

**ASSESSING THE FEASIBILITY OF A TRANSITIONAL SERVICES PROTOCOL FOR  
PREMATURE INFANTS DISCHARGED HOME FROM TERTIARY CARE**

**By Janice Marie Covernton Beveridge**

**A Practicum Project Submitted to the Faculty of Graduate Studies in Partial Fulfillment  
of the Requirements for the Degree of**

**MASTER OF NURSING**

**Faculty of Nursing**

**University of Manitoba**

**Winnipeg, Manitoba**

**June 2004**

**THE UNIVERSITY OF MANITOBA**  
**FACULTY OF GRADUATE STUDIES**  
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**JANICE MARIE COVERNTON BEVERIDGE ©2004**

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**Dedication:**

This practicum project is dedicated to the infants and families that helped me to reach my educational and professional goals. I will be forever indebted to them for allowing me to a part of their lives, and to learn and grow from this practicum experience.

### **Acknowledgements:**

I would like to say a special thank you to Deb Askin. Your patience and expert knowledge were very much appreciated. As well your encouragement was also always welcomed and was timed at crucial steps to keep me motivated and on track with this project.

Thank you to internal committee member Dr. Lesley Degner. Your advice of how to structure my data collection during the practicum project proved to be invaluable.

Thank you once again.

Thank you to external committee member Doris Sawatzky-Dickson. As an advisor and co-worker you helped to encourage me along with this process.

Thanks to external committee member Dr. Diane Moddemann. Your expertise in follow-up of high-risk newborns added greatly to the development of this practicum project.

Thank you to April VonPlaten, who provided me with the inspiration to go forward with this project and helped to answer many questions along the way

A would like to say a very special thank-you to my family (especially Brian) and friends that have supported and encouraged me through this rather arduous process. I would not have been able to complete this program without your support.

This project was partially funded through the financial support of the HSC Nursing Research Fund.

### **Abstract**

#### **Assessing the Feasibility of a Transitional Services Protocol for Premature Infants Discharged Home from Tertiary Care**

The birth of a premature infant can pose an incredible strain on a family. This strain, while evident in hospital, can also extend into the discharge period, especially for families with limited support systems. Health care professionals can be instrumental in helping to mitigate this stress. A transitional care program could provide the proper support and education families require, enabling them to feel supported and empowered during the discharge process and beyond. This practicum project will assess the feasibility of implementing a transitional services protocol as an intervention with assisting families in taking their premature infants home from tertiary hospital care.

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## **Chapter 1 : Overview of the Problem**

### **Background**

In Winnipeg, Community Health Nurses, Pediatricians, family doctors and the Newborn Follow-up Clinic at Childrens Hospital and St. Boniface Hospital, provide care to high-risk infants discharged home from tertiary care at the Health Sciences Centre, and St. Boniface General Hospital. Although these services provide some support to the high-risk infant and his family, they may not fully support the family as they make their transition from tertiary care to home. The care provided may lack continuity, or lack the comprehensiveness required by the high-risk infant and his family, (Von Platen, 2000). For example, community health nurses are very adept at providing care to well newborns and their families in the initial post-partum period. However, community health nurses and some family doctors may not have the experience of dealing with the unique needs the high-risk infant may present with during the initial and ongoing discharge period. These unique needs may include feeding difficulties, the continued use of oxygen and/or other technologically-based care, and neuro-developmental problems associated with prematurity, low birth weight, congenital anomalies (Von Platen, 2000).

Additionally, high-risk infants are also more likely to develop respiratory infections, more likely to utilize emergency room services, be admitted to hospital for longer periods of time, and are less likely to be breast fed after discharge (April VonPlaten, personal communication, December, 2001). Families that do not receive support after discharge are more at risk for abusing and neglecting their infant (American Academy of Pediatrics, 1998), (Overpeck et al 1998). Rates of maternal depression are higher for mothers of high-risk infants, which can negatively impact the mother's ability to interact

with her infant, (Logson & Winders, 1997). All of these factors can potentially increase the use of limited health care dollars. Currently a program that provides transitional, community based care, solely dedicated to the prematurely born infant and family, does not exist in Manitoba. Why is this an issue? Community health nurses, as previously mentioned, although very experienced in providing follow-up care to well, term infants and their families, often do not have the expertise to deal with the unique problems facing the high-risk infant and family.

A transitional program, aimed at supporting the infant and his/her family after discharge home, could make an impact and potentially lessen the use of health care dollars by preventing unnecessary emergency room use, physician visits and hospital stays, (VonPlaten, 2000). Programs that provide follow-up and ongoing support have demonstrated that families have reduced stress and feel more capable of caring for their high-risk infant, (Salitros, 1986). Additionally, follow-up programs can be instrumental in mitigating the effects of prematurity, low birth weight and subsequent biological risk, (Holditch-Davis & Miles, 1997). These programs have been shown to prevent re-hospitalization, promote breast-feeding, and provide early intervention for identified problems, (Broyles et al, 2000). This is especially important in the families at socio-economic risk. Flenady and Woodgate 's (2002), meta-analysis of eight home-based support programs for high-risk, socially disadvantaged families, demonstrated improved infant outcomes. This was related to the improved parenting skills acquired by the families, and the subsequent ability to deal with their infants. In recent years, both Health Sciences Centre and St. Boniface hospital have made changes to their policies and procedures that reflect an increased commitment to provide family-centered care. A logical extension of this commitment would be to assess the feasibility of implementing

a transitional services protocol as an intervention to support families as they prepare to take their premature infants home.

### **Significance of the problem**

With the advance of technology, more high-risk infants are surviving today that would not have earlier. A significant portion of these high-risk infants is premature. In 1995, 6.2 % of female infants and 4.9 % of male infants born in Manitoba were less than 2500 grams (Canadian Institute of Child Health). This number increased to 7.2 % for infants born to mothers living in the downtown Winnipeg (predominantly low socio-economic) area (Brownell et al 2001). These statistics translate into admissions to tertiary intensive and intermediate care for neonates, as infants of low birth weight often present with complications. According to Dr. Molly Seshia, (personal communication, February 2002), at the Health Sciences Centre (HSC) alone, in the years 2000-2001, there were 380 infants admitted to the NICU and 968 admitted to the intermediate care nursery. Additionally from 1998 –2000, there were 321 infants born between 23-34 weeks gestation, at HSC and St. Boniface Hospital (Casiro, Moddemann, Debooy and Granke, 2000).

Premature infants, especially those born less than 27 weeks gestation, are at increased risk for having major disabilities (Davis, 2003). Extremely premature infants have double the amount of disabilities when compared with larger more mature infants (Davis, 2003). The most recent longitudinal study followed 675 infants from 1986-2000. They too found improved survival rates; however long-term developmental problems remained. This was especially true for infants who had experienced severe

intraventricular hemorrhage or severe broncho-pulmonary dysplasia, (BPD) (Hoekstra et al, 2004). Other literature reflects these findings of improved survival rates for premature infants, with morbidity rates staying the same, and with subsequent developmental problems remaining a significant issue, (Hack, Friedman, Avroy, & Fanaroff, 1996). What this means is that although percentages of handicap remain the same, absolute numbers of children born with ongoing developmental issues has increased. (Blackburn, 1998). Although many advances have been made to reduce morbidity and mortality of infants born at lower gestational age, they remain at risk for a variety of neuro-developmental problems. These may include, but are not limited to, behavioral disorganization, attention deficit disorders, language problems and school dysfunction, (Bennett, 1987). In a multi-center trial (Vohr et al, 2000) the outcomes of 1151 infants with birth weights of 401-1000 grams again demonstrated that these infants were at risk for poorer neuro-developmental and functional outcomes. These problems included abnormal neurological exams, and vision and hearing impairments. Lower scores on the "Bayley II Mental Developmental Index" and the "Psychomotor Developmental Index" were also documented. Examples of developmental problems include cerebral palsy, blindness, deafness, and learning difficulties and behavioral problems (Hoekstra, 2004), (Blackburn, 1998). Davis (2003), further states that even children who were previously assessed to have no or minimal disabilities as preschoolers may present with significant scholastic difficulties at a later date. Because of this, a significant portion of these children may require on going assessment and intervention from the supports within the community (Davis, 2003). Additionally, because of these potential long- term problems, these children continue to utilize health care resources (Davis, 2003).

Our ability to provide these services may diminish over time due to the strains being placed on our health care system related to decrease funding and the lack of trained personnel. As health care professionals we are well aware of the incredible strain a family faces when their infant is admitted to the NICU after birth. However, we forget about what the family may experience in preparing to take their infant home. What should be a joyous occasion can be met with uncertainty, doubt, and even fear. Parents may feel extremely isolated after discharge home, especially if they do not have any support systems in place (Kenner & Lott, 1990).

Even after discharge, hospital readmission rates remain a significant issue. It has been long recognized that high-risk newborns have unique needs as compared to the general newborn population, (Brooten 1986). Salitros (1986), also proposed that these infants could benefit from a transitional program that would ease discharge home with "the primary goal being to have parents assume ownership of the high-risk infant" and be able "to plan the care of the high-risk infant with the support of the interdisciplinary team"(p.35). This in turn could help to reduce the incidence of hospital readmission rates. Von Platen (personal communication, December 2001) reports that of 135 high-risk infants discharged home in Calgary, there were 43 hospital re-admissions during the first six months after discharge home. In addition, unscheduled visits to family doctors and visits to emergency rooms during the same time frame revealed that there were 86 emergency room visits. With hospital bed space at a premium, transitional care may help to prevent these visits by addressing some of the parents concerns or by preventing the health care issue and/or concern in the first place. For example, one of the reasons for an emergency room visit was for constipation. A nurse following the infant home and providing transitional care may be able to work with the family through

education to prevent complications such as this. This could ultimately save health care dollars. The numbers of infants that may benefit from follow-up/transitional care therefore is significant. Recent research has examined the role of transitional care home for high-risk infants. It was found that by improving families' levels of support, their infants' developmental outcomes could possibly be improved (Holditch-Davis & Miles 1997). With these facts in mind, infants that require intensive care after birth may benefit from continued support once discharged from the hospital due to these ongoing medical and/or psychosocial needs. This support may vary from reinforcing the care the parent is giving, teaching them how to interact with their infant in order to promote development, helping with breast-feeding and care, and referring them to other health care agencies if problems are identified.

### **Statement of the Purpose**

Is transitional care for high-risk infants and their families warranted in Manitoba, after discharge from NICU? To answer this question, this practicum examined the feasibility of a transitional services protocol as an intervention for premature infants and their families, specifically premature infants born at 28 weeks gestation and less. The transitional services offered consisted of discharge teaching, assessment of the infant and families' support systems, breastfeeding/feeding support, and developmental support sensitive to the unique needs of the premature infant and his family. An experienced NICU nurse (practicum author) provided the transitional care. This nurse participated in discharge teaching and planning and also helped to involve other health care resources deemed necessary, such as home care. After discharge, the same NICU nurse visited the infants and families in their homes. The visits provided did not take the place of public health services being provided. Data was collected via field

## Assessing 7

notes and questionnaire (see Appendix E), in order to determine whether or not this care was of benefit to the infant and his family.

## **Chapter 2 : Conceptual Framework**

The principles of family-centered care provided the framework for this practicum project. Within these principles the concept of empowerment guided the family-centered care framework. Empowerment is a very important aspect of family-centered care. When empowerment is viewed as an outcome process, autonomous decision-making, self-determination, and feelings of self worth result, (McClain & Bury, 1998). Dunst and Trivette (1987) stated that empowering and thus enabling families is key to having functional and capable families. This is the goal for nurses working with families in preparing them and their infants for discharge home. The family needs to establish control over the discharge process and readying their infant for discharge home. Therefore, it is imperative that the family views themselves as active participants in their infant's care (Kenner & Lott 1990). Ideally, this process should be initiated while the infant is still in hospital, well before the actual discharge date. Involving the family in the infant's care can help to achieve this goal. Principles of family-centered care should be incorporated during the stay in hospital and extend into the discharge process (Beveridge, Bodnaryk, & Ramachandran, 2001). Family-centered care provides guidelines to assist the health care provider in promoting self-determination, decision-making, control, and self-efficacy for families, (McClain & Bury, 1998). Adhering to the principles of family-centered care provides the foundation for having the parents resume control over their and their infant's life. It is based on eight principles. These include: 1) Recognizing the family as the constant in the child's life. 2) Promoting parental and professional collaboration. 3) Exchanging of complete and unbiased information. 4) Recognizing the diversity, strengths, and needs of families. 5) Recognizing each family's level of coping and support them through comprehensive programs and



policies.6) Supporting family-family support and networking. 7) Ensuring services and support in hospital, home, and community, are coordinated. 8) Finally, appreciating families as families, (Shelton & Stepanek, 1994). Families who receive care based on these principles will be that much more involved with their infant and when discharge takes place, may feel better prepared in taking the infant home. Families that feel they have been supported by the health care team may also feel more positively when they resume care for their infant, (Steele, 1987). These concepts helped to guide the practicum project by identifying needs that may have shifted the locus of control away from the family. This loss of control can result in continued heavy reliance on the health care team. The goal is not to have the family function independently (at least not initially), but rather to make them feel they are a part of decision making and care giving for their infant. The ultimate goal would be to make families feel they are in control when taking their infant home. Harrison (1993) also advocated for family involvement in the decision-making and care giving of their infants. This would ensure "mutually beneficial and supportive partnerships in the NICU and beyond" (Harrison 1993).

### **Conceptual definitions**

High-risk infant- The American Pediatric Association (1998), defines a high-risk infant, according to four categories. They include, 1) premature infants, 2) the infant requiring technological support, 3) the infant at risk due to family issues, and 4) an infant whose condition will ultimately result in death.

High-risk family - families that are at socio-economic disadvantage, young maternal age, education less than 12 years, abuse situations, and drug abuse situations, (Moran-Finello, Litton, deLemos, & Chan, 1998).

Low birth weight- infants with a birth weight of less than 2500 grams.

Biological risk- infants born prematurely and /or with congenital defects that may predispose them to continued health care and developmental issues.

Prematurity- infants born at less than 37 weeks gestation

### **Chapter 3: Literature Review**

Infants born at high-risk have continued problems after discharge home. Subsequently, families of these infants also continue to experience stress and complications when the high-risk infant is discharged home. The literature reviewed examined the definitions of high-risk infants, and the outcomes of high-risk infants. The effects of the high-risk infant on his family and the roles health care professionals play in identifying needs, and providing of support and care were reviewed. Additionally programs that could aid families after discharge home were reviewed.

