as well.

The visiting policies of the neonatal centers where the study took place resulted in added stress for mothers who required the support of extended family members. Mothers report that visiting restrictions preclude the birth from becoming a "family affair". When family disruptions due to neonatal illness are inevitable, restrictions that result in increased family stress must be recognized and reassessed.

In the study, mothers were asked how they felt about their infants and whether the infants "fit into" a family routine. Only 34% percent of respondents stated that the infants "fit easily" into the family routine. The majority felt this transition process took a few days to a few weeks. Erratic sleep-wake patterns, and infant irritability and "fussiness" were reported as most disruptive to family routines.

Researchers have suggested that premature infants are less rewarding to care for than full term infants (Als & Brazelton, 1981). Interactional deficiencies, fussiness, lack of responsiveness, and disorganized behavior are characteristics of infants who were premature or ill at birth. These factors contribute to difficulties in parenting the infants. Personal observation of behaviors of infants at six weeks postdischarge reinforce validity of this research. Mothers cited difficulties soothing and pleasing infants, and these difficulties were observed during interviews with respondents. Mothers expressed surprise when the researcher informed them that premature or sick infants are frequently described as "fussy" babies who are difficult to soothe. Mothers stated this knowledge would have helped them to understand that "fussy" infant behavior was "normal" and therefore, not their fault. The knowledge would have assisted mothers in parenting the infants. Culp, Culp, and Harmon (1989) document that enhanced parental awareness of the behavioral characteristics of premature and ill infants results in more realistic expectations for the infants. Consistently addressing this need may result in less family disruption and fewer parenting problems in families of high-risk infants.

Mothers reported feelings of guilt when their high-risk infants were born. In spite of repeated assurances from health care professionals, mothers continued to feel that the infants' prematurity and/or subsequent health problems were their fault. Guilt is an intense feeling of having done something wrong, either by commission, omission, thought, or action. Whetsell and Larrabee (1988) report that guilt is one of the primary and often most intense emotions parents experience following the birth of a sick or premature infant. Guilt can interfere with parental attachment to

infants and acceptance of parental role. Long-term effects of unresolved guilt may interfere with mental health, marriage relationships, and parent-infant interaction.

Health care professionals must address unresolved guilt in the postdischarge period. They should engage in active listening which encourages verbalization of guilt, and respond in a manner that affirms that guilt is a normal reaction which can become detrimental if not addressed. Emotional states appear to be related to later parenting difficulties (Caplan, 1960; Kaplan & Mason, 1960; Steele, 1987). Dealing constructively with guilt in the postdischarge period is essential to more positive caretaking roles.

Parents may experience feelings of low self-esteem, failure and inability to cope when their high-risk infants are discharged home (Steele, 1987; Butts, 1988). These feelings may be just as intense as when the high-risk infants were born. Mothers of high-risk infants in this study expressed concerns about their infants and their families six weeks after the infants were discharged home. These concerns support the assumption that the birth of a high-risk infant affects all members of the family unit.

#### The Need For Social Support in the Postdischarge Period

Social support may buffer the effect of stressful life events and enhance coping (Gottlieb, 1983; Hogue, 1985; Heaman, 1987). Mothers participating in this research project were asked whether they required social support after their high-

risk infants were discharged home, whom they turned to for help and support at this time, and which sources of social support were most helpful to them.

### Informal Support

Mothers identified members of their immediate and extended families as most supportive to them after their high-risk infants were discharged home. Sixty-six percent of respondents identified their spouse and 30% identified a close relative (most often their mother) as their most valuable source of support. Respondents stated they relied on these individuals for emotional and tangible support, and felt they would have experienced more difficulties coping, had these individuals not been available to them.

Many researchers have found a similar pattern in adaptation to childhood or neonatal illness. Trute and Hauch (1988) found that families adjusting to the birth and home care of a disabled infant appear to have a small, intense network of friends and extended family which provide different types of human support. Affleck, Tennen, Allen and Gersham (1986) report that mothers of infants who required intensive care approached their spouses and their own mothers for emotional support. Kenner and Lott (1990) report that spousal support is very important to parents following the discharge of their infants from NICU. This study supports these findings.

Seventy-eight percent of mothers stated that they talked to their spouses when they had concerns about the infant, and that they were helped with the

problem 62% of the time. Sixty percent of mothers talked to a close relative when they were worried about the infants and received helpful advice 56% of the time. Mothers identified the support received from family and friends as help they had expected to receive 58% of the time, and as more help than they had expected 36% of the time. It appears that close family networks supported the majority of respondents in the study, and that these family networks positively affected adaptation to the high-risk infants after they were discharged from intensive care.

While 58% of mothers reported they had talked to a friend or neighbour, and 54% identified a friend or neighbour as helpful since the infants were discharge home, only 4% identified these sources as most supportive and helpful. Kenner and Lott (1990) found that the majority of parents of high-risk infants did not view friends and neighbours as supportive because the majority of these individuals did not understand what it was like to have a "sick" infant. Zarling, Hirsch, and Landry (1988) found that friends and neighbours are generally nonsupportive to mothers of high-risk infants after the infants are discharged home. These individuals are often unclear how to respond to the birth of a sick or premature infant and may react ambivalently or negatively to the mother and child. Mothers in this study similarly did not identify friends and neighbours as a predominant source of social support. The availability of more intimate support however, may have lessened the need for support from friends and neighbours after the infants were discharged home.

