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The Information and Support Needs of Primary Caregivers of Premature and/or Medically Complex Infants upon Discharge from the Neonatal Intensive Care Unit.

**By
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Thesis Submitted to the Faculty of Graduate and Post Doctoral Studies in partial fulfillment of the requirements for the degree of Master of Science in Nursing

**University of Ottawa
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Abstract

Objective: To determine the perceptions of primary caregivers of premature and/or medically complex infants regarding information received prior to discharge from hospital and information and support needs four weeks after discharge from a Neonatal Intensive Care Unit (NICU).

Design: Non-experimental descriptive design with administration of two questionnaires prior to and four weeks after discharge. Demographic information was collected prior to discharge.

Setting: Prior to discharge, the NICU of a regional pediatric teaching hospital and four weeks after discharge, the home environment.

Participants: Thirty of thirty-two (94%) consecutively discharged primary caregivers of premature and/or medically complex infants enrolled over a four-month period.

Results: Information related to basic infant care was perceived to have been provided. Information related to infant environment, behaviour and development, the unique characteristics of premature infants and recognition of changes in infant's health status require more attention. Written information and a number of a place to call for information were wanted.

Conclusions: Primary caregivers indicate the need for reinforcement of information provided in hospital once they are at home, especially in the area of infant behaviour and development and characteristics specific to the premature infant. This is relevant to program planning and a method to deliver and/or reinforce this information should be developed.

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CHAPTER ONE

Introduction

This chapter provides an overview of the organization of the thesis. An introduction to the issues facing parents of premature and/or medically complex infants is first presented, followed by a rationale for determining the information and support needs of the families of these children. The chapter concludes with a statement of the objectives of the study.

Organization of the Thesis

The thesis is divided into five chapters. The content of the first chapter is described above. The second chapter provides a critical review of the relevant literature as well as a description of the selected conceptual framework. The third chapter describes the study methodology. The fourth chapter presents the findings of the study. The final chapter discusses the study results, the limitations of the study and the implications for nursing practice as well as future research.

Premature and/or Medically Complex Infants

Preterm birth is recognized as a leading cause of infant morbidity and mortality in Canada and the United States (Canadian Pediatric Society (CPS), 1994; Ladden, 1990a; Moutquin & Lalonde, 1998). About seven percent of babies are born prematurely, before 37 weeks gestation, in Canada (Health Canada,

1999). Mortality ranges from 50 – 90% for an infant born between 23 – 24 weeks gestation (CPS, 1994). Premature infants are more likely to suffer neurodevelopmental impairment and physical disability (Blackburn, 1995; Brooten, Gennaro, Knapp, Brown, & York, 1989; Ladden, 1990a; Ramey et al., 1992). If born between 23 - 24 weeks gestation, up to one third of the survivors will have evidence of mild disability and approximately 10% will have severe disability (CPS, 1994). As gestational age increases the likelihood of disability decreases, however, long-term sequelae may be present in up to 15% of infants born at 32 weeks gestation (CPS, 1994). A proportion of the infants admitted to an NICU will, by virtue of their gestational age or sequelae of their birth, be classified as medically complex and will have an extended reliance upon the health care system.

Parents of Premature and/or Medically Complex Infants

The lived experience of parents of a premature and/or medically complex infant is different from that of parents of a healthy term infant. For parents with a critically ill infant, the transition to parenthood, is compounded by worry and concern about their baby's medical condition, including fear of death (Affleck, Tennen, & Rowe, 1991; Brooten, Gennaro, et al., 1988; Kenner & Lott, 1990; McKim, 1993a). Parents of premature infants recount increased levels of stress (Brooten, Gennaro, et al., 1988; Hughes, McCollum, Sheftel, & Sanchez, 1994; Ladden, 1990a; Roman et al, 1995; Youngblut, Brennan, & Swegart, 1994). McKim (1993a) noted that the less information about infant care a parent had the

higher the stress level. Parents report feelings of powerlessness/helplessness (Kenner & Lott, 1990) and role confusion (Affonso et al., 1992; Rikli, 1996; Scharer & Brooks, 1994). They are less confident in their parenting abilities (Gennaro, 1985) and often feel inadequate as caregivers (Affonso et al., 1992; Gale & Franck, 1998). Information and access to support, professional or social, can mediate parental concern about their ability to care for their infant (Gennaro, 1991; Holditch-Davis & Miles, 2000; Kenner & Lott, 1990; McKim, 1993a). Stewart (1995) defines social support as "interactions with family members, friends, peers and health providers that communicate information, esteem, aid and emotional help" (p. 93).