#### **Who are high-risk infants?**

High-risk infants are identified by the American Academy of Pediatrics (1998), using the following criterion: 1) Preterm infants. 2) Infants requiring technological support. 3) The infant at risk due to family issues, ie drug abuse. 4) The infant whose condition will result in premature death. Infants that are born high-risk can continue to experience long term sequelae after discharge home from the hospital. Brooten et al. (1986) found that the prolonged hospitalization of the low birth weight /high-risk infant can have devastating results. She found that these infants were at greater risk of infection, impaired parental attachment, difficulties in establishing breast feeding, failure to thrive, and greater risk of abuse. These infants are in need of continued support from health care professionals in order to maximize their developmental potentials, (Holditch-Davis & Miles, 1997). Developmental issues that may arise from low birth weight/high-risk infants include, poor neuro-developmental outcomes, vision and hearing problems, chronic respiratory infections, and feeding problems, (Gennaro & Bakewell-Saks, 1991).

With these points in mind, it is imperative that a plan be put in place when readying the infant home for discharge. Based on these observations, transitional programs could

be of benefit to high-risk infants and their families for a variety of reasons. Cronin, Shapiro, Casiro, & Cheng (1995) found that families of premature infants could experience stress for extended periods of time after the infant's discharge home. By involving parents in discharge teaching and planning, needs and supports can be identified, and hopefully the transition home eased (Arneson, 1988). Infants born high-risk are at further risk if premature and born into a high-risk family. Risks include ongoing developmental delay (personal communication, Dr. Casiro, January 1997), increased frequency of illness, and risk of death due to homicide (Overpeck et al, 1998). It was found that developmental outcomes could be improved via the use of continued transitional care with an emphasis on developmental support (Holditch-Davis & Miles, 1997). VonPlaten, (personal communication, December 2001) reported increased family satisfaction with and greater knowledge of community supports, amongst parents who received transitional care services after the discharge of their high-risk infant.

### **Factors associated with Developmental Outcomes**

There are several factors that can promote or hinder optimal developmental outcomes for high-risk infants and children. The following literature was reviewed to make these determinations.

Logsdon and Davis (1997) examined predictors of maternal depression in mothers of premature infants. This descriptive study followed 37 women who had premature infants. Women were assessed for depression, self-esteem and the amount of social support they received. They were interviewed while their infants were still in hospital and then 4 weeks post discharge. They found that levels of maternal self-esteem and depression at the first interview time, were the most predictive of depression at the second interview time. These factors are important to recognize and to offer support ,

as premature infants can be especially vulnerable to the influences of negative parenting that may arise from poor self esteem and depression.

Singer et al. (1999) followed over 200 mothers. The study was a longitudinal study over 2 years, examining maternal psychological stress and parenting stress. Three cohorts were formed of mothers and their infants utilizing the following criteria: 1) High-risk with very low birth weight (VLBW), 2) low-risk VLBW, and 3) normal term infants. They discovered that mothers of high-risk VLBW infants, experienced greater stress, than the other groups examined. This in turn may affect the mother's ability to interact with her child to the utmost potential. Programs that offered support and follow-up may therefore help parents and prevent depression.

Landry, Smith, Miller-Loncar, and Swank, (1997) examined groups of full-term, (n=112) very low birth weight, (n=114), and high-risk infants, (n=73), through the use of growth modeling. They wanted to predict cognitive-language and social growth curves from mothering behaviours. They found that mothering behaviours that were sensitive to the child's focus of interest and were not highly controlling were instrumental in facilitating cognitive-language and social development. This was especially important in the high-risk groups of children.

Laucht, Esser, and Schmidt (2001) followed 347 children, of whom two-thirds suffered some type of perinatal complication. As well, two-thirds of the families experienced psychosocial difficulties. The researchers were interested in learning about what most contributed to behavioural problems in infants of biological (low birth weight), and psychosocial risk. Mothers and their infants were videotaped at three months of age and the interactions evaluated using the Mannheim Rating System for Mother-Infant Interaction. The infants were later seen at 2, 4, 6, and 8 years for

psychological evaluation. They found that maternal responsivity moderated the effects of low birth weight, on some behavioural problems seen at later dates, as well as offering some protection against psychosocial risk factors. With this in mind, strategies that promote maternal responsivity should be utilized.

### **Parenting:**

Parents often want and need guidance when planning to take their premature, high-risk infant home. The following literature was reviewed to provide ideas of how to assist parents in this transition home. Holditch-Davis and Miles, (1997) reviewed several articles to examine nursing research dealing with parenting and also parenting the prematurely born infant. From their literature review, they determined several factors that contributed to the most promising outcomes for high-risk infants. Initially, parents need to become familiar with their child and participate in their care, even while still in hospital. Kangaroo care or skin-to-skin contact is one method of getting parents involved in their infant's care (Ludington-Hoe & Swinth, 1996). Parents who took part in this care were more able to move past the initial shock of the premature birth and establish their role as parents, and thus form a relationship with their child. Mothers who participated in this care were also more likely to breast-feed. Breast-feeding also may promote ongoing maternal involvement during the infant's hospitalization. Parents who were taught how to massage their infant and to interact with them also had more positive outcomes as measured by HOME scores. HOME scores consist of measuring the quality and quantity of stimulation and support available to a child in his environment (Bradley & Caldwell, 1988). Finally, parents who were taught how to read their infant's time-out signals, and cues for interaction demonstrated improved parenting. This process could start while the infant was still in hospital, and extend into the discharge

period. They concluded that when parents are given specific and ongoing roles in terms of the care of their infants, parenting could be improved. This then translates into improved developmental outcomes. Based on these findings, they recommend the development of follow-up/transitional programs to aid the premature infant and his family.

VandenBerg and Hanson (1993) identified several strategies for care giving and promotion of development in high-risk infants. They discussed reading baby's cues, positioning, feeding, communicating and playing with your baby. They also provided specific interventions to promote development in the baby the first year of life. These interventions could prove useful in program development, when designing a follow-up program for high-risk infants.

### **Discharge Planning**

Various themes were identified during the review of relevant research. They included the identified needs of infants and their families when discharged home, what promotes improved outcomes for the high-risk infant, and outcomes of transitional care for the family after discharge home. The ability to identify needs of infants and families is paramount in the development of programs in assisting infants and family home. Other literature examined identified guidelines when planning discharge and transitional care. The American Academy of Pediatrics Committee on the Fetus and Newborn, (1998) provides guidelines that could prove to be useful when preparing an infant for discharge home from tertiary care. These guidelines include identifying the infant at risk, parental education, implementation of primary care, evaluation of unresolved medical issues, development of a home care plan, mobilization of resources, and finally determining and designation of follow-up care.

Bissell (2002) reviewed several studies to determine what should be included in follow-up care and who should provide this care. She determined that individuals with "advanced skills and knowledge in family dynamics, high-risk neonates, and growth and development " should be utilized. The needs of the family should be adequately assessed, and flexibility in the delivery of this care is paramount. Based on these criteria, nurses with advanced preparation at the CNS or NNP level of education could assume the role of providing follow-up support and care of the high-risk infant and his family (Bissell 2002).

Swanson and Miles (1999) identified guidelines to assist families and professionals in preparing their high-risk, technology dependent infant for discharge home. Key points include the need for a multidisciplinary discharge planning team, relative infant stability, competent primary caregivers, adequate financial resources, community support systems, and adequate infant follow-up.

Robinson, Pirak, and Morrell (1999) developed a multidisciplinary, neonatal discharge assessment tool (N-DAT) to aid in discharge planning. This tool has been valuable in identifying those families most at risk for ongoing problems (limited supports, high need for continued medical care at home, abuse, neglect, etc), and those who would subsequently most benefit from intensive transitional care and support. This tool could be valuable for all NICU's discharging high-risk infants home.

In a study done by Brooten et al. (1989) pre and post discharge teaching needs of 36 families were identified. The pre discharge teaching required consisted of feeding issues, the recognition of infection in the infant and growth and development. Post discharge teaching focused on feeding, the infant's current health concerns, growth and development and also how to manage within the health-care system.



Hamelin (1991) interviewed a convenience sample of 50 mothers of high-risk infants. She found these mothers of high-risk infants were in need of "continued formal and informal support in the discharge period". For example, very often the mother and family needed breast-feeding support. She advocated the use of community health nurses familiar with the needs of high-risk infants as the ones providing support in the post discharge period.

Sawatzky-Dickson (1996) examined the educational, support needs and self-efficacy of parents of high-risk infants. A convenience sample of 50 parents of high-risk infants was chosen. Several outcomes of the study were documented. Parents identified that the hospital presented various barriers to their establishing a relationship with their infant. Parents often saw nurse as the "gate-keepers" in terms of their access to their infant. It is therefore important that nurses are aware of this and facilitate parental involvement with the parent and their child. Her study also determined that educational needs were often not met in terms of medications or medical problems. After discharge, the public health nurse was not always helpful as these nurses had little experience dealing with the very premature infant. Most of the families' need for information was given from the infants' pediatrician and/or family doctor. Written information found to be the most helpful was the "The Premature Baby Book, Baby's First Year". Hospital information in the form of pamphlets was deemed as below average in terms of being helpful.

May (1997) gathered data from 14 mothers about how they sought resources and help when discharged home with their high-risk infant. The mothers were searching for "normalcy" in terms of what had happened to them and their infants in the NICU experience. Normalcy was defined in terms of health and development for the infants.

Normalcy for mothers was defined as "the attainment of a family lifestyle that was not centered on infant vulnerability, care-giving and care-giving burden". The areas that mothers sought information on were: how to care for their high-risk infant, how to recognize the infant's "normalcy" and consequently question their own care-giving, and normalizing of their environment and home. They also revealed they needed more information on how to access resources and respite help in order to cope with the needs of a high-risk infant. The information obtained from these mothers could help to guide nurses when preparing the infant and his family for discharge home.

Keehner, Engelke and Engelke (1992) conducted a longitudinal study in which they followed 106 high-risk infants and their families. Data collection consisted of self-administered social questionnaires given prior to discharge and at 6, 12, 18, and 36-month follow-up appointments. Mothers were also interviewed at the 6-month follow-up visit. They discovered that the most consistent predictor of an optimal home environment was the internal parental locus of control. If the parents (mothers) felt that they were the ones in control, they could provide for their infant's needs. Nurses should therefore look at an empowerment model of intervention with a focus on the needs of young mothers and their children. This identification of needs could then be incorporated into a follow-up program.

### **Outcomes of Follow-up or Transitional Care Programs**

Follow-up/transitional programs can provide many benefits to individuals when discharged home. Several studies support the use of transitional programs that continue to follow and support the individuals when discharged home. Today, health care dollars are scarce. It is imperative to look at programs that may offer better

utilization of health care dollars, and that could also benefit the individuals concerned. Often, they can facilitate earlier discharge, improve family coping, prevent re-admission back to hospital, and in some instances save health care dollars. Several programs/studies were examined in the literature review. They are as follows.

Dorothy Brooten, has been a long time proponent of early discharge programs and follow-up into the community. Most recently, Brooten, Brown, and Neff (2001) demonstrated an improved outcome for women experiencing high-risk pregnancies through a randomized trial of nurse specialist home care throughout their high risk pregnancies. She followed 173 women and their infants who were randomized to control and experimental groups. The groups were similar in their demographics and their high-risk pregnancies. Clinical Nurse Specialists provided nursing care to the experimental group of women who demonstrated fewer complications, fewer hospitalizations, and improved fetal outcomes. There was an overall reduction in costs of almost 3 million dollars. Although this study was not specifically related to high-risk infants, it demonstrates the effectiveness of a community based program, and documents improved outcomes for mothers and ultimately their fetuses and high-risk infants.

Pharis and Levin (1991) identified 30 high-risk mothers (young mothers, drug or alcohol abuse, or those who had had other parenting neglect issues). These mothers were followed through an intensive program that supported them in helping them make changes in their parenting that would benefit both the mother and their infant. Mothers found the program to be positive, and rated their relationship with individual support people within the program, as one of the most important aspects of the program. The least important influences were concrete services. Although this program is not specific

to the high-risk infant, information about what families of socio-economic risk may need could be relevant.

Moran-Finello, Litton, deLemos, and Chan (1998) examined the effectiveness of aftercare programs, knowing that infants discharged home to potentially high risk social situations (poverty, social isolation, lack of support, etc.), were most at risk for poor developmental outcomes. Eighty-one infants and their families were randomly assigned to one of four after-care programs. They found that overall, the provision of any after care program, although it did not significantly reduce the incidence of maternal depression, did influence the families' abilities to provide an environment that met the needs of a developing infant and toddler. They also found that discharging the infant as soon as possible also had a positive effect on the families' ability to cope. Finally the provision of long-term services seemed to contribute mother's satisfaction in her role as a parent.

Ramey et al. (1992) conducted an eight-site randomized controlled trial examining the efficacy of early intervention programs. There were 377 intervention families and 608 control families. The control families received the regular pediatric follow-up following discharge home. Intervention families had infants that demonstrated improved IQ scores and developmental outcomes through early intervention strategies for high-risk infants, especially those at socio-economic disadvantage. Intervention strategies consisted of pediatric follow-up, and family support through home visitation. The goals of these visits were to provide emotional, social and practical support to parents, provide parents with developmentally supportive information to help them interact with their infant, and support their development, and also teach them methods to cope with the problems of high-risk infants. Other strategies consisted of child development

centers and parent support groups, which provided support for the infant and family.

Sparling and Lewis (1991) developed a two-part curriculum that promotes development for those infants deemed at risk after discharge from hospital. "Early Partners" and "Partners for Learning" were the two components of the program. "Early Partners" was designed to support parents in the first few months following discharge home with their high-risk infant. Some of the support strategies consisted of teaching parents cues for interaction, calming the baby, and assisting with the baby's sleep/wake cycles. The "Partners for Learning" portion of this program overlapped with the early portion of the program. It continues to give support and guidance for families of the infant to 36 months of age. They wanted to help families to become partners in their infants' care by learning how to interact with them and to promote their development. This is especially important in those families deemed to be of socio-economic risk. Their study found improved scores for infants on the Stanford-Binet IQ test, when enrolled in this program. This information would be beneficial to have when developing a follow-up program for high-risk infants and their families.

Finello, Litton, deLemos, and Chan (1998) followed 81 low birth weight infants after discharge home from tertiary care. They found that infants who received the highest level of after care services achieved the best health care outcomes.

A low cost intervention strategy of providing in-home care to low birth weight infants was utilized in a developing country. What was discovered was that maternal infant interaction and cognition was improved in the study group. This was accomplished through weekly home visitation by paraprofessionals (Gardner et al. 2003).

Broyles et al. (2000) conducted a large randomized controlled trial to determine the outcomes of 784 infants who received comprehensive follow-up care. Infants were

randomized to routine follow-up or comprehensive care. The routine care consisted of well baby care and physicians care for chronic illness. The comprehensive care consisted of the routine care, clinics that were open 5 days a week, plus a primary nurse practitioner/physician assistant that was accessible to the family 24 hours a day via pager, as well as treatment for acute illness. Outcomes of the study revealed that the comprehensive care group had fewer life-threatening illnesses, fewer intensive care admissions, and "did not increase the mean estimated cost per infant for care".