Ninety-six percent of mothers reported they were coping very well or fairly well six weeks after their high-risk infants were discharged home. In spite of

continuing worries and concerns for the infants, mothers coped well with the crisis of their infant's home care. This finding is not surprising given the family support received by the majority of mothers after their infants were discharged home. Only one mother reported she was not coping and needed help. This mother of high-risk twins reported she had received less help than expected from family and friends, and identified a hired homemaker as her most helpful source of social support. She further reported that her marriage had deteriorated since the infants were discharged home, and that her spouse was not supportive. This represents the only report of difficulty coping at this early postdischarge stage and it must be acknowledged that high-risk twins present an even greater challenge than one LBW infant. This mother's responses emphasize the importance of family support in adaptation to the home care of high-risk infants.

### Formal Support

It is generally accepted among health care professionals that the NICU graduate requires health care of a different quality and quantity than the normal newborn (Ariagno & Glotsbach; Berger & Schaefer, 1985; Censullo, 1986). Both the infant and family experience added stress during the transition from hospital to home care, and are vulnerable to the effects of stress on the family health and well-being. Although families often feel overserved while the infant is still in hospital, many feel abandoned by health care professionals after discharge, when the need for support may be most intense. Health care professionals must recognize

that ongoing community care and support are essential to alleviate the crisis which accompanies the discharge of a high-risk infant from hospital. Continued care and support may ensure adaptation of the family unit to the crisis of high-risk birth.

Providers of formal support can supply many resources valued by individuals who are coping with stressful life events. Resources include opportunities for the expression of distressing feelings, information about the problem, advice and feedback about different efficacious problem-solving strategies, and concrete aid. Mothers participating in the study were asked whether they required continued formal support and whether they received adequate support from health care professionals after their high-risk infants were discharged from hospital, whom among health care professionals was most supportive to them at this time, and why these individuals were considered a valuable source of formal support.

Mothers reported a continuing need for comprehensive support from health care professionals after their infants were discharged from intensive care. All mothers approached health care professionals on a regular basis to receive health care advice and reassurance that their infants were progressing well. Seventy-two percent of mothers reported receiving help and advice from pediatricians, 30% from general practitioners, and 58% from community health nurses. A smaller percentage of respondents utilized hospital nursing staff, social workers, and other sources of support.

Respondents in this study support research findings which suggest that parents of high-risk infants utilize professional assistance to help them care for high-risk infants in the home. Affleck, Tennen, Allen and Gersham (1986) report

mothers of infants who required intensive care rely on pediatricians for informational support. Crnic, Greenberg and Slough (1986), while not differentiating among sources of professional support, report professional support, along with informal support networks, contributes significantly to later parent and infant competencies. Young, Creighton and Sauve (1988) document that parents of infants receiving continuous oxygen therapy at home rely on regular medical monitoring by physicians and pulmonary specialists. These authors report that subjective appraisal of the need for and adequacy of professional sources of emotional, informational, and tangible support were associated with the infant's postdischarge status. Mothers of high-risk infants needed support on a more frequent basis when the infants condition at discharge was relatively more severe. Mothers in general felt they received this support.

Respondents in this study reported health care professionals were considered supportive for several reasons. Mothers appreciated information and advice about the infants, reassurance that the infants were progressing well, and emotional support offered to the family unit. These components reflect House's (1981) typology of social support (i.e. emotional support, appraisal support, informational support, and instrumental support) and research that is more specific to support during neonatal illness (Affleck, Tennen, Allen, & Gershman, 1986).

The most predominant reason mothers rated health care professionals as most supportive, however, was their availability. Fifty-two percent of respondents reported that most supportive health care professionals were available on a constant



basis to provide the facets of social support listed above. This finding has implications for the provision of social support by community health nurses.

Respondents were asked to rate the care they received from community health nurses since their high-risk infants were discharged from hospital, and to discuss how community health nurses were supportive and/or nonsupportive during the six weeks infants were cared for at home. While 82% reported community health nurses had visited the home since the infants were discharged from hospital, nine mothers (18%) reported they had not seen community health nurses during this period of time. Two of these mothers had received phone calls from community health nurses, while six mothers were still waiting for community health nurses to call. Four of these six mothers stated that visits from community health nurses would have been helpful in the period immediately following their infants' discharge from hospital.

Mothers who had received visits from community health nurses were asked to rate the usefulness of the visits. Eighty-three percent rated the visit as very useful or fairly useful. This data is similar to a recent American survey in which more than 60% of mothers of high-risk infants rated visits from community health nurses as helpful or very helpful, and 85% recommended the community health nurse visit all families with high-risk infants in the home (Ritchie & Mertens, 1987).

Community health nurses were rated as helpful to mothers in this study for several reasons. These included the information and advice they offered, reassurance they gave concerning infant progress, and emotional support they extended to the

respondent. Support from community health nurses therefore reflects the components of social support described by House (1981). These components include emotional support, appraisal support, informational support, and instrumental support. Only 17% of respondents reported community health nurses were helpful because of their availability. These mothers appreciated the opportunity to phone community health nurses if they had questions concerning infant care, or if they required community health nurses to visit.

Suggestions to improve the care offered by community health nurses indicated respondents felt community health nurses were poorly trained in the care of high-risk newborns, and lacked the knowledge and expertise necessary to provide follow-up care to the infants and their families. This is not unexpected given community health nurses provide health care within a broad scope of practice, thereby precluding expertise in any one area of care. Samson (1989) and Noga (1982) recommend educational programs directed at high-risk neonatal follow-up as necessary for community health nurses to provide formal support to these infants and their families. Feedback from mothers of high-risk infants in this study lend support to the identified need for enhanced educational preparation of community health nurses involved in providing follow-up care.