Family well-being and the caregiving environment are important predictors of infant outcome (Able-Boone & Stevens, 1994; Brazy, Anderson, Becker, & Becker, 2001; Gennaro, 1991). Immediate separation of mother and baby, prolonged hospitalization, and loss of the idealized child can lead to altered parent-child attachment and parenting behaviours (Brooten, Gennaro, et al., 1988, Coffman, Levitt, & Deats, 1990; Ladden, 1990a; Leonard, Brust, & Nelson, 1993; Miles, Funk, & Carlson 1993; Singer et al., 1999). Parents of premature and/or medically complex infants experience an increase in caregiver burden (Ray & Ritchie; 1993; Singer et al., 1999; Teague et al., 1993). These attributes all have consequences for family well-being and coping with the premature and/or medically complex infant after discharge (Brooten et al., 1989; Coffman et al., 1990; Klein Walker, Epstein, Taylor, Crocker, & Tuttle, 1989; Miles, Holditch-Davis,

Burchinal, & Nelson, 1999). Knowledge and skills have been identified as adaptive resources to help parents cope (Canam, 1993; Deatrick & Knafel, 1990; Kenner & Lott, 1990; Leonard et al., 1993; Stephenson, 1999; Sterling, 1990).

Parents of premature and medically complex children need information about the following: 1) basic infant care (feeding, bathing and handling); 2) prevention and recognition of illness; 3) growth and development; 4) behaviours specific to premature infants; 5) infant's medical condition; 6) technology in the home and 7) interaction with the health care system (Brooten et al., 1989; Drake, 1995; McKim, 1993a, McKim et al., 1995) as they prepare to take their child home. Selder (1989) suggests that the quest for knowledge can reduce uncertainty in a transitional state. Parents with unmet informational needs experience greater anxiety and decreased confidence when caring for their baby (McKim, 1993a, 1993b).

To date, no studies have investigated the information and support needs of primary caregivers with premature and/or medically complex infants in Ottawa. This study will seek to identify and then describe parental information and support needs as they are discharged from a Neonatal Intensive Care Unit and four weeks after discharge. As parental needs are articulated and met, the transition to home can be facilitated and parental coping enhanced.

Study Questions

- 1) What are the primary caregivers' perceptions of the information provided by the NICU nurses related to the care of their premature and/or medically complex infant prior to discharge from the hospital?
- 2) What are the informational and support needs identified by the primary caregivers of premature and/or medically complex infants after four weeks at home?
- 3) Do the primary caregivers' perceptions of the information provided by the NICU nurses change over time?

CHAPTER TWO

Literature Review and Conceptual Framework

This chapter describes the search methods for the literature review, and provides a literature review on the following topics: alteration in parental role; stress related to the birth of a premature or ill infant and hospitalization; information and support needs; transition to home and follow-up. The conceptual framework for the study is described.

Search Strategy

The following databases were searched for the literature review: PubMed (1980 - 2000), Cumulative Index to Nursing and Allied Health Literature (CINAHL) (1982 – 2002), Medline (1982 – 2002), PsycINFO (1988 – 2002), Sociofile (1974 – 2002) and Cochrane Database. Key search terms included transitional care, neonatal home care, follow-up, high-risk, neonatal discharge teaching/discharge teaching and neonatal, early discharge, medically fragile infants, medically complex infants, discharge planning, neonates, information needs and support needs. The reference lists of key articles were also reviewed to glean other appropriate references.