In previous research, Brooten (1986) found that hospital costs could be significantly reduced and developmental outcomes improved in those infants discharged home earlier. However, she strongly suggested that follow-up by skilled practitioners was warranted to provide the best outcomes.

Bruder and Cole (1991) identified several key elements that should be employed when infants are being prepared for transition home from the NICU. These included the utilization of a parent-parent support network, and using a discharge summary to improve communication between the family and health care providers post discharge. They also advocated using a care plan that would extend through the discharge process home to provide continuity of care, and finally identifying on-going education that may be needed by the family and other health care providers.

Swanson and Nabe (1997) described a program that cross trains RN's from the NICU to provide care at home after discharge. This program provides continuity of care and helps to ease the transition home. It also is cost effective, safe and reduces the incidence of re-admissions.

Casiro et al. (1993) demonstrated that length of hospital stays could be reduced safely and positively influence the home environment via their randomized trial of

community-based interventions for low birth weight infants. One hundred infants were enrolled in the study. Public health nurses and home care workers provided follow-up care for the intervention group. The control group was discharged home at the discretion of the attending physician. Follow-up at one year of age demonstrated that there were no difference in re-hospitalization rates, ambulatory services and Bayley developmental scores. The intervention group had significantly higher 1-year "Home Observation for the Measurement of the Environment" (HOME) scores. Cost savings per day were significant.

VonPlaten et al. (2000) examined the role of transitional care for high-risk infants in the Calgary, Alberta area. This care was compared to the care infants received from standard community health nurses, via a randomized control trial. A total of 135 infants were enrolled in the study. Transitional care consisted of home follow-up for 4 months in the community after discharge teaching and care in the hospital, and was provided by clinical nurse specialists. The care provided varied according to the individual needs of infants and their families. Some of the care consisted of breast-feeding and other feeding support. High risk and/or premature infants often required additional support in establishing breast feeding and some of these infants were being gavage fed at home to supplement their oral feeds. This was to conserve calories and promote growth. Additional teaching and support was given to help parents interact with their high-risk infant. For example, high-risk infants can often be "fussier" babies and have different needs in terms of being able to settle. The nurses were able to help parents interact and support their infants in their adjustment home. Additionally, some of these children were oxygen dependent. The nurses, with their expertise in neonatal respiratory physiology, were able to accurately assess the high-risk infant's respiratory status. The findings of

the study were as follows: the intervention group was more likely to continue breast-feeding and utilized physicians and emergency room facilities less often. They had fewer days in hospital when admitted (for example with hernia repair). Mothers were more confident and knowledgeable about community services available to them, and more satisfied with the preparation for the infant's care. Both the intervention and control groups had similar weight gains at 6 months of age, although the control group initially gained weight faster. Control group mothers believed their infants to be healthy and seemed less afraid of doing something wrong with their infants. In summary, this program could prove beneficial to the high-risk infant and family during their transition home from a tertiary care setting.

### **Summary of the Literature**

In summary, the literature review demonstrates that continued support for high-risk infants and their families can have a positive influence on many outcomes. These include: better fetal and infant outcomes, increased parental confidence, less physician and emergency room utilization, improved parental confidence and satisfaction, and less chance of child abuse. With improved outcomes, there is less likely to be utilization of higher costing health care and social support systems. This could result in an overall cost saving to our health care system.

As VonPlaten (2001) has demonstrated, families with high-risk infants in Calgary can benefit from transitional care programs. It needs to be determined if a program similar to Calgary's would be of benefit to people in Winnipeg and Manitoba. The program may not be of benefit to Manitobans, as the Calgary program provides services only to those high-risk infants and families residing in the Calgary Regional Health Authority. Additionally, they provide services to many different types of high-risk infants, not just



premature ones. This practicum project replicates aspects of the work done by Von Platen and her colleagues, but with a focus on the unique population found in Manitoba. This population consisted of infants born at 28 weeks gestation or less born in Manitoba, and their families. The project helped to fill some of the gaps in care families experienced when taking their premature high-risk infants home. This practicum project also provided continued support and continuity of care to infants and their families, after discharge from tertiary care.

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## **Chapter 4 : Methodology**

### **Assumptions**

*The assumption guiding the basis of this practicum is that premature infants and their families are in need of continued support from health care providers as they make the transition home.*

### **Objective**

The practicum project utilized past research to provide guidelines for the transitional care provided to the premature infant and his family. This practicum will involve providing care only to premature infants and may extend to infants and their families residing outside of Winnipeg. The overall objective for this practicum project was to assess the feasibility of a transitional care program as an intervention for families with a premature infant discharged home after receiving tertiary care at the Health Sciences Centre or St. Boniface Hospital.

### **Setting**

The initial phase of the practicum took place in the NICU/ Intermediate Care Nurseries (IMCN) at the Health Sciences Centre and also in the Neonatal Intensive/Intermediate Care Nursery (NIICU) at St. Boniface Hospital. Post discharge, transitional care was provided in the infant and families' homes

### **Sample**

Ethical approval was obtained from the University of Manitoba, Health Sciences Centre, and St. Boniface Hospital, to conduct this practicum project.

All of the infant's parents were 18 years and/or older. When initially approached by the bedside/primary nurse, it was made clear to the parent(s), that their participation in the practicum project was entirely voluntary. The practicum student reinforced this, when

consent was obtained. After obtaining informed consent from the parent(s), a convenience sample of 5 premature infants and their families were chosen based on the following criteria:

- 1) 28 weeks gestation or less.
- 2) Discharge home was an almost certainty, (barring any unforeseen circumstances, the infant's survival was assured).
- 3) Infants were being discharged home to their own families (not to foster care).
- 4) Parents were able to understand written and verbal English.
- 5) Parents were 18 years or older.
- 6) Families lived within a 2-hour driving distance from the city of Winnipeg.

Recruitment of the subjects took place with the help of bedside, primary care nurses. The bedside primary nurse initially approached families. This was to ascertain whether or not they would be interested in participating in the practicum project. The primary nurses were given an explanation and a script to help guide them when they approached parent(s). The explanation and script (see Appendix A) helped the primary care nurses to describe to the parents the main purposes of the practicum project. The primary care nurse then gave the parent(s) a letter that more thoroughly outlined the project (Appendix B). Additionally, prior to the practicum student approaching the bedside nurse, the practicum student met with the charge nurse to ascertain whether or not the infant and family would be a good match for the practicum project.

If they expressed interest in participating in the project, the practicum student met with the families, and then explained and gave a detailed explanation of the project. Any questions regarding the project were answered at this time. Informed consent (see Appendix C) was then obtained from the parent(s).

**Budget**

A budget was formulated and utilized to anticipate the costs of driving and telephone calls, (see appendix F). This proved to be helpful to the practicum student during the practicum experience.

**Procedure**

The practicum was completed using the following criteria as guidelines. It provided the basis for a model similar to one that would likely be adopted if this program proved to be of benefit to infants and their families born in Manitoba.

- 1) The practicum student cared for the infants while they were in the NICU/Intermediate Care Nursery. The numbers of shifts ranged from 1-6 shifts. In addition to these shifts, parents were met a minimum of two times and sometimes up to four times prior to discharge. Caring for the infant while he was in the NICU/Intermediate Care Nursery and meeting the parents prior to the infant's discharge accomplished two things. 1) A detailed explanation of the project could be given and informed consent was obtained. 2) It gave the practicum student and the infant and his family time to gain familiarity with one another prior to the discharge home. This would help to establish trust between the practitioner and the infant and family, and also to help the practicum student establish what the infant's usual behaviour patterns. Contact in hospital ranged between 20-40 minutes. This ensured that the discharge teaching was completed prior to the going home from tertiary care (see Appendix D), and to answer any questions prior to discharge home.
- 2) Post discharge, most of the families took advantage of the maximum amount of visits (four). One infant and his family were only visited once at home, but this was due to a 2-hour drive time. However, phone contact was maintained with this family

for a total of 4 contact times. It was initially thought that visits would take 30-60 minutes, however most of the visits were 60 minutes in length sometimes up to 90 minutes. All families had their initial visit within 24-36 hours of going home.

- 3) As previously discussed, premature infants had various needs that differ from term newborns. The practicum student, because of her familiarity with high-risk infants was able to address these unique needs of the infant and family, and help them to care for their recovering premature infant. Information collected from the families focused on discharge planning and their first week at home with their infant; however the actual transitional care provided did extend past the first week home. In addition to providing transitional services to the premature infant and his family, data were also collected. Two rural families were visited and provided with transitional care as they were within a two-hour driving radius of the city. Phone contact was also utilized. Field notes were taken after each visit with the family in their home.

The following techniques were utilized for data collection.

Interview: A questionnaire (see Appendix E) was utilized as a guideline when interviewing families as to whether or not they felt they were prepared to take their infant home. It focused on what families needed to feel more in control of the hospital experience, discharge home and what would make them feel empowered and in control of what was happening to them and their infant. Families were asked what supports were in place, and whether or not they were adequate. Interviews were conducted in an informal fashion in the family's home, while providing the transitional care to the families as necessary, (eg additional answers to questions teaching, etc).

Observation: The method of observation utilized was "no concealment and intervention" in an unstructured forum, (LoBiondo-Wood & Haber, 1990). Field notes were taken

after each visit.

4) Care giving: Care giving was provided for via home visits and phone contact. As previously mentioned, VonPlaten (personal communication, December 2001), stated that very often parents are so overwhelmed during the first week home that they often require help with very basic needs. This practicum project therefore focused on interventions in the following areas during the first week home; infant feeding, sleep, interaction with their infant, helping to identify sources of stress, assessing the families' knowledge of community supports, and reinforcing the discharge teaching done in the hospital. Nursing care was organized into categories utilizing the "Nursing Lexicon and Taxonomy" (NILT) (Grobe, 1996). NILT helps to develop a lexicon (vocabulary) and taxonomy (orderly classification) of nursing intervention statements (Grobe, 1990). Following the categorization of nursing care, themes relating to the nursing care were identified and then utilized for collecting data, (see Appendix G). It helped to determine what types of nursing care were the most utilized.

### **Ethical Consideration**

Anonymity was maintained throughout the project, as family's were referred to as "Infant A and family", "Infant B and Family", etc, when data was entered into the computer software program. Initial field notes and questionnaire results from the data collection piece of the practicum were stored in a locked drawer. This data will be destroyed at completion of the practicum project.

The risks associated with this practicum project were minimal, however some of the parents appeared to experience some stress when talking about the NICU experience, and how it related to them and their infant. The practicum student was able to help

parents talk through these experiences. When problems were encountered, and the practicum student felt the family could benefit from more information, they were given the support to access specific medical or counseling services. For example, one family was referred to "Compassionate Friends" as they had experienced the loss of their infant's twin, early in the NICU stay. When other difficulties were encountered parents were encouraged to follow up with their infant's pediatrician. In one case the number for a dietician was given to parents for their infant, who was experiencing some intolerance with his feeds.

Benefits to the families were realized, as all families stated they were happy with the advice and support given by the practicum student. Long term benefits of the project as the information collected during this project may be utilized to help all families with high-risk infants. This could be accomplished by improving supports and educational services for all high-risk infants and their families post discharge.

Finally, the practicum student is cognizant of the fact that data collected about her services provided to the families may be biased, due to the involved nature of the practicum project.

**CHAPTER 5: RESULTS:**

This pilot project examined the feasibility of implementing a transitional services protocol for recovering premature infants born at 28 weeks gestation or less. The transitional services provided were guided by VonPlaten's research and focused on the following areas: review of discharge teaching, assessment of how well the infant is sleeping, feeding, and interacting with family members, and finally assessing their knowledge of community supports. The practicum project was also guided by the discharge teaching record and meeting with and observing the infant and his family prior to discharge. The practicum student cared for the infant during the NICU and/or Intermediate Care Nursery stay, during the discharge process and then following discharge. The nursing teaching and tasks were organized using the Nursing Lexicon and Taxonomy (NILT). A questionnaire was also utilized to help with information gathering during the practicum project. Using the NILT classification and the questionnaire helped to identify major themes from the information gathered during the project.

**Demographic Data**

Data for the practicum project was collected over a ten and a half-month time period, from January 2003 to November 2003. Nine infants and their families, born at either the Health Sciences Centre or St. Boniface Hospital, were approached to participate in the practicum project. Five agreed to participate.



Infant Demographic data is summarized in the following table.

<b>Table 1: Infant Demographics</b>	
<b>Gestational age in weeks</b>	
24-25 weeks	three or 60%
26-27 weeks	one or 20%
27-28 weeks	one or 20%
<b>Birth Weight</b>	
<500 grams	one
500-750 grams	two
750-1000 grams	two.
<b>Infant Type</b>	
Singleton	Four or 80%
Twins	One or 20% (one twin died)
<b>Days in Hospital</b>	
	Range : 72-133 days
	Mean : 102.5 days
<b>Hospital of Admission</b>	
Health Sciences Centre	2 or 40%
St.Boniface	3 or 60%
<b>Method of Feeding at Discharge</b>	
Bottle/Formula	3 or 60%
Breast/Bottle/Formula	2 or 40%
Exclusive Breast Feeding	0%

<b>Table 2: FAMILY DEMOGRAPHICS:</b>	
Maternal Age	25-30 years
Marital Status	All married or common-law relationships
Mothers	All had some post secondary education
<b>Maternal Complications</b>	
PIH	1
PROM	2
Twin Pregnancy	1
<b>Residence</b>	
Urban	3
Rural	2
<b>Children</b>	
No previous	3
Previous	2
<b>Caucasian</b>	3
<b>Aboriginal</b>	1
<b>Immigrant</b>	1

The sample included 5 infants and their families. Three of the families were Caucasian, one family aboriginal and one family immigrant. All families were either married or living common-law. Eighty percent of the mothers had experienced some antepartum complications prior to the birth of their infant. Forty percent of the families had previous children. Sixty percent of the families lived in the city while 40% lived in the rural areas. At time of discharge 60% of families were formula feeding and 40% were doing a combination of breast and formula bottle-feeding. All of the infants experienced a high rate of complications during their NICU stay, associated with their premature birth of less than or equal to 28 weeks gestation. Mean length of stay was 102.5 days. At time of discharge 2 of the infants were experiencing definite long- term consequences of their premature birth, (hearing and vision impairment). It remains to be seen how the infants will progress developmentally. All infants will be seen at six months corrected age, for a developmental assessment.