Respondents also suggested community health nurses should reevaluate timing of their visits to improve community nursing care. Researchers have documented the first few days after high-risk infants are discharged from hospital as most stressful for the family. The daily regime for parents in this initial phase is time consuming and exhausting. Practical problems arise which were not an issue

during hospitalization. Many parents initially are afraid to fall asleep and spend many hours hovering over the high-risk infant. Kenner and Lott (1990) describe the initial reactions of parents when their high-risk infants are discharged home. During the first few days to weeks, parents see their efforts to care for the infants as "trial and error". Feelings of powerlessness which parents experienced when they first learned their infants required intensive care return as parents assume total responsibility for infant care. Parents express the need for more support than they expected to need in order to cope with actual infant care. Many parents express a need for follow-up care and social support in the immediate postdischarge period.

Mothers in this study reported the need for community health nurses to visit in the first few days after infants were discharged home. They also suggested a second or third follow-up visit would be useful. The study therefore, supports the need for follow-up care in the immediate postdischarge period, before scheduled visits to medical follow-up care. Community health nurses, if properly prepared, can offer this support in the immediate postdischarge period.

### Additional Findings

Although data were not collected with the intention of comparing populations within the sample, several observations of interest can be made. The researcher interviewed mothers of high-risk full-term infants as well as premature infants, presuming that the birth of a sick full-term infant is just as stressful an event as the birth of a premature infant. Respondents supported this assumption. Mothers of

the nine infants in the sample who were 36 weeks gestational age or greater reported significant concerns regarding their infants at discharge, continuing concerns six weeks after the infants were discharged home, disruption in marriage relationships, fear of having another high-risk infant with subsequent pregnancies, and difficulty coping in the postdischarge period. Thus, mothers of full-term infants who required special care experienced a similar crisis to mothers of premature infants. Considering the fact that neonatal illness after a full-term pregnancy is often unexpected and that follow-up programs are often directed at populations of premature infants, the need for nursing follow-up and support for mothers of full-term infants who have required special care may be even more acute.

Mothers residing in the city of Winnipeg and the rural area within a 160 kilometer radius of Winnipeg were interviewed in the study. All mothers from rural Manitoba were visited by community health nurses in the postdischarge period and the majority ( $n=14$ , 77%) identified community health nurses as helpful at this time. Forty-four percent of mothers from rural Manitoba ( $n=8$ ) identified community health nurses as their most supportive health care professionals since their infants were discharged home compared to only 18% of mothers ( $n=6$ ) from Winnipeg city who similarly identified community health nurses as their most valuable professional support. The availability of community health nurses in rural Manitoba, coupled with the unavailability of pediatricians, may have influenced maternal perceptions of the usefulness of community nursing support for mothers in rural centers who are caring for a high-risk infant at home.

### Application of the Research Findings to the Conceptual Framework

This study supports previous research which suggests that the birth and subsequent home care of a high-risk infant is a crisis event (Salitross, 1986; Arenson, 1988). Family systems theory and crisis theory assists researchers to understand the impact of the crisis of neonatal illness on the family system.

Hospitalization of a sick or premature newborn disrupts the family system. Subsystems which are affected include the parent-infant subsystem, the sibling subsystem, and the marital subsystem as well. When the high-risk infants is discharged home, family disruption may continue, escalate, or abate.

Crisis theory proposes that human beings strive to maintain a balanced state and attempt to restore that balance when disrupted. Resolution of crises typically involves mobilization of internal and external resources, and willingness to consider outside assistance and support. Disorganization and discontinuity of customary patterns of behavior are characteristic of a crisis event. Resolution of the crisis, return to former levels of effective functioning, or movement toward balance at a more dysfunctional level of functioning usually occurs in approximately six weeks.

A systems model of crisis intervention emphasizes the social context in which the individual and the crisis stimulus come together. An individual's ability to successfully resolve crises depends to a large extent on the availability of a supportive social network. This social network may include the individual's family, work groups, or the health care community.

Findings of this study emphasize that the discharge of a high-risk infant from hospital is a crisis for the family. Respondents reported that family roles and routines were disrupted during the transition from hospital to home care. Stress from infant care responsibilities were felt by the entire family system including marriage partners, siblings, and extended family members. Respondents reported a need for continuing support from formal and informal sources during this stressful period of time.

Mothers of high-risk infants utilized various sources of formal and informal support. Spouses and close relatives provided emotional support and concrete aid in an attempt to maintain family functioning. Health care professionals provided informational support and reassurance that infants were progressing well. Thus the social network assisted parents to cope with the crisis of caring for a high-risk infant in the home.

Respondents reported that support was especially valuable in the immediate postdischarge period when stress of the infant's homecoming was most intense. The majority of respondents felt that this crisis abated slowly during the six weeks following the infant's discharge home, and by six weeks after the infant's discharge, family members had succeeded in reestablishing family balance. One family with limited formal and informal support had moved toward a more dysfunctional imbalance.

Family systems and crisis theories aid in understanding the reactions and subsequent behaviors of families experiencing neonatal illness. Mothers in this study reported lack of time for other children, marital relationships that were strained,

difficulty incorporating the high-risk infant into family life, and family disorganization in general. The conceptual framework utilized in the study assists health care professionals to recognize and comprehend this initial family disorganization and subsequent adjustment in this crisis situation.

### Summary of Findings and Implications For Nurses

Respondents in this research study provided insight into the crises that occurred when their high-risk infants were discharged from hospital. Concerns for the infants and other family members in the immediate postdischarge period illustrate the unique problems that mothers of high-risk infants experience at this time. Mothers reported need for additional information and the need for continuing support in the postdischarge period. These needs and concerns can be addressed by nurses in the hospital setting and in the community.