Introduction to the Literature

There is an extensive literature on the issues associated with prematurity, including challenges during hospitalization and after discharge. Most of reviewed literature addressed the needs of caregivers of uncomplicated preterm infants (Affleck, Tennen, Rowe, Roscher, & Walker, 1989; Affonso et al., 1992; Brooten et al., 1989; Butts et al., 1988; Crnic, Greenberg, Ragozin, Robinson, & Basham, 1983; Drake, 1995; Edwards & Allen, 1988; Gennaro, 1985; Kenner & Lott, 1990; McKim, 1993a, 1993b; Minde, Whitelaw, Brown, & Fitzhardinge, 1983; Perehudoff, 1990; Ritchie, 2002; Termini, Brooten, Brown, Gennaro, & York, 1990; Zahr, Parker, & Cole, 1992) or normal newborns (DeSimone & Gottlieb, 1987). Much research has been done on the long-term impact of the medically complex, chronically ill or technologically dependent child/young adult on the family (Able-Boone & Stevens, 1994; Bond, Phillips, & Rollins, 1994; Diehl, Moffitt, & Wade, 1991; Horner, Rawlins, & Giles, 1987; Klein Walker et al.; 1989; Leonard et al., 1993; Patterson, Leonard, & Titus, 1992; Ray & Ritchie, 1993; Teague et al., 1993; Youngblut et al., 1994). A limited number of studies have addressed family adaptation to the medically complex infant (Arenson, 1988; Miles, Carlson, & Brunssen, 1999; Miles, Holditch-Davis, et al., 1999; Stephenson, 1999; Sterling, 1990; Sterling, Jones, Johnson, & Bowen, 1996). There is, however, a lack of investigation into the information and support needs of families with a medically complex infant, premature or term, during their transition to home and the immediate post-discharge period (Arenson, 1988; Brunssen & Miles, 1996). Issues related to this important life transition, the new and unpredicted reality in which families find themselves and the attempts to

reduce uncertainty during the emergence of this new reality have not been well described to date.

Alteration In Parental Role

The birth of a premature and/or medically complex infant is, often, an unexpected and critical life event for families and is fraught with new and unforeseen circumstances and challenges. Families with a premature and/or medically complex infant experience prolonged hospitalization and as a result, alteration in attachment and parenting behaviours (Affonso et al., 1992; Brunssen & Miles, 1996; Crnic et al., 1983; Miles, Funk & Carlson, 1993; Minde et al., 1983; Perehudoff, 1990). Several authors describe barriers to parenting in the NICU (Affleck et al., 1989; Brunssen & Miles, 1996; Gale & Franck, 1998; Griffin, 1990; Kenner, 1990; Ladden, 1990a; Miles, Carlson, & Funk, 1996; Wereszczak, Miles, & Holditch-Davis, 1997). Barriers have been categorized as physical (Brunssen & Miles, 1996; Wereszczak et al, 1997), psychological (Gale & Franck, 1998) and environmental (Brunssen & Miles, 1996; Ladden, 1990a; Perehudoff, 1990). Griffin (1990) reported that parents identified the nurse(s) as a principle barrier to parenting as a result of the relationship the staff had developed with the infant and staff attitudes about parental participation and provision of care.

In a Canadian study, Minde, Whitelaw, Brown & Fitzhardinge (1983) observed and digitally recorded parental interactions in 184 parents of singleton infants weighing <1501 grams at birth and found that length of hospitalization and

neonatal complications adversely affected parental, especially maternal, interaction with the infant. Maternal-infant interactions were decreased and parents whose infants were seriously ill continued to interact relatively little with their infants, even after the infants had recovered. Medically complex infants and multiples were excluded from this study, limiting the generalizability of the results.

In another Canadian study Pehudoff (1990) measured parental reactions to the NICU environment and found parental role alteration caused more stress for mothers than fathers. The issue of alteration of parental role is an important one – not only in the short term but for the post-discharge period as well. Nurses need to develop interventions and strategies that assist mothers to adapt to their unique parental role and to enhance maternal-infant attachment, a crucial component of healthy post-discharge adaptation (Kenner, 1990; Pehudoff, 1990; Singer et al., 1999).