<b>TABLE 3: COMPLICATIONS OF HOSPITAL STAY</b>	
<b>Intraventricular hemorrhage</b>	
Grades 1-2	two or 40%
Grades 3-4	three or 60 %
<b>Hyaline Membrane Disease</b>	
Mild-moderate	One or 20%
Severe	Four or 80%
<b>Sepsis</b>	
At delivery	Five or 100%
During length of hospital stay	Five or 100%
<b>PDA</b>	
Treated with Indomethacin	Two or 40%
Surgical Ligation	Three or 60%
<b>BPD</b>	
Oxygen therapy past 28 days of life	Four or 80%
Oxygen therapy at discharge	0%
<b>Retinopathy of Prematurity</b>	
Stages 1-2	Three or 60%
Stages 3 +	Two or 40%
Laser surgery	Two or 40%
Sight restoration	One or 20%
Sight impairment	One or 20%

All infants experienced complications associated with their prematurity and low birth weight. It is evident from the table that some infants experienced more complications or more severe complications than other infants. The complications experienced are typical of infants born at this gestational age (Broyles et al. 2000).

**TABLE 4: COMPLICATIONS AT DISCHARGE HOME**

<b>Inferior Vena Blood Clots</b>	One or 20% requiring enoxaparin therapy
<b>Inguinal Hernia</b>	Two or 40% awaiting surgical repair
<b>Sight Impairment</b>	One or 20%
<b>Hearing Loss</b>	One or 20%

Complications experienced by these infants at discharge are commonly seen in infants born at this gestational age, (Broyles et al. 2000).

**TABLE 5: SUPPORT FIRST WEEK POST DISCHARGE**

<b>Family Doctor/Pediatrician</b>	Five or 100%(One visit)
<b>Public Health Nurse</b>	Four or 80%
<b>Practicum Student</b>	Five or 100% (One –two visits)
<b>Family</b>	Four or 80%
<b>Readmission</b>	0% ( One infant was admitted one month post discharge for further eye surgery, and one infant was admitted two and a half months post discharge for hernia repair
<b>Unscheduled physician visits</b>	0%

Table 5 illustrates the support given to the infants and their families during the first week home after discharge from tertiary care.

**Hours Seen by Practicum student:**

Time spent with the family is summarized in the following table. This care was provided for over a period of 3-4 weeks.

<b>TABLE 6: HOURS PROVIDED BY PRACTICUM STUDENT( not including shifts worked) :</b>	
<b>Family A</b>	
Hospital –prior to discharge	Two hours and 15 minutes
Visits Post discharge first week home	Two hours
Visits Post discharge past first week home	0
Telephone contact pre and post discharge	76 minutes
Time researching information/resources	One hour and 15 minutes
<b>Family B</b>	
Hospital-prior to discharge	One hour and 5 minutes
Post discharge first week home	Two hours and five minutes
Post discharge past first week home	One hour and 25 minutes
Telephone contact pre and post discharge	15 minutes
Time researching information/resources	20 minutes
<b>Family C</b>	
Hospital-prior to discharge	One hour and 40 minutes
Post discharge first week home	45 minutes
Post discharge past first week home	One hour 30 minutes
Telephone contact	20 minutes
Time researching information/resources	One hour
<b>Family D</b>	
Hospital prior to discharge	40 minutes
Post discharge first week home	One hour 20 minutes
Post discharge past first week home	One hour 50 minutes
Telephone contact	35 minutes
Time researching information/resources	15 minutes
<b>Family E</b>	
Hospital prior to discharge	One hour
Post discharge first week home	Two hours and 5 minutes
Post discharge past first week home	One hour and 30 minutes
Telephone contact	66 minutes
Time researching information/resources	45 minutes
<b>Range of Hours</b>	
	Four hours and 40 minutes – Six hours and 46 minutes
<b>Mean of Hours</b>	
	Five hours and 39 minutes

**CARE PROVIDED**

As previously mentioned nursing care, teaching and other interventions were categorized using NILT (see Appendix G). The purpose of using the NILT is the development of a lexicon or vocabulary and a taxonomy, which aids in the classification of nursing intervention statements (Grobe, 1990). This is especially important when providing nursing care as it is sometimes difficult to quantify what nurses do (Grobe 1996). The NILT was very helpful to organize the interventions carried out by the practicum student. NILT utilizes cognitive science principles with the construction and naming of seven basic nursing intervention categories. It has been invaluable at establishing "care" as a "organizing concept" (Grobe 1996). Most of the care was provided to infants and their mothers as most of the fathers had returned to work. The following data emerged:

**Care Need Determination (CND):**

The primary concept governing this category of care is "determining need for care". CND involves interventions whereby information is gathered to make "rational decisions about what is needed by an individual or family who are the focus of care" (p55, Grobe 1996).

CND in this case was utilized to facilitate information gathering to determine what the care needs for families of premature infants less than 28 weeks gestation. The interventions that governed this category are as follows.

*Take families' history regarding past experience with health care services:*

When asked, most of the parents of the infants had had some prior experience with

health care services. Two of the families had older children and therefore had exposure to the services the public health nurse provided. Two of the Mothers had been treated for complications prior to delivery. One mother had been hospitalized due to prolonged rupture of membranes. Another was treated for high blood pressure in the antenatal home care program. Most of the parents cited that their past health care experiences had been positive, except for the mother treated for hypertension. She stated that she felt that this was because of a personality clash with the nurse caring for her. However this did not deter her from accepting other health care.

One of the infants was being transported back to his community hospital prior to discharge via air ambulance. Mom was concerned about the process and how it would affect her infant. The effects of the transfer were discussed with Mom. She was assured that because the infant was stable and requiring little oxygen that he would likely do well on the flight. The practicum student explained that the infant may require additional oxygen due to the flight, but that most stable infants return to their baseline FiO<sub>2</sub> requirements once they are settled post flight. The practicum student also had the attending neonatologist speak to Mom about these concerns. Mom was appreciative of the explanations and looked forward to having her child closer to home.

*Seek information about families' normal routines and habits:*

Each of the families was quite different in what they termed to be their normal habits and routines. In one family, dad was a shift worker. Most families identified the ability to get adequate rest and meals as part of their normal routine. But as one mother described "it seems as if a life time has gone by. I am not sure what I would call a normal routine right now". Fathers described the return to work as part of the resumption of their previous routine. Two of the families had older children therefore

they anticipated the discharge of the infant home as an addition to their normal routine of having children. These families anticipated that they would be getting less sleep, but seemed to be accepting of this fact. They knew that a return to a “new” normal was going to happen eventually, that is as one parent expressed “It will be a bit wild at first but we will get through it” The other families were unsure of how the infant’s home coming would effect their routine. They did expect to get less rest/sleep.

*Assess families’ awareness of community supports:*

All of the families were aware that the services public health nurse would visit them, but were unsure of what they would do. They were told that public health could weigh baby for them, and also give information regarding baby care, illness etc. The families were also aware of the newborn follow-up program at Children’s Hospital and St.Boniface Hospital. However there seemed to be confusion surrounding their ability to access occupational therapists either at St. Boniface Hospital or the Health Sciences Centre. Some parents were told to come while others were not told to come for follow-up, to assess the infant’s ongoing neurodevelopment. They also did not seem to be aware that they could make this request via their pediatrician. One family was referred to Compassionate Friends, as they had lost one of their twins. They felt they needed to get some help with sorting out their feelings of grief. They stated that they did not have the opportunity to really think about it until they got home with the surviving twin. They had been overwhelmed during the stay of the surviving twin, and therefore had not thought as much about dealing with a memorial for the twin that had died.

Another infant’s family was given the contact number for the CNIB as the infant had experienced a significant loss of vision, and although she was going for further laser surgery in Edmonton it was uncertain as to whether or not she would regain any of her



vision.

One family was given the number for the dietician at Childrens hospital as their child seemed to be experiencing intolerance to formula.

In summary, although parents seemed to be aware of some of services available to them, however it wasn't always clear as to exactly whom they should contact. They didn't always know if they could self refer or if they needed a referral. The practicum student was available to help with this information.

*Assess families' knowledge of premature baby care:*

All of the parents seemed cognizant of how to handle and interact with their recovering premature infant. They did not over-stimulate the infant, but did engage him/her if the infant showed signs of interacting with them. They all stated they were limiting the numbers of visitors to decrease the risk of infection and also to prevent over-stimulation to the baby. Families were given reinforcement of their interactions with their infants. One mother made inquiries as to when she could start doing "normal" thing with her baby, like taking them to a "Mom's and One's" group. Mom was told that by that time there would be no reason why she couldn't do that with her baby.

*Ask families knowledge of feeding care of premature babies:*

As part of their discharge teaching, all the parents seemed familiar with premature baby feeding care. All of the parents seemed comfortable with their chosen feeding method for their baby. Most of the parents were able to also better able to feed their infants as compared to other caregivers, ie they could often get the baby to eat more with less fussing. Formula preparation was reviewed with one family as they had a question as to how long powder formula was good for after mixed and placed in the fridge. They had received information from the hospital on how to mix formula prepared

from concentrate, and how long this was good for in the fridge, but they had not been given information on the powder formulation. They wanted to make sure they were doing it right. The formula can was reviewed with the family, which gave clear instruction as to how to mix the formula and how long it was good for in the fridge.

*Assess families' knowledge of how illness presents in a premature baby:*

Prior to discharge, parents could identify how illness presented in a premature infant and also felt they were comfortable in telling how their infant would present with illness. However once at home 3 families did call the practicum student to discuss concerns regarding their infant. They wanted reassurance that they were assessing the infant properly and not missing anything with them. In all cases, although it was felt that the infant was probably fine, the parents were advised to contact the pediatrician. The practicum student was operating on the premise that the parents were in fact the ones that were getting to know their infant the best. Therefore, if they noted a change in the infant's behavior that should be taken seriously. In one instance, the practicum student went and assessed the infant. In all cases the infant was in fact fine.

**Care Vigilance (CV):**

CV involves observation and monitoring activities that are utilized to determine the physiologic status of the infant and his family (Grobe 1996).

*Evaluate infant to assess physical and behavioral state*

The practicum student examined all infants prior to discharge and at home. The student used mainly visual assessment and palpation during home exams. A stethoscope was not utilized. This was to reinforce the fact that the infant, although

required close monitoring of his recovering condition, did not require intensive care any longer. While examining the infant the practicum student told the parent(s) what she was doing. For example, when the baby was at rest she would note and tell the parents, "look how easy his respirations are, see his pink color". The parents therefore had the discharge teaching reinforced and they were able to become comfortable with assessing the infant's respiratory status.

The infants' charts were reviewed prior to discharge and in particular, the physiotherapist's notes were looked at to see if there were any major neuro-developmental concerns. When the child was visited at the home, general parameters of neuro-development were assessed. These included the baby's state control, or how easily he could be calmed, his general level of alertness, sleeping patterns, and how well he moved his limbs etc. About half of the children were being seen by OT/PT post discharge for ongoing issues with development. One child was being seen because of hearing loss and the other because of poor vision.

*Check feeding, hydration and elimination patterns:*

The infants were also assessed regarding their feeding and elimination patterns, and their hydration status. All parents were familiar with how to assess this and were comfortable with the same.

*Check family's ability to get proper rest and nutrition:*

Most of the families stated they were able to eat properly, as they had family members cooking meals for them. All reported feeling tired, but most of the families had extended family that would come and help them so they could get naps. The practicum student also encouraged them to rest when baby was asleep.

**Care Environment Management (CEM):**

This category of care utilizes interventions that are performed to “influence the context of the environment”. They may be seen as indirect care activities but many times nurses are the ones that are arranging and monitoring the effects of this care (Grobe 1996).

***Assess environment to ensure safety and appropriateness for recovering premature infant:***

All environments of infants and their families discharged home, were assessed to be clean. The crib and bedding was assessed to be appropriate for a recovering premature infant. There was an abundance of toys for all the children. Parents were aware of not over stimulating the babies at this time, and knew when to offer a toy for the baby and when to withdraw if the infant seemed overwhelmed.

One environment was extremely warm due to a baseboard heater malfunction. As it was late fall, the parents were unable to open windows in their rental apartment as they were afraid of giving the baby a draft. They had contacted the building superintendent, however he had failed to remedy the situation. It was only after several calls to the building's owner by the practicum student and the public health nurse, that the situation was finally remedied. The practicum student had to threaten the building's owner with contacting public health before anything was done. She also had to explain the dangers of overheating an infant, and that the infant was at risk for SIDS if the situation was not quickly remedied.

***Involvement of support systems:***

As previously discussed, some families were given numbers for extra information and support they may need. One family was referred to Compassionate Friends, as

they had lost the twin of their surviving son. Another family was given the number for CNIB to get additional information on how to interact with their vision-impaired child. A mother was given a contact number for a dietician to assess whether or not her infant required a change in his formula. Families that continued breast-feeding their infants post discharge were aware of the number for the breast feeding hotline. Another mother was aware of the local number for the La Leche League in her neighborhood.

### **Therapeutic Care General (TCG):**

TCG describes hands-on "procedures and therapies that are the focus of nursing care (Grobe 1996).

#### *Perform hands-on care:*

There was some specific nursing activities carried out during the home visits. For example one of the infants had an inguinal hernia, therefore the hernia was assessed along with a general exam of his physical state. His Mother was also taught how to assess the hernia and what to do if any problems presented with the hernia. Another infant had an insuflon catheter in place for enoxaparin therapy. This was for treatment of a clot in the infant's IVC. The student examined the catheter site and showed the Mom what she was assessing in the process. Mom in turn became more comfortable with the monitoring of the catheter. A rash was examined on one infant. It was milia. The infant's pediatrician later confirmed this.

### **Therapeutic Care Psychosocial (TCP):**

This focus of care centers on those nursing activities that support the infant and his family " psychologically and improve or maintain their psychological status"(Grobe 1996).

*Discuss families coping with introduction of infant at home:*

Families seemed for the most part, to be coping fairly well with the introduction of the infant home. All reported feeling tired.

Most of the families had some additional help from extended family members after bringing the baby home. All fathers returned back to work shortly after baby came home (within 1-3 days). Family members that came to help were grandparents. They were available to the family their first weeks at home. Extra support came in the form of assuming care for other children, and helping to cook meals and look after the home. Most mothers and fathers therefore had some time to get used to the baby being at home and did not have to worry about other details of running the home while getting used to their infant at home.

Discussions involving feelings surrounding finally having infant home took place. Most parents expressed relief that baby was home. They said although they were comfortable with the infant's care in hospital, getting home and being on their own was an adjustment. One mother stated, "what happened to my easy going baby". This Mom was reassured that her infant would be going through an adjustment period after coming home. Discussions with this Mom focused on how to ease this adjustment and reinforced Mom's care giving as she was very adept at calming her baby. It was also reinforced to Mom that while they were going through this adjustment phase that she should let her family help her with the housework and that she sleep when baby did.