### Informational Needs

In spite of stating that they were prepared to care for their infants at home, mothers of high-risk infants reported having to "muddle through" the first few days or weeks after their infants were discharged from hospital. They expressed a need for additional information concerning the infants and reported that this need was not addressed in hospital or after the infants were discharged home. In particular, mothers felt they lacked information concerning the unique characteristics and needs

of high-risk newborns, and their normal variations in behavior, development, and growth. Mothers also expressed concerns about weight loss and insufficient nutrition from breast milk and this was related to lack of breast feeding success. Thus inadequate information and lack of understanding hampered maternal adjustment in the postdischarge period.

Nurses can address the need for information which mothers of high-risk infants perceive. Hospital-based nurses can participate in comprehensive discharge planning programs and encourage mothers of high-risk infants gradually to assume responsibility for infant care. Implementation of these strategies may result in mothers "knowing" the unique personalities and needs of their infants before discharge and a less stressful transition from hospital to home.

Discharge planning should be initiated upon admission of the high-risk infants to special care and should continue through out the period of hospitalization. Utilization of a formalized discharge planning program ensures all relevant information is consistently addressed, yet allows nurses to concentrate on individual maternal and infant needs. In addition, mothers reported gaining intimate and practical knowledge of the infant through participating in direct infant care. "Rooming-in" is recommended as an excellent way to optimize the opportunity for mothers to learn the physical care needs as well as the unique personalities and behavioral traits of the infants.

Community-based nurses can provide information to mothers after their high-risk infants are discharged home. While the informational needs of mothers of high-risk infants often centered on specific care needs related to the diagnosis of the



infant, these mothers also identified a need for information concerning general well-infant care and normal expectations for infant growth and development. The extensive general knowledge of community health nurses and their awareness of supportive community agencies and services can assist mothers at this time. Community health nurses, however, must be available for mothers when the need for information is greatest. This entails contacting all mothers of high-risk infants within the first few days after the infants are discharged home.

Expertise in the care and problems of high-risk infants is necessary to provide mothers with the specific information they require in the postdischarge period. Community health nurses can attain this expertise through additional educational preparation in neonatal intensive care. Since mothers of high-risk infants in this study reported lack of specialized knowledge as a limitation of community nursing care, educational programs for community health nurses should be considered.

While there remains a dearth of information concerning the nursing care requirements of mothers and their high-risk infants in the community, results from this study suggest that follow-up by nurses who specialize in the care and problems of high-risk infants is necessary. Hospital-based nurses with expertise in neonatal intensive care can provide many advantages to high-risk infants and their families after the infants are discharged home. Extensive knowledge of prematurity and neonatal illness enables these nurse "experts" to provide mothers of high-risk infants with the information and advice they need. In addition, knowledge of each infant's illness, complications, and long-term sequelae facilitates the recognition of potential

health problems. Clinical nurse specialists, therefore, can address the unique community nursing needs of high-risk infants and their families.

### The Need For Continuing Support

Respondents reported that social support was necessary to cope with the discharge of a high-risk infant from hospital. Spousal support was especially important and played a predominant role in family adjustment. Close relatives were considered a significant source of support as well in this stressful transition period from hospital to home care.

In addition to informal support, however, mothers continued to rely on health care professionals to provide reassurance and emotional support. Community health nurses and pediatricians were most frequently identified as valuable providers of continuing social support. Community health nurses were valued as individuals mothers could talk to, who were willing to listen, and as combinations of friend, social worker, and nurse.

Mothers expressed a need for emotional support in the immediate postdischarge period. Nurses in NICU or ICN should be available to mothers in the first few days after the infant is discharged home. Mothers should be encouraged to phone the neonatal unit after their infants are discharged if they have concerns or require emotional support. The availability of neonatal nurses provides a supportive option during the stressful transition from hospital to home.

Mothers identified a need to talk with other parents who are experiencing or have experienced similar neonatal crises. Informal parent-to-parent support which occurred in neonatal units among parents whose infants were similarly ill was reported to be an especially valuable emotional outlet. Parent volunteers have successfully offered this informal support in several neonatal units. The organization and implementation of a parent support network could provide continuing support to mothers of high-risk infants before discharge and after their infants are discharged home.

#### Limitations of Research Project

This study has several limitations. Because a descriptive research design was employed, causal relationships cannot be tested. This research could be classified as *ex post facto*: "Instead of introducing or manipulating independent variables, the investigator selects subjects who have undergone some life experience" (Wilson, 1985, p. 157). The nature of this research precluded pretest observations since the treatment (prematurity and/or neonatal illness) was implemented before the research began. Thus cause and effect relationships between the stress of caring for a high-risk infant at home, the support necessary during this time, and the effect of a high-risk infant on the family cannot be established. However, the goal of the study was to describe maternal perceptions of the experience of neonatal illness and need for continuing help and support. Thus cause and effect relationships were not expected and this limitation does not adversely affect the study.

The use of non-probability sampling is another limitation of the study. Non-probability sampling may have introduced bias, since every member of the population from which the sample was drawn did not have an equal chance of being selected. The convenience sample utilized in the study limits generalizability of the results to the study respondents who voluntarily participated in this study. These respondents were predominantly Caucasian, married, twenty to thirty years of age, had attained at least high-school education, and the majority were earning over \$23,000 per year. As previously discussed, respondents were atypical of mothers characteristically associated with LBW and neonatal illness. Non-probability sampling contributed to this bias. In addition, criteria for inclusion in the study limited participants to mothers who were English speaking, to mothers who lived in Winnipeg or within a 160 kilometer radius of Winnipeg city, and to mothers who could be contacted by telephone.