Interactive behaviour is a measure of maternal-infant attachment. Crnic et al. (1983) found that stress and support were associated with maternal attitudes at one month and interactive behaviour at 4 months. In this study 52 mother-premature infant dyads and 53 mother-full term infant dyads were interviewed and observed to examine whether stress and social support affected maternal attitudes and early mother-infant interaction. Interviews were completed at one month and interactive behaviours were evaluated at four months. Mothers with greater stress, regardless of the gestation of their infant, were less positive in their attitudes (general life satisfaction, satisfaction with parenting) and interactive behaviour (mothers' sensitivity to their infant's cues). Mothers

with greater support, specifically support from a significant other, were more positive in their attitudes and behaviour. Maternal social support was associated with interactive behaviour at 4 months. These results support the important relationship of both stress and social support to the maternal-child relationship, particularly during early infancy and the transition to parenthood.

In summary, the birth of a premature or ill infant has impact upon the parental role. Maternal-infant interactions, a measure of attachment behaviour, can be adversely affected (Kenner, 1990; Minde et al., 1983; Perehudoff, 1990; Singer et al., 1999) and have consequences for the infant's development and outcome if stress is not reduced and social support provided (Crnic et al., 1983).

Stress Related To the Birth of a Premature Infant and Hospitalization

There are many sources of stress and uncertainty for parents after their baby's birth and during their infant's hospitalization. The literature revealed the following: appearance/behaviour of the premature infant (Gennaro, Zukowsky, Brooten, Lowell, & Visco, 1990; Goodman & Sauve, 1985; Miles et al., 1993), infant condition and outcome (Brooten et al., 1989; Butts et al., 1988; Gennaro, Zukowsky, et al., 1990, Holditch-Davis & Miles, 2000; Kenner, 1990); anxiety related to parental role (Affonso et al., 1992; Brooten, Gennaro, et al., 1988; Brunssen & Miles, 1996; Holditch-Davis & Miles, 2000; Kenner, 1990; Miles et al., 1993; Minde et al., 1983; VandenBerg, 2000; Wereszczak et al., 1997) and the environment itself (Brunssen & Miles, 1996; Miles et al., 1993; Perehudoff, 1990). The chronic nature of the infant's condition can lead to

increased financial burden (Diehl, Moffitt & Wade, 1991; Sterling, 1990), altered coping (Blackburn, 1995; Deatrick & Knafelz, 1990; Gennaro, 1985; Ray & Ritchie, 1993; Sterling, 1990; Teague et al., 1993), and impaired family functioning (Diehl et al., 1991; Ray & Ritchie, 1993; Teague et al., 1993).

A number of research studies found parents of premature infants experienced psychological distress, including stress, fear, guilt, anger and depression (Baker, 1995; Dokken & Sydnor-Greenberg, 1998; Gennaro, York & Broton, 1990; Gennaro, Broton, Roncoli, & Kumar, 1993; Johnston & Marder, 1994; Singer et al., 1999). Feelings of distress can continue for a prolonged period of time (Beveridge, Bodnaryk, & Ramachandran, 2001; Singer et al., 1999). Brunssen and Miles (1996) studied 57 mothers of medically fragile infants, a unique subset of infants in the NICU. The two main sources of maternal stress in this study were: 1) alteration in the parental role and 2) infant appearance and behaviour. Interestingly, the severity of the infant's illness, as measured by the Severity/Worry Scale (Miles et al., 1996) was not found to be a significant predictor of maternal worry or satisfaction with social support.