One family did not have much extra support. Dad was working a second job as they had accumulated bills while their baby was in the NICU as they were from out of town. Additionally this Mom was also back at work as she ran a home daycare and did not qualify for UIC benefits, as she was self-employed. The practicum student spent time

with this family helping them to identify some ways to ease the stress of having to work and care for a premature infant plus two other children. This Mom was high energy, independent, and not used to asking for help. The practicum student spoke with Mom and she was able to identify some people she could call for help. For example as it was winter, she was going to ask another mom if she could take her daughter to nursery school for her. She had given favors in the past to other people, so I encouraged her to call those favors in. The practicum student also spoke with social work prior to this family going home to see if there was any help available for them, be it financial or home-care services. Unfortunately, they did not qualify for any of this support.

One family for whom the twin of the study infant had died stated that they had not adequately dealt with the death of that baby. They had not yet had the time to have a proper memorial for the infant. They talked about their feelings and the fact that the intense environment of the NICU had not allowed them even think about the baby, "We were so overwhelmed...He had died and we didn't know if our other son would live. We got through one crisis only to experience another. Even when he got better (the surviving twin) we were still very busy at the hospital caring for him. It's now that we are home that we have had a chance to think and we would like to get some help" dealing with the loss of the other twin. The family was encouraged to discuss their feelings. Their feelings were validated by telling them that it was not unusual to experience these feelings and that other parents who had lost one of their twins, also experienced feelings similar to what they were experiencing. They were encouraged to continue to talk about these feelings and how they wanted to remember their son. They were told that there was no right or wrong way to have a memorial, but that they should have one if they felt that this was what they wanted.

All mothers discussed feelings about the NICU experience. Anger, sadness, depression, and feelings of helplessness were common. They stated as the infant's condition improved they felt more involved with the care and thus felt more in control of their situation. As one mother stated "I know that they (Doctors and Nurses) were doing their job, but sometimes I would be very angry, not necessarily at anyone or anything in particular, just mad". When talking to the families about these feelings they were reassured that these feelings were very normal and to be expected when experiencing the birth and illness of a premature infant. The families were also reassured that these feelings were found in other studies of parents who had experienced the birth of a premature infant. They were also told that this information could be shared with the NICU staff (in an anonymous forum), to help them to better understand the feelings and experiences of families who are going through this event.

*Assessing for post-partum depression:*

Discussions surrounding depression were held with mothers of the infants. All mothers reported feeling depressed at some point of their infant's stay in the NICU. Most felt they were fine at this time. They were told that it was normal for them to have experienced depression. They were asked whether or not they had support systems in place now that they were at home, in case they experienced depression. The families stated that would be able to contact either the public health nurse or their own family doctor if they felt they were having feelings of depression.

**Therapeutic Care: Cognitive Understanding and Control (TCCU&C):**

This care consists of "interventions that are directed toward helping the infant's



family maintain control and self direction in the care of their infant (Grobe 1996). The care in this category would help parents to feel more empowered when making decisions about their infant's care.

The practicum student spent time with all the families reinforcing to them that the care they were providing to their infants was good and they were getting to know their infants the best. Because of this, they were also told that if they felt something was not right with the infant that they had every right to have it checked by their doctor, or to insist that they be referred to other health care professionals if they felt a situation needed more attention. One example of this was the Mom who was told by her pediatrician that her infant's hearing didn't need assessment until 6 months of age. After discussing this with the practicum student, Mom was helped to get in touch with the audiologist to arrange a hearing assessment of her baby.

All families had a review of how to call and who to call first in the advent of the need for advice. Families were then able to recognize when they needed advice and referral when they identified specific needs.

Examples of contacts given to families so they could set up appointments that fit with their needs and schedules.

Contact number for dietician given to one family.

Contact number for CNIB to another family.

Contact number for "Compassionate Friends".

Physiotherapist contacted for Mom for infant assessment.

Audiologist was contacted for a family to ensure the infant's hearing was checked.

Audiologist then phoned Mom to set up an appointment.

Contact number was given to one family to set up an appointment for RSV

immunization.

**Care Information Provision (CIP):**

CIP involves nursing care that focuses on “teaching individuals about their care and the course of therapy” (Grobe 1996).

*Teaching families about community resources:*

All families had support from the public health nurse, and were knowledgeable about the services public health could provide. Information was given to parents as needs were identified and at their request. Other resources the families needed were given to the families as described earlier.

*Reinforcing Care by Parent:*

Care that parents were giving their infant was reinforced as identified. For example breast -feeding and pumping was reinforced with one Mom. Another mother was given some general information about how to communicate objects to her vision-impaired child. Mom was encouraged to talk to the baby about the thing that was being done. For example when baby was in the tub, Mom was told to talk to her about the water and that she was having a bath. Before dressing her and touching her, Mom was told to tell baby what she was doing prior to her doing it. Mom stated that she would talk to her baby from the kitchen if she had to go get something so that the baby would still know that she was around. She recognized that her infant would require support in this area in order to promote her development. Mom was grateful for this information, and stated that it made sense to her. She said she was already doing some of these things without being fully aware of doing it. She said that because it was now pointed out to her she would be approaching her infant in this manner from now on.

A family was given additional reading information on enoxaparin therapy, as they were unable to get this from the pediatrician. Mom was thankful for the information as it made her feel more comfortable about giving the medication.

Two families attempted to use tympanic thermometers. One family had actually used the thermometer and got a high reading. They thought the baby was getting ill. When it was discovered they were using a tympanic thermometer, they were taught about not using the tympanic thermometer for children under the age of two. The families were not aware of this and were glad that they the right information of how to take a temperature on their infant once they got him home.

Another family was provided information on what to watch for with their infant when his diuretics were discontinued. The pediatrician had taken the baby off the medication and Mom was confused as to why the infant no longer required the medication. The practicum student was able to provide her with the information required so that she understood why the medication was discontinued. She was taught what to watch for now that he was no longer on the medication, such as increased work of breathing, reduced urine output and puffiness especially around the eyes, hands and feet.

In summary the NILT was instrumental in helping the practicum student to categorize the nursing care she provided to the infants and their families. Much of the care involved teaching families, helping them to contact other community resources and providing them with information to care for and make decisions for their recovering premature infant.

### **INTERVIEW:**

Various themes were identified from the interview questions. They are as follows.

**INFORMATION and COMMUNICATION:**

All parents interviewed that they felt reasonably well informed about their infant's care on most days when the infant was critically ill and in NICU. However, some parents felt that the ability to get information on their infant's status became more difficult as their infants got better. Often, they were referred to the pediatrician to have their questions answered but stated that it was sometimes difficult to get in touch with the pediatrician, "I would leave messages, and he would phone back when I was not at home". Most of the nurses were willing to give information on a daily basis to the families regarding their infant's condition. However, in some cases they felt like they were bothering some of the nurses.

Most families wanted all the information they could get about their infant's condition. Most said they looked on the Internet for additional information, or read the parent books available. However, one family stated that they did not like to get so "much information". They said although they realized that the neonatologist was trying to let them know what was happening, they found it very "scary" to get a list of all the potential complications their son might experience. They said it was like a getting hit in the face. When questioned they said that they did want the information but maybe not all at once. They found it very difficult to "absorb all that information anyway".

Parents often cited that although communication was strong at the beginning of the infant's stay at times it was inconsistent. Continuity of care was identified as a big concern, and they felt that if there was more continuity of care that communication links would be stronger. One family stated that they felt rather shocked when a neonatologist told them their son was ready to go home at the start of the summer. This was because

only days earlier an another neonatologist had told them that he would not be ready to go home until the fall because of his BPD. The family felt that "Obviously they had not communicated with one another".

One mother felt that communication and continuity of care was even more important as they were getting ready to go home. They felt that the nurse often didn't know what they (the family) was comfortable doing. "I was comfortable and knew what to do if the baby had a desat. But one nurse just grabbed him out of my arms. It made me feel like I didn't know what I was doing. There should be more communication or the same nurse looking after you, the same way as when you first come". Additionally she stated that she and her husband were confused as to what was happening with the nursing care of their infant. "One day he shared a nurse with another baby and the next he shared a nurse with 2-3 other babies. We thought maybe they were short staffed. It took us a few days to realize that because he was better he didn't need the same attention as he did before. It would be helpful to let parents know that".

### **Decision Making:**

Although, as previously stated, most parents felt reasonably well informed they did not always feel involved in the decisions regarding their infant's care. One father stated "it is very hard to make those decisions based on the limited information you get. If we didn't do what they said we our son would have died. The whole experience is very overwhelming". Most parents identified this theme. However, they felt somewhat more involved in some decisions as the infant's condition improved and they were more involved in the infant's care. "It was easier to make decisions as he got better. Because it was easier to get a grasp on what was happening". At other times, however, this was

not the case. For example, one family expressed frustration that their child was remaining in tertiary care facility, despite needing minimal oxygen therapy and feeding well. They wanted him transferred back to their community that had a level two neonatal facility. "I keep asking them why he needs to be here. Are they really doing anything different here that couldn't be done at home?" The family was under severe financial strain and having to commute and only see their infant a few times a week. This was adding to the incredible strain they were under. Eventually, after much negotiation, and support from the nursing staff, the infant was transferred back to the community hospital.

### **Concerns and Fears:**

A concern expressed by 3 sets of parents was the intense feelings of helplessness, and being at the mercy of others for the survival of their children. They said often they would ask questions but at times felt they were bothering the staff. "Sometimes you would be upset with something...what somebody said about your baby or what they did to your baby. But you didn't want to say anything about to them (doctors or nurses), because you didn't want to get them mad at you. Your baby is dependent on them to live". Another parent said that she could only come in on the weekends. Because of this, she often could not get a hold of the pediatrician or talk to the neonatologist as much as she would have liked. Subsequently, she always felt like she was bothering the nursing staff. She also described a situation where she was looking at another baby and was given "hell" from the nurse.

"I was looking at this baby because I had heard he had been as sick as my baby had. He looked so good it gave me hope that my son would do as well. I was not being

nosy. Sometimes you need to have some hope, especially at that time my son was so ill and they were not sure that he would survive”.

One of the main fears expressed by parents prior to discharge was the fear that the infant would have an apnea or bradycardic event. As parents readied themselves and their infant for discharge, the fear remained but they became more comfortable about taking the infant home. One parent stated “It’s a good thing that they take the baby off the monitors before going home. It gives you time to get used to the idea.”

Another general fear expressed was “what if the infant became ill”. Parents wanted to go over this information, and learn how to assess whether or not their infant was becoming ill.

Specific fears addressed by some families were as follows. One family was taking their infant home on enoxaparin therapy for a clot remaining in the child’s inferior vena cava. This was a residual side effect from having an umbilical venous line insitu during the first week of life. They wanted specific information on how to give the medication, and what to monitor at the site of injection. They were also anxious about the clot itself. After teaching and going over the information the parents were somewhat less anxious. Mom also wanted to have a nurse come and give the shots because “I am his Mom, and I shouldn’t have to poke him, especially after what he has been through”.

Another Mother expressed fear that her child would not have much remaining eyesight despite laser treatment and further surgery that was going to take place in Edmonton. “I’m not sure how I can help her, it’s hard when you are not sure how much sight she has or might get after surgery.” Information was given about talking to the infant when approaching her, telling her about her hands, and feet while touching and rubbing them, and playing games with her. She was also put in touch with occupational

therapy and was seeing them before and after discharge. Mom was also given the contact number for the CNIB, so she could get further information on how to help a sight-impaired child.

Mothers also cited concerns with the collection of employment benefits. Two of the families said they got completely different information, on the same day, after they tried to get the paper work done for the benefits. The problem seems to be in the fact that they are eligible for sick benefits, but only if you speak to the right person. These families stated that it would be helpful if consistent information could be given to them about how to apply for benefits. As this is a very stressful time, it would be helpful if they did not have to worry about finances.

### **Preparing for Home:**

Most parents felt they had been adequately prepared for home and felt involved with the discharge planning and teaching. However there was a concern expressed by 3 of the 5 families, as previously mentioned, that there was not enough continuity of care as the child was getting ready to go home. "It seemed that every day there was someone different looking after my son. It didn't seem to matter to them (the nurses) if it was someone who didn't know us. But it did make a difference to us because nobody would know us and what we could do so you always felt like you had to prove yourself or explain yourself." On the day of discharge, a nurse who had never cared for their infant discharged the infant home.

One of the families was discharged home from their community hospital. They were very happy with the care their son received at this facility. Mom stated that this was due in part to two variables. The first being that they were now close to their son and could



visit him every day and be more involved with his care. The second was that because of the smaller nursing staff they got to know all of the nurses and “they knew me and what I could do for my baby”. These parents were also happy with the fact that they could see the baby’s pediatrician almost on a daily basis before the baby went home and get information from him.

In summary, parents said that having the same nurse throughout the discharge process would have helped ease the transition home from the hospital. They said this was also because they often got “conflicting information amongst the nurses that added to some of their confusion” and did not help with their confidence in caring for their baby.

**Supports:**

1) All families had some sort of family support when bringing their baby home.

This support was as follows:

Full support with house keeping and cooking first week home: 2 families

Food preparation: 2 families

Went home to extended family: 1 family

2) The public health nurse visited most families at least once during the first week home. Visits were as follows:

No visits: 1 family (This family took the baby to grandparents during first week home)

1 visit: 2 families.

2 visits: 2 families.

The care provided to the families by the public health nurse consisted of weighing the baby and giving the family information on community resources available to them, such as the community health clinics. The public health nurse also gave them

information on general baby care. Specific information given to the families based on their unique needs were as follows:

The public health nurse came to monitor enoxaparin injections for one family, and checked the weight of an infant for the other family. She also had to contact the building's owner, in addition to the practicum student, as the heat was too much in the apartment for this infant. The four families that saw the public health nurse stated they were happy with the care that they had received from the public health nurse.

Family was also given information on the support group "Compassionate Friends" by the public health nurse (as well as the practicum student) as they had lost a twin.

### 3) Pediatrician:

All infant's and their families saw the pediatrician during their first week home. When the families were questioned they said the doctor performed a physical exam of the baby, weighed the baby and questioned them on how the baby was eating and if he was voiding and stooling OK. Only 2 doctors asked how the family was adjusting to the changes that were occurring at home since the baby had been discharged. However, all families said they were happy with the care their baby was receiving from the doctor.

### 4) Practicum Student:

The practicum student saw families the first week at home as follows:

1 visit: 2 families

2 visits: 3 families

The practicum student provided support to the families as outlined in the NILT classifications. All families took the maximum amount of visits offered, except for the family that was more than a 2-hour drive from Winnipeg. That family however, was supported through phone contact. All families were very happy with the care they

received from the practicum student. Parents often stated "It was helpful to see a familiar person", "Somebody knew us and our baby".