Time and resource constraints did not permit utilization of a longitudinal research design. Although crisis theory suggests that crisis resolution occurs within a six week period, this short-term followup of mothers caring for high-risk infants in the home may be insufficient to appreciate the long-term effects of this neonatal crisis.

Mothers in the study appeared hesitant to criticize health care professionals providing follow-up care. The fact that the investigator is a nurse may have influenced mothers to respond positively concerning nurses. However, some mothers critically rated and commented upon the health care provided to them in general,

leading the researcher to conclude that response sets did not influence results to a large degree.

Concerns of mothers of high-risk infants in the postdischarge period were examined in this study. Family research in general tends to be research on mothers. Mothers and infants, however, are members of family units, and events involving mothers and infants have impact on the entire family unit. Data from both mothers and fathers would have been particularly helpful to explore the impact of the high-risk infant on the family.

#### Future Research Considerations

Further research projects are planned as a continuation of this study to enhance an understanding of the effect of a high-risk infant on the family and the implications of nursing support at this time.

Crisis theory suggests that it takes approximately six weeks for resolution of family crises. This short follow-up period, however, is inadequate to explore the long-term effects of neonatal illness on the family. A follow-up study is planned to examine the effect of high-risk infants on the family when the infants are approximately one year old. Consequently, mothers who participated in this research study will be asked to participate in a follow-up interview when their infants are approximately one year old. Mothers consenting to the follow-up study will provide insight into the long-term effects of neonatal illness on the family and the continuing need for formal and informal support.

Respondents in the study reported a need for community follow-up from nurses who were knowledgeable in the problems and care of high-risk newborns. A pilot project is being planned to provide follow-up care and support to families of high-risk infants after the infants are discharged home. Results from the present research project comprise pre-test data, postdischarge support from the researcher as a clinical nurse specialist in neonatal intensive care will comprise the intervention for the pilot project, and data collected from mothers receiving this support will comprise posttest results. This pilot project may provide insight into the significance of postdischarge support from nurses with expertise in neonatal intensive care.

Finally, mothers in the study expressed a need for informal support from parents who had experienced neonatal crises similar to those they were experiencing themselves. Parent counsellors can provide this support. A network of volunteer parent counsellors will be organized to offer support to parents experiencing neonatal crisis. The usefulness of an organization of veteran parents in minimizing stress for parents of high-risk infants in hospital and after discharge can be evaluated by parents utilizing this resource.

### Conclusions

The presence of a medically fragile infant at home inevitably disrupts normal family routines and can lead to family disruption. As survival rates for high-risk infants continue to escalate, home care of the high-risk infant becomes a nursing

concern. This study illustrated that all family members are affected by the discharge of a high-risk infant from hospital. Mothers of high-risk infants reported a need for continuing formal and informal support in the postdischarge period. Community health nurses and nurses with expertise in neonatal illness can effectively support mothers of high-risk infants during the stressful transition from hospital to home care. Further study into the long-term concerns of mothers of high-risk infants and their need for continuing community support will assist nurses in providing comprehensive care for these families and their special infants.

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## Appendix A

Permission for access to Health Sciences Center

DATE: APRIL 9, 1990

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

TO: MS. K. HAMELIN

SUBJECT: Research Protocol Approval

NO: N#90/03

TITLE: A DESCRIPTIVE STUDY OF THE FORMAL AND INFORMAL SUPPORT  
RECEIVED BY MOTHERS WHO HAVE HAD AN INFANT IN INTENSIVE  
CARE.  
THE PERCEPTIONS OF MOTHERS WITH AN INFANT RECEIVING  
NEONATAL INTENSIVE CARE: A DESCRIPTIVE STUDY.

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

COMMENTS: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
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\_\_\_\_\_  
\_\_\_\_\_

Dr. D. Harper, Director of Research

\_\_\_\_\_  
April 9, 1990  
Date:

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

## Appendix B

Permission for access to the Children's Center

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

March 12, 1990

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

Dear Mrs. Hamelin:

RE: Thesis Proposal

Your thesis proposal submitted to the Pediatric Research Coordinating Committee was reviewed at their meeting of March 5, 1990 and was given full approval.

Yours sincerely,

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

HJD\*jdd

## Appendix C

Permission for access to St. Boniface General Hospital

Hôpital Général - St. Boniface - General Hospital  
409 Tache Avenue,  
WINNIPEG, MANITOBA R2H 2A6

(204) 233-8563

March 26, 1990

Ms. Kathryn Hamelin  
83 Jewett Bay  
Winnipeg, MB, R3R 2M9

Dear Ms. Hamelin: *Kathy*

Your two-part collaborative study entitled:

A descriptive study of the formal and  
informal support received by  
mothers who have had an infant in  
intensive care - Phase II

has been approved for access at SBGH.

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

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

Sincerely,

Eleanor J. Adaskin, RN, PhD  
Director of Nursing Research  
Tel. 235-3480

EA/mj

## Appendix D

### Protocol for Nurse in NICU or ICN to Approach Potential

#### Subjects Concerning Research Project

Marion Saydak and Kathryn Hamelin are Graduate Students from the University of Manitoba School of Nursing. They are conducting a research project to explore how parents of infants who have been cared for in Intensive Care or Intermediate Care feel about this experience.

Would you be willing to have one of them contact you by telephone to further explain the study?

You are under no obligation now or when they contact you to participate in the study.

Reply to potential subject if permission is granted:

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

Telephone # \_\_\_\_\_

Reply to potential subject if permission is not granted:

Thank you for your time and attention.