Again, parents mentioned that continuity of care at times was a concern. Some pediatricians had minimal contact with parents and the infant when the infant was in hospital. One mother stated, "it was concerning to me to have to tell his doctor what had happened", to the baby while in hospital. This was right after the baby had been discharged home. She felt he should have gotten more of the history on the baby, or taken the time to learn all the things the baby had been through, and not just have a "rough idea". Another doctor assured a mother that her son did not have to have his hearing checked until 6 months of age (this child did not have it done prior because of isolation procedures being carried out in the NICU at the time his discharge). The practicum student contacted the audiologist who stated that in fact the child did have to have his hearing checked in the next few weeks. The clinic stated they would contact the family directly to set up an appointment.

### **Summary of Results:**

Observations and care utilizing NILT and results of the questionnaire provided information about the needs of premature infants and their families prior to and post discharge. It was found that infants and their families still required support after their discharge from a practitioner familiar with the NICU/Intermediate care environment.

Most of the families' needs revolved around getting additional information on how to care for their children's specific problems. Unlike VonPlaten's (2001) research, most families seemed to be reasonably comfortable with meeting the basic care needs of their infant. For those that did have problems related to feeding, the problems were

generally related again to the need for information. For example one family required information on formula preparation, and another about pumping of breast milk. They were not having issues with the actual feeding care of their child. All of the families were comfortable with their chosen method of feeding and generally could get the infant to feed reasonably well. Families were providing an appropriate environment for their recovering premature infant and were comfortable in supporting their infant's development. Parents were able to freely discuss concerns and most were able to recognize when they needed extra support. For the one family that did not have a lot of support, strategies were discussed for how this family could obtain the support they needed. Overall, most of the care provided to the families was information giving, reinforcing their care giving and reviewing some of the discharge teaching as required. It also involved helping the families to access information and community resources they required to enable them to provide the care that was required by their children.

The questionnaire revealed that most parents had similar feelings regarding their infants stay in the NICU. As previously stated, parents felt that they were usually well informed about their infant, but found the lack of continuity of care at times to be disconcerting. Parents felt that continuity of care would help through the entire stay of their infant while in hospital and also as they are getting them ready to go home. Discussions with parents revealed that their ability to be involved with decision making was hampered by the sheer volume of information being presented to them. Some parents felt that they really couldn't make decisions based on this, and also felt that the critical nature of their infant's condition would be worsened if decisions were not immediately made. Therefore they felt they had no choice but to put their trust in the medical staff. However, some parents felt that there were clear situations where they

were capable of making decisions for their infant and should therefore be allowed to do so.

Families often cited that they felt helpless during the initial phases of their infant's hospitalization. These fears subsided as the infant's condition improved. However they experienced other concerns as their child's condition in the NICU improved. These fears included concern about the possibility of long term consequences of the infant's premature birth.

Families felt they were adequately prepared for discharge home, however, for some of the families, the lack of continuity of care was a major concern. They felt that the discharge process would be greatly facilitated if there were more continuity of care provided to them and their infant.

All of the families had some level of support available to them post discharge. This support consisted of formal support from the pediatrician, public health nurse and the practicum student. Most families had some family support to help with housework, cooking and childcare. Some families could have used more support in this area. It was found that some of the families required information and support to access other care they required. This information had not been given to them by other health care providers but had come from the practicum student. All of the families were happy with the care provided to them by the pediatrician, public health nurse and the practicum student.

**Chapter Six: Discussion of Findings**

This practicum experience allowed for the in-depth assessment and support of five premature infants and their families, prior to and after discharge home. Although all of the families were different in terms of their demographic profiles, there were still identifiable themes that emerged in terms of their and their infants' needs once they were discharged home.

The use of a transitional services protocol for premature infants discharged from tertiary care was shown to be both feasible, and from the point of view of the parents to be desirable. This is related to some of the problems encountered with the families as previously discussed. This chapter will discuss the various themes that were identified in Chapter 5. These include the care giving activities categorized thorough NILT. It will also discuss the themes identified through the use of the questionnaire.

Most of the infants were similar in terms of the length of stay and the complications experienced. One of the infants had a very stable course, however two of the infants were already experiencing long-term deficits. One had profound hearing loss, and the other vision impairment. It remains to be seen how all of the infants will continue to progress and if they will all experience long-term problems related to their premature delivery.

The most overwhelming theme obtained from this practicum experience is the varied level of support that is available to families. The only consistent variable seems to be the lack of consistency in the discharge follow-up of these children. It is interesting to note that some basic follow-up care would have been missed if not for the intervention of the practicum student. Examples include the infant who would not have had his follow-up hearing assessment until 6 months of age, as well as the basic teaching that

was not given to the family when another infant's diuretics were discontinued

### **Time with Families:**

All of the infants were cared for in the NICU/Intermediate care nursery for 1-6 shifts during their hospital stay. Families were also met with prior to discharge home to obtain consent and review discharge teaching. Within the initial proposal for the practicum, families were offered 1-4 visits ranging in time of 30-60 minutes. All the families took advantage of the 4 visits except the family that lived over a 2-hour drive time. This family was given phone support after one in-home visit. Most of the visits extended past the 30-60 minute range. It was noted that the first home visit was usually the longest with the subsequent visits becoming shorter. As the families became more comfortable with being at home with their infant, they did not need to check everything they did with the practicum student.

From this analysis of the time spent with families, it can be assumed that parents still need or would like some contact with a health care professional that is familiar with them and their baby. Most of the families stated that they were happy with the care received from the practicum student. One of the families did not respond to messages left after the 4 visits. This family, along with the other families, was sent a formal note thanking them for their participation in the project.

### **Care Provided:**

Care provided to the families was categorized using NILT and from these categorizations various themes emerged.

In the CND category, most families had past experience with health care agencies in the past with most of the experiences being positive. It is imperative that health care

providers ascertain this information. It can help to explain a family's apparent distrust of the care staff may be providing their infant. In the case of the mother who had a bad experience with the antenatal home-care program, she was able to discuss her feelings surrounding this event. She was able to identify that it was more of a personality conflict with the individual. It also did not dissuade her from seeking out other health care resources from the community. Overall, she was pleased with the care her and her infant had received.

There were some instances when the practicum student had to help families identify their needs and subsequently how to take the steps to meet those needs. Care need determinations were found to mainly involve informational giving or putting families in touch with other resources in the community other than the public health nurse or the family doctor. Sometimes, the families were not even aware that a resource was available or if they were aware of a resource they needed some guidance as to how to access this information. For example, one of the families was having difficulties with their infant's feeding and tolerance to formula. This infant was throwing up, had loose green stool and was extremely gassy and fussy. The family doctor was unwilling to try another formula as the infant was "gaining weight".

A thorough assessment by the practicum student found that this Mom was extremely frustrated that she could not help her infant. Through the practicum student, the mother was able to access a contact number for the services of a dietician at the Childrens Hospital. The Mom would not have gotten this information from the infant's doctor or even been aware that it was within her rights to get a referral for this care. As the literature previously states, parents need information to empower them to care for themselves and their infants (McClain & Bury 1998). By listening to what a family is



saying and giving them the tools to get informatio, they can participate as partner in their infant's care. Subsequently, the care of the infant would be improved. The same could be said for helping the parents to recognize how illness presents in infants. Again, reinforcing the information taught in hospital can empower families to feel more capable and competent in caring for their children once they are taken home from the hospital.

### **Care Vigilance:**

The infant's progress was monitored during the visits. Most of the visit was not preoccupied with this, as parents seemed to have the feeding and monitoring of the infant's elimination patterns under control. Parents wanted reassurance that the things they were checking in their infants were being assessed correctly. Parenting skills were reinforced and information from the discharge teaching reviewed as necessary. Parents were also reassured that they were providing good care to their children. The information gathered from this category demonstrated that these parents still required reassurance post discharge. Often they did know what to do they just wanted to check it out. This reinforcement is crucial for parents to feel that they are capable of caring for their infants. This reflects the principles of family-centered care and helps parents to be empowered to be active caregivers and decision-makers in their infant's care (Harrison 1993).

### **Care Environment Management (CEM):**

The parents all were able to provide an appropriate environment for their recovering premature infant. They were sensitive to how to handle the infant and what was the best strategy to calm them. In one apartment the heating was problematic. The parents were aware of the problem but were unsuccessful in getting it fixed. The public health nurse along with the practicum student took action to have the situation remedied. It

was very concerning to the practicum student that she had to leave several messages and also resort to threats before the heater was fixed. This demonstrates that the general public still may require information on how to prevent SIDS in babies.

#### **Therapeutic Care General (TCG):**

It was found that some of the hands on care of the infant needed to be reinforced. It was discovered that a family had never been shown how to assess their infant's hernia. The practicum student had followed the discharge teaching record when helping these parents prepare for home; however, this record did not include anything about hernias. Mom also stated that the pediatrician had not shown or told her what to watch for regarding the hernia. This is important information for them to know in case the hernia were to become incarcerated. This would be a medical emergency that would warrant immediate medical attention. If we are going to send children home with medical conditions prior to surgery then we must educate their families about these conditions. This is what makes parents feel in control and a part of the ongoing care of their children. This information enables them and empowers them to be informed decision-makers regarding the ongoing care and treatment of their children (Harrison 1993). Consequently we should continue to monitor and evaluate discharge-teaching records to meet individual needs.

#### **Therapeutic Care Psychosocial (TCP):**

It was extremely illuminating to have parent's discuss their feelings regarding the NICU experience. It is quite different to read about these experiences of parents in the literature and then have a parent tell you almost the exact same thing about how they felt about their experience. It would be beneficial for NICU staff to be made aware of these findings. This would hopefully guide how they approach families during their stay

in the NICU.

It is important to screen for postpartum depression. Studies have demonstrated attachment to their infants can be impaired if mothers are experiencing problems with depression (Logson and Winders, 1997). Mothers need to be reassured that they are not deficient or somewhat lacking in character if they do experience depression. There is still a lot of stigma surrounding mental illness, and this is why discussions about depression/postpartum depression need to be initiated in this high-risk group of families. Mothers/parents need to realize that this could happen to any new mother, but they are at risk because of the compounding effects of the birth of a premature infant, and the subsequent prolonged hospitalization of the infant (Logson and Winders 1997). They also need reassurance that help is definitely out there. Health care professionals need to always have this at the forefront of their conversations with mothers of infants in the NICU, so that they can recognize early on and help mothers get treatment as soon as possible.

#### **Therapeutic Care: Cognitive Understanding and Control (TCCU&C):**

Parents of high-risk premature infants often need to be told that they have certain rights when it comes to their care and their infant's care. Because of the overwhelming nature of the premature infant's care, parents may be so caught up in the day-day care of their infant they may not feel it is their right to question certain treatment modalities. It should be reinforced to parents that not only do they have a right to do this they should be encouraged and empowered to do so (Harrison 1993). They need information so that they identify their and their infant's needs prior to and when they are discharged home. They can then effectively advocate for their child. This would also help them to maintain control and direction of their infant's care (Salitros 1986).

**Care Information Provision (CIP):**

All parents received supplemental information from the practicum student above what was covered in the discharge teaching record. Information from discharge was reviewed, but often the families raised other concerns once they got their infant home. One example was the family whose infant had his diuretics discontinued shortly after discharge. Mom was concerned because the infant's pediatrician initially stated that the baby should have them for another month post discharge and now he was saying it was OK to take him off. Mom stated "I don't understand why he is doing this. "E" is the same as he was a few days ago. I don't think his condition changed". Mom was given information about monitoring for a decrease in urine output, increased puffiness in the baby, especially around the eyes, or any increased work of breathing that would signal the baby still required this medication. Mom was more comfortable with the discontinuation of the medication once she received this information.

Even something as simple as taking an infant's temperature may require additional information and teaching. This is evidenced by the fact that two families were attempting to take their infant's temperature with a tympanic thermometer.

Again, these examples demonstrate the need to teach and keep parents informed about their children's treatment plan so that they can be active participants in their care (Beveridge, Bodnaryk, & Ramachandran 2001).

**Questionnaire**

Various themes were identified from the questionnaire. The practicum student was involved with infant and family care therefore questions were asked in an informal fashion, rather than in a structured fashion.

**Information and Communication:**

The lack of continuity in the delivery of information is also supported by other studies. This seemed to be an overwhelming concern for 3 out of 5 of the families, and somewhat of a concern for one of the other families. Caregivers need to bear this in mind when providing information and care to families. Primary nursing from the time of admission through discharge would be one strategy to help parents. Families would then only have to communicate with a select number of nurses as opposed to the whole nursing staff. However, this practice is often hard to implement due to staffing shortages, and the need to often pull more experienced nurse to care for the more critically ill infants. When primary nursing is not available, the use of care plans, which include input from the family, would also help to provide more consistent information and care giving. For example, one of the parents had her infant was taken from her when he experienced an oxygen desaturation. A care plan with information stating Mom could handle incidents and that she would call for assistance if needed would have been helpful. Another consideration would be to assign primary neonatologists to assume care of the infant until care is transferred to the pediatrician. Although in principal, the pediatrician is to be the primary communicator to the parents about their infant, this often does not happen in practice. A primary neonatologist would be able to provide a more consistent approach to care and information giving. Parents are also often assigned a pediatrician, and also do not realize that it is their right to request a pediatrician that they would be more comfortable with. Therefore, all parents for whom a pediatrician was assigned should have their feelings explored about how comfortable they are with the pediatrician. If they are to form a partnership with this person for ongoing health care issues concerning their child, they need to have somebody of

whom they feel they can effectively communicate with to ensure the best possible care of their child.

It also important to realize that although most parents want to be given all information, some parents may need to be given information in measured doses to avoid being overwhelmed. This was the case with one family seen during the practicum project. When questioned, they stated that they realized the neonatologist needed to give them the information, and they needed to get it, but they didn't "hear" the information that was being given to them. The stated when they started to hear the "list" of complications they "shut down", and couldn't absorb it all. Health care professionals need to be aware of this and therefore recognize why families often need multiple explanations of what is happening to their infant. Health care professional should therefore not become impatient with the families' repeated requests for information.

### **Decision Making:**

Families' abilities to take part in decision making are correlated partly with how well they are informed and how well they feel involved with the care of their infant (Ward 2000). One strategy that has been recently implemented in the NICU at HSC is the welcoming of parents to morning and checkout rounds. Parents have the chance to hear the treatment plan for the day and ask any questions of the staff. However, this strategy is a still fairly recent implementation of family-centered care, and staff is still feeling out their comfort levels when it comes to parents participating in rounds. It is sometimes dependent on the neonatologist in charge as to how involved the parents are on rounds. Additionally, parents sometimes need support as to what to expect on rounds and some clarification of what their rights are. This is also dependent on

support from the medical and nursing staff. This is crucial to enable families to be able to trust what we are doing, feel more in control of events while their child is in the unit, and to enable effective communication between the parents and the rest of the health care team (Cescutti-Butler and Galvin 2003).