## Appendix E

### Protocol for initial approach to potential subjects after receiving permission to contact them about the study.

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

I am a Registered Nurse and a Graduate Student in the Master of Nursing Program at the University of Manitoba. As part of my education at the University, I am conducting a research study in conjunction with another Graduate Student. The research project explores how mothers feel when their infant is cared for in Neonatal Intensive Care or Intermediate Care Nursery, and examines the concerns they have after their infant is discharged home. The study is being conducted with mothers of infants who were cared for in the Neonatal Intensive Care Unit or the Intermediate Care Nursery at St. Boniface Hospital or the Health Sciences Center. Because your infant received this special care in one of these units for 10 days or longer, you meet the criteria for inclusion in the study.

Participation in the study involves being interviewed twice. The first interview is conducted at the hospital by Marion Saydak in the week before your infant is discharged home. This interview takes approximately 20 minutes and is arranged at your convenience. The focus of the first interview is your opinion of the care you and your infant received in the hospital and how prepared you feel to take your infant home. The second interview is administered by Kathryn Hamelin six weeks after your infant is discharged home. This part of the study concerns your perceptions of the care and support you have received since your infant was discharged from special care. This interview occurs in your home at your convenience and takes approximately 60 minutes to complete.

Participation in the study is strictly voluntary. If you choose not to participate, it will in no way affect the care you or your infant receives. You may withdraw from the study at any time. Any answers you provide will be held in strict confidence and only Marion Saydak and Kathryn Hamelin will have access to identification of the source of the study data. It is not expected that the study will not have any appreciable benefit to you or your infant but the knowledge gained from it will hopefully help future mothers and infants who have experienced special care.

I will leave a written description of the study for you with the Assistant Head Nurse in the nursery. If you agree to participate in this study, we will set a convenient time and place for the first interview to take place. Please do not hesitate to contact me with any questions or concerns you have. Thank you for your consideration.

## Appendix F

### Invitation to participate and description of the study

You are invited to participate in a study designed to identify the concerns of mothers of infants before and after discharge from special care.

Mothers of infants who have been hospitalized in Neonatal Intensive Care or Intermediate Care Nursery for at least 10 days are being invited to take part in the study.

Participation in the study involves being interviewed on two separate occasions by two students in the Master of Nursing Program at the University of Manitoba. The first interview will take place in the week before your infant is discharged home. Participation will take approximately 20 minutes of your time. The second interview will take place approximately six weeks after the discharge of your infant. Participation in this part of the study will take approximately 30 minutes.

The questionnaires will ask several questions regarding your experience of having an infant cared for in Neonatal Intensive Care or Intermediate Care Nursery. In addition, the questionnaires will ask your opinion of the care you and your infant received after discharge from special care. There are no right or wrong answers to any of the questions; you are simply being asked to describe your thoughts on this subject.

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. Although it is not expected that there will be any immediate benefits to participants, the study may produce information that will improve the care of mothers and their infants in the future.

The study results may be published in the form of a journal article in the future, but confidentiality will be maintained to protect the identity of subjects. A summary of results will be provided to those requesting it.

If you have any questions about the study, we would be pleased to answer them before you make a decision to participate.

Thank you very much for your consideration.

Marion Saydak  
Kathryn Hamelin



## Appendix G

### Consent to be a research subject

Kathryn Hamelin, R.N., a graduate student from the School of Nursing, University of Manitoba, Winnipeg, Manitoba is conducting the second part of a collaborative research project. The purpose of this part of the study is to identify the concerns that mothers have after the discharge of their infant from Neonatal Intensive Care or Intermediate Care Nursery at The Health Sciences Center or St. Boniface General Hospital. This study will be supervised by Dr. Ina Bramadat, School of Nursing, University of Manitoba.

I understand that I will be interviewed by Kathryn Hamelin once, for approximately 30 minutes, about the experience of having an infant who required special care, and about my opinion of the care received after discharge. The interview will take place in my home, at my convenience, approximately 6 weeks after my infant is discharged home.

I understand that only the researcher and Marion Saydak, who is conducting the first part of the study, will have access to my name and any identifying information. My name will not be used in the transcribed data, or in any publications that arise from the study. Interview data will be identified by number only, and no one will have access to the name-number combination except these researchers. Questionnaires will be stored in a locked container and will be destroyed following data analysis. However, coded data will remain stored in the computer as part of the collaborative data bank to be used for further analysis. This data will not be identifiable with individual subjects. 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 require special care 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 Kathryn Hamelin or Dr. Ina Bramadat by telephone at (204)-474-8202 or by writing to them at the School 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.

My signature below also indicates that I give permission for Kathryn Hamelin to have access to the demographic data collected in Phase 1 of the study.

Date \_\_\_\_\_

\_\_\_\_\_  
(signature of participant)

\_\_\_\_\_  
(signature of researcher)

Please send me a copy of the study results.

Name : \_\_\_\_\_

Address : \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

## Appendix H

### Protocol for telephone conversation with potential subjects for phase 2 of the research project

Hello. My name is Kathryn Hamelin. I am a Graduate Student from the University of Manitoba School of Nursing. We met six weeks ago when you agreed to participate in the first part of a research study concerning the experience of having an infant cared for Neonatal Intensive Care or Intermediate Care Nursery. At that time, you completed an interview with another Graduate Student, Marion Saydak. Are you still interested in participating in Phase 2 of the research project?

Reply to the subject if agreement to participate is indicated:

Phase 2 of the study examines the concerns that mothers have after the discharge of their infant from special care. Participation in Phase 2 involves a second interview that takes approximately 60 minutes to complete. Would you like to set up a convenient time for the interview to take place?

Thank you again for your participation in this research project.

Reply to the subject if further participation is not indicated:

Thank you for your attention and the time you have given us in the past.

## Appendix I

Ethical Approval

The University of Manitoba

SCHOOL OF NURSING

ETHICAL REVIEW COMMITTEEProposal Number N#90/03

Proposal Title: "A descriptive study of the formal and informal support received by mothers who have had an infant in intensive care."

Name and Title of

Researcher(s): Kathryn Hamelin, R.N., B.N.Graduate Student in Master of Nursing ProgramUniversity of ManitobaDate of Review: March 05, 1990Decision of Committee: Approved: Apr. 04/90 Not Approved:       

Approved upon receipt of the following changes:

APPROVED with revisions submitted on March 13, 19, and  
April 04, 1990.

Date: April 5<sup>th</sup> 1990

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

Position

NOTE:

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

## Appendix J

### Interview schedule: Phase 2

Thank you for agreeing to this interview and for all the assistance that you have given in the past. As before, everything that you tell me will remain confidential and you will not be identified in anything written about the study.

We are interested in following up babies who have recently been discharged after a stay in the Neonatal Intensive Care Unit or the Intermediate Care Nursery, to see how they are getting along after six weeks at home.

\*\*\*\*\*

1) How long did your baby stay in the hospital altogether before you took him/her home.

Number of days: \_\_\_\_

2) It has been \_\_\_\_ days since your baby came home. Looking back on your experiences, do you think that you were as involved with your baby as you wanted to be when s/he was in Neonatal Intensive Care?

More involved than I wanted to be	1
As involved as I wanted to be	2
Less involved than I wanted to be	3

3) If your baby was admitted to Intermediate Care at birth or transferred from Neonatal Intensive Care to Intermediate Care, do you think, looking back on your experiences, that you were as much involved with your baby as you wanted to be during the time s/he was on this unit?

More involved than I wanted to be	1
As involved as I wanted to be	2
Less involved than I wanted to be	3
Not applicable, baby stayed in NICU	8

4) How did the Intermediate Care Unit compare with the Neonatal Intensive Care Unit in terms of how involved you felt?

Made me feel more involved	1
About the same involvement	2
Made me feel less involved	3
Not applicable, baby stayed in NICU	8

5) Did your involvement with your baby in either unit give enough preparation for coming home?

Very well prepared	1
Fairly well prepared	2
Adequately prepared	3
Some preparation	4
Poorly prepared	5
Didn't need preparation	6

6) Since coming home, has there been anything like a book, leaflet, or a radio or television program which particularly helped you to understand more about looking after your baby?

Yes \_\_\_ No \_\_\_

If YES, please specify.

7) Did you have any particular worries about your baby when s/he came home?

Yes, worried all the time	1
Yes, worried sometimes	2
Rarely worried	3
Had no worries	4

8) If YES, please specify.

9) Do you think that you were adequately prepared for looking after your baby when s/he came home?

Yes	1
No	2
Not sure	3

10) 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?

11) What suggestion would you like to make which might improve the way parents are prepared for their discharge by the nurses in Intermediate Care?

12) Did you breast feed your baby at any time?

Yes	1
No	2

13) If YES, how long did you breast feed?

14) Was your baby breast fed or bottle fed when s/he was discharged from Neonatal Intensive Care?

Breast	1
Bottle	2
Breast and Bottle	3

15) How do you feed your baby now?

Breast	1
Bottle	2
Breast and Bottle	3
Breast and mixed feeding	4
Bottle and mixed feeding	5
Breast, bottle and mixed feeding	6



16) Do you feel you were given adequate instruction in breast feeding your baby when s/he was in Neonatal Intensive Care?

Not applicable, did not attempt to breast feed	1
Not applicable, baby was tube fed	2
Yes, was given enough help	3
Was given some help	4
Was given a little help	5
Was not helped at all	6

17) Do you feel you were given adequate help in bottle feeding you baby when s/he was in Neonatal Intensive Care?

Not applicable, baby was breast fed	1
Not applicable, baby was tube fed	2
Yes, was given enough help	3
Was given some help	4
Was given a little help	5
Was not helped at all	6

18) Do you feel you were given adequate help and instruction in breast feeding when your baby was in Intermediate Care?

Not applicable, baby was bottle fed	1
Yes, was given enough help	2
Was given some help	3
Was not helped at all	4
Not applicable, baby stayed in Neonatal Intensive Care	5

19) Do you feel you were given adequate instruction in bottle feeding your baby in Intermediate Care?

Not applicable, baby was breast fed	1
Yes, was given enough help	2
Was given some help	3
Was not helped at all	4
Not applicable, baby stayed in Neonatal Intensive Care	5

20) Do you feel you were given adequate instruction in breast feeding your baby when s/he was discharged home from either unit?

Not applicable, baby was bottle fed	1
Yes, was given enough help	2
Was given some help	3
Was given a little help	4
Was not helped at all	5

21) Do you feel you were given adequate instruction in bottle feeding your baby when s/he was discharged home from either unit?

Not applicable, baby was breast fed	1
Yes, was given enough help	2
Was given some help	3
Was given a little help	4
Was not helped at all	5

22) How did you feel when your baby first came home?

23) When your baby came home, did s/he fit into the family routine?

Yes, fitted in easily	1
Yes, after a few days	2
Took a few weeks	3
No, still has not fitted in	4

24) If NO, please specify.

25) How well do you feel you have coped in caring for your baby since s/he came home?

Coped very well	1
Coped fairly well	2
Just about coping	3
Not coping, need help	4

26) Since your baby came home from hospital how much support have you received from family and friends?

More support than I need	1
As much support as I need	2
Less support than I need	3
No support	4

27) Among family and friends, who would you say had offered you most support since your baby came home from hospital?