There is also a need to identify and integrate the values of parents when decisions about intensive care and subsequent discharge of their infant (Raines 1996). Medical staff need to acknowledge these values if comprehensive, and individualized care is to be given to the high-risk infant and his family (Raines 1996).

### **Concerns and Fears:**

Although most of the parents interviewed were mostly happy with the care their infants received they still had concerns regarding some staff. Additionally, three of the families identified that at times they felt unhappy with the way the infant was treated but didn't say anything because they did not want to upset the staff and risk their infant not receive good care. This concern is also echoed in previous research. Sawatzky-Dickson's (1996) research demonstrated that parents are reluctant to express how they felt about the care their infant received for fear of creating a negative impact on their infant. Parents may also not feel safe registering their concerns whilst their infant remains under the care of the NICU staff. They expressed fear that their infant would not receive good care if the nurses were "mad at them" (Sawatzky-Dickson 1996). Additionally, families identified the following as concerns with staff: staff that did not want to talk to them and address their concerns, seemed cold/distant, and were rough with their babies (Wereszczak, Miles, and Holditch-Davis 1997). This also supports the concerns echoed by the families in this project.

It is concerning that some parents would feel this way while their infant is being

cared for in the NICU. Nurses and other staff caring for infants should bear this in mind when caring for the high-risk infant and his family. Nursing staff and other health care professionals caring for the infant need to realize that parents' perceptions of competency often has very little to do with how well tasks and procedures are performed. It is often measured by how effectively staff communicates with them, how they make them feel while they are visiting in the unit and also how they treat their baby (Cescutti-Butler and Galvin 2003). The neonatal staff needs to remember how vulnerable parents and family is at this very stressful time in their lives. The more control the parents feel about what is happening to them and their infant the less likely they will feel like outsiders in the care of their infant. This is the core principal of family-centered care and should be encouraged. Nursing and other health care staff need to realize that the fostering of parent's self esteem and their capacity to care for their infant is also highly correlated with attachment behaviours to their infant. Bearing this in mind will help to achieve the goal of discharging these children home with parents that feel enabled and empowered to care for their children (Chen and Conrad 2001).

### **Preparing for Home:**

As previously addressed, most families felt adequately prepared to take their infants home after their stay in the NICU. However the lack of continuity of care again was raised as a major concern when preparing for home. Health care staff need to be made aware of this concern to enable them to put into practice the principles of family-centered care. It does not help families to have their child in a unit with a "Family-Centered Care" philosophy and not implement this philosophy at the time of discharge of the premature infant. We need to realize that the family is the constant in the life of the infant, and as they are preparing to assume full care of the infant, it is our job to



empower and enable them as much as we can. This does not mean that we cut them off without adequate support in place, but rather we help them feel that they are capable of caring for their child (Chen and Conrad 2001). One of the strategies would be to ensure that primary nurses or a core group of nurses assumes care of the infant and makes a plan of care with the family to assist with the infant's discharge. This would hopefully prevent some of the problems previously described. Parents would feel more in control of how the discharge process was proceeding and not have to worry that somebody caring for their infant does not know him or them. This would make parents feel more comfortable with and trusting of the medical staff as they are prepared to take their infant home.

**Supports:**

It is important to note the varied levels of support that is available to each family after they are discharged home to their family. The support in these families varied from little to adequate support post discharge. The one family that had little family support in place was encouraged to ask friends for help as needed. They were also given the number for other support services in their area.

In this era of mobile family units, it is crucial that a thorough assessment of support systems is carried out prior to the infant being discharged home. If the family has no extended family members that are available to help them when they get home, contact numbers of various support groups (eg. Laleche League), public health programs (eg. breast-feeding hotline), and numbers for the community health clinic in their area should be given to the parents in advance of the infant's discharge. If they are able to do so, parents could be encouraged to go and see the community programs at their community health clinic and get to know some of the staff prior to the infant's discharge.

This is what one Mom did prior to the discharge of her infant. She found this to be extremely helpful later when her baby was discharged, because she was familiar with the staff at her community health clinic. It is unfortunate that most of these families do not qualify for extra formal support from home care programs. It would be especially nice for those families that do not have anyone to help with cooking and cleaning. This would give them time to be with and adjust to changes associated with bringing a recovering premature infant home from hospital.

Additionally it would be helpful to gather information regarding maternity and parental benefits for families. Most of the families encountered difficulty, misinformation and inconsistencies when applying for benefits. Neonatal staff, either nursing or social work, should prepare information for families about whom to call and what questions to ask when applying for benefits. This would help to ensure that all families get the benefits that they are entitled to.

### **DISCUSSION OF RESULTS:**

There were certain differences encountered when assessing the needs of these families as compared to other programs that support high-risk infants and their families. VonPlaten (personal communication 2002) stated that often parents are so overwhelmed with day-day tasks when the first week home, that support offered during this time frame consisted of basic feeding, calming of the baby and sleeping support. This practicum project found that although parents did need some level of support in these respects, overall, most of them seemed to know their babies the best and what worked for them in terms of interacting with them, getting them to sleep and feeding them. The one family that required additional feeding support had been given the

number for a dietician to help with their infant's feeding intolerance. Parents encountered during the practicum project seemed to need information in order to feel that they were providing their infants with adequate care. Families often needed specific information, and needed to be put in touch with various community resources in order to deal with the specialized needs of their infant. Examples of this include the family who had the vision impaired child and also the family who had the child going home on enoxaparin therapy.

It is interesting to note that all of the 4 families that declined participation had young mothers between the ages of 19-20 years. This led to speculation that perhaps the mothers' developmental stage may have influenced their decisions (Robinson 1992). Teens and young adults struggle with the development of their identity and life goals, and want to be seen as independent and capable of making their own decisions (Robinson 1992). Having another health care provider (the practicum student) factored into the care giving of their infant may therefore have been seen as taking some of that independence and decision making away from them.

In discussion with VonPlaten (personal communication March 2004), there are differences in the population served in Calgary as compared to the infants seen in this project. These differences include the following. The infants they see in their program are less than 1250 grams. Gestational age is not a factor. They will also see other infants if they are referred to them, including infants with congenital anomalies. Length of stay was comparable to that noted in this practicum project. It is interesting to note that about 80% of the infants discharged home from Calgary Hospitals require oxygen therapy and may also need their feeding supplemented through tube feedings. This may be a factor in the reason why families in Calgary require so much help with basic

care activities surrounding their children's care. The fact that there is a program dedicated to this specific group of high-risk infants may also influence an earlier discharge. However, many children were sent home on technologically based care prior to the inception of this program. The transitional care program sees families that reside outside of Calgary within an hour's drive. Public health nurses see those infants that live beyond the Calgary Regional Health Authority after discharge home. Perhaps these families would experience needs similar to those encountered in this practicum.

Of the high-risk neonatal patients discharged home in Manitoba, most do not require any technology-based care. For those that do, the home care program based out of Children's Hospital follows them and provides care. However, home care only supports families that require technology- based care, and provides care to all children of all ages, just not the neonatal population. This practicum project was able to identify that even if premature infants are relatively healthy at the time of discharge there are still identifiable needs experienced by the family that are not necessarily met by the current support systems in place. This was evident by the care provided by the practicum student and also the information given that allowed families to access care specific to their infants' needs. Families may eventually been able to access this care, but the contact numbers provided through the practicum project allowed the families to access the information and care they required in a more timely fashion.

#### **Limitations of the Practicum Project:**

There were limitations of the findings of this practicum project. The most obvious is the small sample size. The sample was also a convenience sample. A convenience sample was utilized, as it was difficult to find infants and families that met the requirements outlined above. It would have been preferable to follow a larger group of

infants and their families, however the availability of such a focused group was difficult to obtain. As such, it took almost 11 months to recruit five infants and their families. Additionally, it would have been beneficial to randomly assign groups of infants to transitional care provided by the practicum student and traditional community health based care, and then compare the results between the two groups. Again, this would have been difficult given the limited availability of infants born at 28 weeks or less.

Another limitation of the project was the involved nature of the practicum student with the infant and his family. This is because the student got to know the families quite well, and this may have resulted in biased information being shared by the families with the student. Although the parents were told that findings would be kept confidential, they may have given answers to the questions based on what they thought the student might want to hear. The families did share some candid reflections about their infant's stay in the NICU, however, and they did so without prompting by the student.

Although parents stated they were happy with the care provided to them by the practicum student, they may have felt pressure to do so. Again this is related to the involved nature of the practicum and the parents not wanting to disappoint the practicum student.

### **Relationship to the Theoretical Framework:**

The theoretical framework guiding this practicum project is that families should be provided with care that is family-centered in its philosophy. The mission statement of Childrens Hospital also reflects this philosophy. Neonatal staff must continue to strive to provide family-centered care during the infant's stay in the NICU, the Intermediate care nursery and right through to the discharge process. Policies and guidelines surrounding care must continue to reflect the principles of family-centered care. The NICU at

Children's Hospital has taken several steps towards the provision of family-centered care. The practicum project attempted to incorporate the principles of family-centered care at all times. Parents and the extended family were seen as the constant in the infant's and when the infant was discharged home. Collaboration between the practicum student and the parents was ongoing. Information was given to the parents in a complete and unbiased format. Strengths of families were reinforced and needs were assessed. Each family was supported according to their unique needs and referred to programs they required caring for their infant. Services and supports in the community were arranged for families. Families were also given contact numbers so they could arrange appointments and meetings that coordinated with their schedules. Hopefully these strategies empowered parents so that they will be able to make more informed decisions about their child's care.

Although family-centered care in the NICU/Intermediate Care Nursery has been adopted in principle, putting theory into practice continues to be improved upon. These areas will be discussed in the following implications for practice.

### **IMPLICATIONS FOR PRACTICE:**

Despite the small sample size of the practicum project, it was evident that these families were still in need of professional support from a practitioner familiar with the unique needs of premature infants post-discharge. This has certain implications for our practice. Unfortunately, there is not a program in place that offers this level of support to families when they are discharged home with their premature infant. With this in mind, NICU staff should make note of some of the resources families may need to access and discuss these resources with the family prior to discharge. For example, with an infant

that has vision impairment, arranging a meeting with CNIB for the family prior to the infant's discharge may prove to be invaluable. It could help to introduce resources that would be available to them.

The discharge teaching records should be reviewed on a regular basis as technology progresses and also to determine gaps in information given to parents. For example, electronic tympanic thermometers are now available for home use. Two of the families were using this product without realizing that this product is not appropriate for use in infants. Additionally, each discharge teaching record should be carefully reviewed to ensure it meets the needs of each individual infant and their family.

Most of the families encountered in this project were comfortable with the basic care requirements of their infants. They required help and support accessing community supports and information to deal with the specific health concerns of their infant. For example, one family required the services of a dietician. This family was not sure how to this and also did not realize that they had the right to request this service for their infant. Often parents require support and reinforcement that they can and should be the advocates for their children's ongoing care. If the staff anticipate there may be concerns regarding the infant that may not be addressed by the parents' current support systems, they can provide parents with the necessary information prior to discharge.

The lack of continuity in information giving and of care cited by some of the families is concerning. Neonatal staff should be made aware of these concerns and take measures to improve in this area. As previously discussed, primary neonatologists and primary nursing would improve communication and care giving between the neonatal staff and the families. Families need to be given information at a level they can understand so that they can be active partners in the decision making concerning the

care of their infants. Neonatal staff often remains reluctant in having families as active participants in decision making. However, the family is the constant in the infant's life. They should be supported in decision making to enable them to become informed decision makers and advocates for their children's' care once discharged from the NICU. This would hopefully prevent problems with parents being unable to request care or information regarding their infant's care. One strategy to help parents feel more enabled to make decisions or take part in decision making is to describe what happens on rounds and what their role would entail. Another strategy would be to explore their relationship with the infant's pediatrician. Parents should feel comfortable talking with the pediatrician and happy with the information they receive. Parents need to know that this is within their rights and will help them with the care of their infant once discharged home. The parents should be supported in obtaining the care of another pediatrician, if they feel they are not getting the care they require. A good relationship between the parents and the pediatrician is crucial for the ongoing care of the premature infant. This is especially true if the infant has ongoing medical concerns.

Although in the past neonatal staff has encouraged informal networking between parents during their infant's stay in the NICU, recognition of the need for a formal program is required. Formal parent groups can help parents adapt to the crisis of the infant's prematurity and hospitalization, and offer information and support to the family (Bracht et al. 1998). The NICU at Children's Hospital is in the process of initiating a formal parent to parent support group. The coordinator of this program will be a parent who has had a premature infant in the NICU. This will be a part-time paid position. The purpose of the program will be to allow parents a chance to voice concerns and talk to somebody who has experienced what they are going through. Parents and family are



more likely to feel that they are being supported through a program such as this. Being able to talk to some one who "has been there" can validate some of their feelings (Preyde and Ardel 2003). They are then less likely to think that what they are feeling is abnormal. This program could prove to offer additional support to families when they bring their premature infant home. They would be able to talk to someone who has gone through the process, and would be able to find out what worked for some families and what may work for them.

Finally, a program that would allow cross training of neonatal nurses to provide care from the NICU right through to discharge and to home would be the ideal goal for families when they take their premature or high-risk infant home from a tertiary care facility (Swanson and Naber 1997). This would be the best possible way to provide seamless healthcare to the infant and his family. Additionally, a program such as this could potentially decrease NICU stays, decrease the rates of readmission's and most importantly provide the continuity of care that these families expressed as a need (Swanson and Naber 1997). Most of the families in this practicum project stated they found it extremely helpful to have contact with someone that knew their infant while he was in the hospital. They found it helpful to have someone reassuring them that their infant was adapting to the transition home.

### **CONCLUSION:**

Although differences were found in the populations served in Manitoba vs. Calgary the practicum project was found to be a success. Implementation of the transitional services protocol for premature infants discharged home from tertiary care, was indeed feasible to carry out. Although the families were reasonably comfortable with feeding and calming of their infants, the practicum student helped families to identify needs and

access community resources to care for their recovering premature infant. The practicum project may have also prevented some problems surfacing in infants that may have required more intensive therapy. Future directions for the care of high-risk infants and their families would be to implement a transitional program. This would provide the utmost in continuity of care from tertiary care to home. The WRHA wants to promote seamless health care for individuals from hospital to home care. The development of a transitional services program for high-risk newborns would be the epitomize continuity of care of the high-risk premature infant and his family. It would also help identify any developmental or family problems that could impede the optimal development of the premature infant.