Spouse/Partner	1
Close Relative	2
Friend	3
Neighbour	4
Other (please specify)	5

28) Have you received more help from the family than you had expected in caring for your baby?

I received <u>more</u> help than expected	1
I received the help I expected	2
I received <u>less</u> help than expected	3

29) If you have a partner/husband who lives with you, does he help with your baby?

Yes, can do everything for her/him	1
Yes, can do most things	2
No, does very little	3
No, does not do anything	4
Not applicable	5

30) If the baby's father does not live with you, does he help with your baby?

Yes, can do everything for her/him	1
Yes, can do most things	2
No, does very little	3
Visits, but does not do anything	4
Never sees baby	5
Not applicable	8

31) How do you feel about what he does for the baby?

32) Have you had help and support in caring for your other children since your baby came home from hospital?

Yes, a lot	1
Yes, some	2
Not very much	3
Not at all	4
Not applicable, no other children	5

33) Who would you say had offered you most help and support in caring for your other children?

Spouse/Partner	—
Close Relative	—
Children's Father (if different from present partner)	—
Friend	—
Neighbour	—
Nobody	—
Other	—
Not applicable	—

34) In what ways have they helped you?

35) How do you think your other children feel about the arrival home of the new baby?

36) How do you think your partner/husband feels about the baby?

37) Do you feel that having the baby has affected your relationship with your husband/partner at all?

Better	1
Worse	2
Made no difference	3
Not applicable	4

38) How do you feel having the baby has affected you as a woman?

39) How do you feel having the baby has affected your extended family?

40) What would you say were the main things concerning your baby which worried you the most when you brought her/him home?

41) Your baby has now been home from hospital for \_\_\_\_ weeks. What would you say were the main things concerning her/him which worry you now?

42) From whom have you been able to seek help and advice since your baby came home from Neonatal Intensive Care or Intermediate Care?

Spouse/Partner	_____
Close Relative	_____
Friend	_____
Neighbour	_____
General Practitioner	_____
Community Health Nurse	_____
Social Worker	_____
Neonatal Intensive Care Staff	_____
Intermediate Care Staff	_____
Pediatrician	_____
Other (please state)	_____

43) Has your baby had to go back into hospital since s/he came home?

Yes	1
No	2

44) If YES, how many times has your baby been readmitted since s/he was discharged? \_\_\_\_

45) For how many days did your baby have to stay in hospital when s/he was readmitted? \_\_\_\_

46) For what reasons was your baby readmitted?

47) In general, do you think that your baby has more problems than other babies of the same age?

Yes	1
No	2

48) If your baby was premature, how do you think that being premature has affected her/his health?

49) Do you compare your baby with other babies of the same age?

Yes, all the time	1
Sometimes	2
Very occasionally	3
Never	4
Unsure	5

50) If YES, what are you looking for?

51) If your baby was premature, do you take her/his prematurity into consideration?

Yes	1
No	2
Sometimes	3
Not Applicable	4

52) If your baby was premature, do others allow for her/his prematurity?

Yes	1
No	2
Sometimes	3
Not Applicable	4

53) If your baby was premature, do you worry because of her/his prematurity?

Yes	1
No	2
Unsure	3
Not Applicable	4

54) If YES, what do you worry about?

55) Have you talked to anyone else about your worries?

Not applicable, have no worries	1
Spouse/Partner	2
Close Relative	3
Friend or Neighbour	4
General Practitioner	5
Community Health Nurse	6
Pediatrician	7
Neonatal Intensive Care Nursing Staff	8
Intermediate Care Nursing Staff	9
Social Worker	10
Other	11
Have not spoken about them	12
Have told everybody	13

56) Has your baby been seen by your General Practitioner since s/he came home from hospital?

Yes	1
No	2

57) Has your baby seen your Pediatrician since s/he came home from hospital?

Yes	1
No	2

58) Has the Community Health Nurse called to see you since your baby was discharged from hospital?

Yes	1
No	2

59) How often does the Community Health Nurse call to see you since your baby was discharged from hospital?

Weekly	1
Every Two Weeks	2
Longer Intervals	3
Has Not Visited	4

60) Do you find her visits useful?

Yes, very useful	1
Sometimes useful	2
No, not useful	3

61) If YES, in what ways did she help you?

62) If NO, what would you have liked her to have done?



63) Among health care professionals, who would you say has given you most help and support since your baby came home from hospital?

Community Health Nurse	1
Neonatal nursing staff	2
General Practitioner	3
Pediatrician	4
Social Worker	5
Other (please specify)	6

64) In what ways did they help you?

65) How would you describe your own health at the time of you baby's discharge from hospital?

Very Good	1
Good	2
Fair	3
Poor	4

66) If POOR, please specify.

67) How would you describe your own health now?

Very Good	1
Good	2
Fair	3
Poor	4

68) If POOR, please specify.

69) Are you planning to have any more children?

Yes	1
No	2
Unsure	3

70) If YES, when do you plan to have another child?

In 1 year	1
In 2 years	2
In 3 years	3
In 4 years	4
More than 4 years	5

71) Has the birth of this baby affected your plans for future pregnancies?

Yes	1
No	2
Unsure	3

72) How would you rate the care YOU have received from health care professionals since the birth of your baby?

Very Good	1
Good	2
Fair	3
Poor	4

73) Looking back, do you think that there are any 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?

74) Is there anything else you would like to tell me about your experience of bringing home a baby from Intensive Care or Intermediate Care?

75) 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?

76) 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?

THANK YOU FOR PARTICIPATING IN THIS INTERVIEW