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**Appendix A****Script for nurses:**

As you are getting ready to take your infant(s) home, I would like to make you aware of a project being undertaken by a graduate-nursing student, who is also a nurse in the NICU. She is trying to determine whether or not providing transitional care may help when you are preparing to take your infant(s) home. Transitional care means that you and your infant will be seen in hospital prior to discharge and then seen in your home after discharge. Care that will be provided would consist of reviewing discharge teaching, feeding support, assessing your baby's sleep and interaction with other family members, and assessing your knowledge of community supports. Your infant's medical records will also be accessed prior to the home visits (after obtaining informed consent from you). The medical chart will be reviewed to determine your infant's gestational age and also to assess what type of complications he/she may have had, such as intra-ventricular hemorrhage, bronchopulmonary dysplasia and feeding problems. If you are interested in the project there is a letter describing what this care consists of and the project itself. If you wish to receive this care and participate in the project you may do so, and let us know of your willingness by signing the consent form.

**Appendix B****Invitation to participate and description of the practicum project:**

Hi, my name is Janice Beveridge. I am a graduate student at the University of Manitoba. To fulfill part of the requirements towards a Masters of Nursing degree, I am undertaking a practicum project titled "Assessing the Feasibility of a Transitional Services Protocol for Premature Infants Discharged Home after Tertiary Care". As part of my practicum project, I wish to provide families transitional care, and assess its effectiveness, when they are preparing to take home a premature baby who has spent time in the Neonatal Intensive Care Nursery (NICU) and/or Intermediate Care Nursery at the Health Sciences Centre, or St. Boniface Hospital. Transitional care means that you and your baby will be visited in the hospital prior to discharge and then again when you are discharged home. This practicum project will be supervised by professor Debra Askin M.N., of the University of Manitoba. Her contact number is 474-9972.

This care will provide you and your baby with additional support after going home. It will consist of assessing and supporting your baby's feeding, sleeping, and you and your baby's interaction with one another. It will also reinforce the hospital's discharge teaching, assess for any stressors you may have and assess your knowledge of community supports. You and your baby will receive a minimum of one visit, and up to four visits after leaving the hospital. These visits will range approximately 30-60 minutes in length. It is entirely up to you whether or not you would like this/these home visit(s). If you decide not to it will not influence the care your baby receives while in the hospital. These visits would NOT take the place of visits made by the public health nurse, or your baby's scheduled visits with his doctor. Additionally, I wish to determine your care needs during the first week at home, and whether or not you felt your discharge preparation

and support were adequate. This will take place by an interview lasting about 15 minutes. I also will observe you in your home with your baby, and take field notes about these observations for my practicum project. This information would be collected and may be used at a later date to assist other families when they are taking a premature baby home from hospital. If you have any questions, feel free to contact me at \_\_\_\_\_, and leave a message.

Thank you,

Janice Beveridge RN BN

**Appendix C**



**Research Project Title:** Assessing the Feasibility of a Transitional Services Protocol for Premature Infants Discharged Home from Tertiary care

**Researcher:** Janice Beveridge R.N. B.N.

**Sponsor:** Health Sciences Centre Nursing Research Committee

**This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.**

## PURPOSES OF THE PRACTICUM PROJECT:

The purposes of this practicum project are as follows: 1) To provide transitional care support to you and your premature infant who has spent time in the Neonatal Intensive Care Unit (NICU), or Intermediate Care Nursery at the Health Sciences Centre. Transitional care consists of helping you to prepare for your infant's discharge home and continues when you take your infant home. This care would consist of reviewing discharge planning and teaching, feeding support, determining how well your infant is sleeping and interacting with other family members, and assessing your knowledge of community supports. Transitional care may help to lessen the stress of bringing a recovering premature infant home. 2) To collect data about the family and their transition home, to see if this care is indeed helpful. 3) Finally, this practicum project will be undertaken to also fulfill part of the requirements of a Master of Nursing Degree.

## PROCEDURES INVOLVED:

After obtaining informed consent, your infant's medical chart will be reviewed. The purpose of this review is to determine your infant's gestational age, the time he has spent in hospital, and to determine any complications he had, including but not limited to, respiratory distress syndrome, feeding difficulties, intra-ventricular hemorrhage, and bronchopulmonary dysplasia. The practicum student, who is also a nurse in the NICU, would provide transitional care and support. The care would take place first in hospital before going home, and then via home visits. There would be a minimum of one, and up to four home visits. Visits will vary in length from about one half hour, up to one hour if needed. You will be visited within a few days of going home. As previously mentioned, care that would be provided would consist of reinforcing the discharge teaching done prior to discharge, feeding support, determining how well your infant is sleeping, assessing your infant's interaction with their family, and assessing your knowledge of community supports. This care would not take the place of public health nurse visits and other scheduled and unscheduled visits to your family doctor. You will be one of five families with infants born at 28 weeks gestation or less that will be provided with transitional care/support. Information will be collected to determine how well prepared you felt in taking your infant home from the NICU or Intermediate Care Nursery and what could have made the transition home easier. Information will be collected by an informal interview lasting about 15 minutes, with you and your family. Field notes will be taken while at your home and also after the student leaves your home, which will be utilized in the practicum project. Please note that if an abuse situation is encountered during the home visits, the student will be ethically bound to report the situation to the proper authorities.

## RISKS AND BENEFITS INVOLVED:

There are no anticipated risks or minimal risk for you and your infant. As previously mentioned this care supplements but does not replace the care your infant would normally receive from family doctors and public health nurses. Benefits to you and your infant and include help with infant feeding, settling of the infant, reinforcement of discharge teaching, and referral to community supports that may be helpful to you and family. You will not be paid for your participation in this project, however you will not incur any costs. The information collected about your transition home may be utilized to help other families when they take their premature infant home.

## ANONYMITY and CONFIDENTIALITY:

Provisions will be under taken to safeguard personal health information and to ensure compliancy with the Manitoba Health Information Act. They are as follows: 1) Prior to accessing personal health information from your infant's chart, consent will be sought from you (see above) to access this information. Only the information outlined in the consent form will be accessed. Medical records that contain your child's identity will be treated as confidential in accordance with The Personal Health Information Act. By signing the attached consent form, you consent to direct access to your child's medical records. 2) The information will only be handled or seen by those actively involved in the practicum project ie the student, the advisor and the student's practicum committee. Participants will be referred to as Infant "A" and family, etc. The practicum project will later be presented in a practicum defense to fulfill the Masters of Nursing degree requirement. However, participants will not be identifiable in this presentation. 3) During the project, the personal health information, and all other data collected will be kept at the student's home, and locked in a file cabinet when the project is not being actively worked on. At the end of the project, and after successfully defending the practicum, all data and information collected will be stored for the appropriate amount of time and then destroyed.

## FEEDBACK:

A letter will be sent to you and your family outlining the findings of this project. This letter will followed up with a phone call to determine if you have any questions about the findings.

**Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.**

If you have any questions or concerns about this project, please contact Janice Beveridge, R.N. B.N., at \_\_\_\_\_ or \_\_\_\_\_, or the supervisor of this project, Professor Debra Askin M.N. at 474-9927.

**The Education/Nursing Research Ethics Board has approved this research. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat at 474-7122. A copy of this consent form has been given to you to keep for your records and reference.**

Participant (printed name) \_\_\_\_\_

Participant's Signature

\_\_\_\_\_ Date \_\_\_\_\_

Researcher (printed name) \_\_\_\_\_


Researcher and/or Delegate's Signature

\_\_\_\_\_ Date \_\_\_\_\_



## Appendix D

Copies of discharge teaching forms

 <b>Health Sciences Centre</b> <b>INTERDISCIPLINARY</b> <b>PATIENT EDUCATION RECORD</b> Premature Infant - Discharge Teaching		DATE _____ HSC NO. _____ PATIENT _____ DOB _____ MHSC _____ DOCTOR _____ CLINIC/UNIT _____ LOC'n _____	
<b>ASSESSMENT</b> Date Assessed: _____ (please initial) Learner(s): _____ Ready to Learn: <input type="checkbox"/> Yes <input type="checkbox"/> No If no, IPN is required (see criteria on reverse)			
<b>EXPECTED OUTCOMES</b> <i>Indicated outcomes to be signed off by professionals other than word RN if consulted</i>		Date/Initial Outcomes Achieved	<b>VARIATION FROM EXPECTED OUTCOMES</b>
1. Received Discharge package 2. Other resources received: _____ 3. Understands: 3.1 feeding: - considerations - supports 3.2 bathing precautions 3.3 respiratory: - precautions - signs of distress 3.4 elimination: - possible changes - resources 3.5 oral hygiene considerations 3.6 sleep: - tips for getting baby to sleep - balancing sleeping and eating 3.7 signs of stress 3.8 promoting growth & development 3.9 preparing the home 3.10 hints on coping 3.11 safety issues for prems 3.12 follow-up 4. Demonstrates: 4.1 bathing & diapering 4.2 feeding 4.3 medication administration 4.4 positioning: - for sleep - in car seat			
Init.	Signature & Classification	Init.	Signature & Classification



## NEONATAL DISCHARGE PLANNING

## AREA OF LEARNING

## DATE DISCUSSED

## SIGNATURE

## FEEDING:

Positioning (breastfeeding film, handouts given)		
Frequency/Duration of feed/Suck assessment		
**Hydration assessment (# of wet diapers, colour of urine, mucous membrane assessment, skin dryness)		
Jaundice (handout given)		
Production/Engorgement/Nipple Care		
Breastmilk collection, storage and transportation		
Lactation consultant		
Formula Preparation (handout given)		
Tube care (ie: gastrostomy supplies needed and skill demonstrated)		
Related feeding issues		

## RESPIRATORY:

Normal pattern		
Distress, signs & symptoms		

## BABY CARE:

Baby bath/Video/Return demo		
Diapering Cord Care: preterm vs. term Stools: variations		
Circumcision care (handout given)		
Positioning for sleep (handout given)		

DATE DISCUSSED

**SIGNATURE**

ROM exercises (skill demonstrated)		
Choking baby		
Car seats/Car Seat Tolerance Testing		
Transportation arranged		
Temperature taking/aware of norms		
Medications Immunizations (handout given) Administration: side effects, times, method, prescription given		
Infant referral form completed		
Letters sent (i.e.: area physician, area hospital)		
Native Services Worker Involved/Social Work		
Respite Care Information		
Special Services Information Given		
Supplies needed and information to obtain additional supplies		
Return appointment(s)		
Home safety (handout given)		
CPR (where to access course)		

## Comments/Additional Information

[illegible]

## **Appendix E**

### **Interview Guideline**

- 1) How long was your baby in hospital?
- 2) While your baby was in hospital, how involved did you feel in his/her care?
- 3) How well informed did you feel about his/her condition?
- 4) How much did you feel your opinions and feelings about your baby and his care were taken seriously by the health care team?
- 5) While your baby was in hospital, did you feel like a member of his team, in terms of being informed and a part of his care?
- 6) When preparing for discharge home, what were your biggest concern(s) and/or fear(s)?
- 7) How involved did you feel in the discharge planning of your baby?
- 8) Did you feel adequately prepared to take your baby home?
- 9) How much did you feel your opinions and feelings about your baby's discharge plans were taken seriously by the health care team?
- 10) Did you feel a part of the health care team when preparing for your baby's discharge home?
- 11) Was there any information provided to you that you felt was particularly helpful in preparing you to take your baby home?
- 12) Do you feel you were given enough help and support in the method you feed your baby?
- 13) What supports did you have in place for when you brought your baby home?
- 14) Did you feel you could have utilized additional support?

- 15) Have you been visited from the public health nurse?
- 16) How helpful was the public health nurse in giving you additional information/advice about the care of your baby?
- 17) Have you found your pediatrician and/or family doctor to be helpful in providing you with advice and support?
- 18) Who has provided you with the most help since you have come home?
- 19) Do you have any concerns at present times that have not been addressed by the health care professionals previously discussed?
- 20) How helpful has it been to have a nurse (myself) from the NICU visit you?
- 21) When looking back at your baby's first week home, what suggestions do you have that would have made the transition home better?
- 22) What community resources are you aware of that could help you in your transition home with your baby?
- 23) Did you find these resources helpful in your transition home with your baby?

**Appendix F****Budget****Proposed Budget**

<b>Expense Items</b>	<i>Jan</i>	<i>Feb</i>	<i>Mar</i>	<i>April</i>	<i>May</i>	<i>June</i>	<b><i>Total</i></b>
<i>Automobile</i>	\$10.00	\$20.00	\$20.00	\$20.00	\$10.00	\$10.00	\$90.00
<i>Telephone</i>	\$10.00	\$20.00	\$20.00	\$10.00	\$10.00	\$10.00	\$80.00
<i>Photocopying</i>	\$5.00	\$5.00	\$5.00	\$5.00	\$5.00	\$5.00	\$30.00
<b>Total Budget</b>							<b>\$200.00</b>

Automobile - 450 kms @

\$0.20/km

Telephone - 25 calls at approx. \$3.00/call

Photocopying - 300 pages @

\$0.10/page

**Appendix G****NILT CATEGORY DEFINITIONS AND PROTOTYPICAL INTERVENTIONS**

<b>Conceptual Definition</b>	<b>Interventions</b>
Care Need Determination (CND)	<p>Take history of families' past experience with health care services.</p> <p>Seek information about families' normal routines and habits.</p> <p>Assess families' awareness of community supports.</p> <p>Helping families' to identify stressors.</p> <p>Assess families' knowledge of premature baby care.</p> <p>Assess families' knowledge of feeding care of premature babies.</p> <p>Ask families' knowledge of how illness presents in a premature baby.</p>
Care Vigilance (CV)	<p>Evaluate infant to assess physical and behavioural state.</p> <p>Monitor color, hydration, and breathing patterns.</p> <p>Check elimination patterns.</p> <p>Check feeding patterns.</p>
Care Environment Management	Assessment to determine if the environment is

(CEM)	<p>appropriate for recovering premature infant (eg comfortable, clean, reduced stress, and with appropriate developmental toys etc.)</p> <p>Involvement of support systems if needed and/or wanted by families' to enable them to interact with and get used to their infant being at home.</p>
Therapeutic care general (TCG)	<p>Assessing families' ability to get adequate rest, and meals.</p> <p>Assist with baby care.</p>
Therapeutic Care Psychosocial (TCP)	<p>Discuss feelings about being home "alone" with their infant.</p> <p>Assessing families' coping with the introduction of the infant home and assessing for any maternal post-partum depression.</p>
Therapeutic Care: Cognitive Understanding and Control (TCCU&C)	<p>Support families' knowledge of community supports, family supports how to recognize the need to call for help, and who to call for help.</p> <p>Promote families' independent care of their infant.</p>
Care Information Provision (CIP)	<p>Teaching families about community resources, high-risk developmental clinic, breastfeeding support services, and community mental health</p>



	<p>resources.</p> <p>Reinforce recovering premature infant care.</p> <p>Discuss premature infant development vs term infant development.</p>
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