Singer et al. (1999) found that psychological distress, as measured by the Parenting Stress Index (Abidin, 1986 in Singer et al., 1999) was similar in mothers of low-risk very low birthweight (VLBW) infants and mothers of term infants. Mothers of high-risk VLBW infants had higher levels of distress, even after two years. Maternal stress and depression is related to poorer child development outcomes in VLBW infants (Gennaro, York & Broton, 1990; Singer et al., 1999). Gennaro (1985) found that mothers who were more anxious displayed better

problem solving skills ($r = .35$, $p = .05$). Gennaro (1985) investigated the relationship between maternal anxiety, problem solving ability and adaptation to the premature infant in a convenience sample of 35 mothers of premature infants without congenital anomalies (<37 weeks gestation; birthweight between 1000 and 2500 grams). She found that maternal anxiety and problem solving ability were positively correlated, contrary to most studies of anxiety and coping (Crnic et al., 1983; Minde et al., 1983; Gennaro, York & Brooten, 1990; Singer et al., 1999). Gennaro (1985) suggested that anxiety in mothers of premature infants motivated them to mobilize their resources and resolve problems so that they could care for their baby. Butts and colleagues (1988) concur and suggest that parents' readiness to learn is heightened as they assume total responsibility for the care of their infant. Parental stress, regardless of the source, is mediated by the provision of information that facilitates the transfer of caregiving responsibilities (Griffin, Wishba, & Kavanaugh, 1998; Kenner & Lott, 1990; McKim, 1993a; Miles, Carlson & Brunssen, 1999) and provision of emotional and instrumental support (Affleck et al., 1991; Holditch-Davis & Miles, 2000; Ladden, 1990b).

Perehudoff (1990) examined the degree of stress families experienced related to the NICU environment in a descriptive comparative study of 31 parents of premature infants who had spent less than seven days in a tertiary level NICU. In addition to the infant's appearance and behaviour, parental role alteration and staff communications, the sights and sounds of the NICU were a source of stress for both mothers and fathers

of premature infants. This study highlights the impact of the NICU environment on parental stress.

In summary, stress after birth, during the infant's hospitalization and upon discharge from hospital, is multifaceted. It has consequences for parental-infant interaction in the immediate and longer term (Crnic et al., 1983; Gennaro, 1985; Gennaro, York & Brooten, 1990; Minde et al., 1983; Perehudoff, 1990; Singer et al., 1999). In particular, maternal stress and depression can lead to poorer developmental outcomes for the infants (Gennaro, York & Brooten, 1990; Singer et al., 1990). Health care professionals need to recognize the effects of stress and to intervene in such a way as to minimize its negative impact.

Information and Support Needs

The goals of discharge teaching and planning in the NICU are to: a) maintain infant health and minimize the risks of illness/rehospitalization; b) maximize parental confidence/competence in caregiving; c) decrease the stress of transition to home and d) to re-establish the family unit (McGinley et al., 1996). Discharge teaching and planning is an ongoing and organized process and involves a multidisciplinary assessment of patient/family needs and coordination of care, services and referrals (Barton & Lawlor-Klean, 1994; McGinley et al., 1996). Knowledge about the parents' perceptions of their information and support needs prior to and after discharge can facilitate the discharge planning process, ease the transition to home (Drake, 1995; Kenner & Lott, 1990) and build parental capacity, competence and autonomy.

Information Needs

Primary caregivers of premature and/or medically complex infants have considerable informational and support needs both during hospitalization (Arenson, 1988; Bond et al., 1994; Brunssen & Miles, 1996; Diehl et al., 1991; Gennaro, 1985; Kenner & Lott, 1990; McKim, 1993a, McKim et al., 1995; Sheikh, O'Brien, & McCluskey-Fawcett, 1993; Vecchi, Vasquez, Radin, & Johnson, 1996) and at the time of discharge (Gamblian, Hess & Kenner, 1998; Goodman & Sauve, 1985; Raddish & Merritt, 1998; Reiger & Henderson-Smart, 1995; Termini et al., 1990). A number of research studies identified that parents wanted information about basic infant care (Brooten et al., 1989; Brooten et al., 1991; Butts et al., 1988; Gehl & Lantzy, 1990; Goodman & Sauve, 1985; McKim, 1993a; McKim et al., 1995; von Platen, 2000), signs of changing health status/illness (Brooten et al., 1989; Brooten et al., 1991; Butts et al., 1988; Gennaro, York & Brooten, 1990), growth and development (Brooten et al., 1989; Gennaro, York & Brooten, 1990; von Platen, 2000), infant behaviour/temperament (Brooten et al., 1991; Gennaro, York & Brooten, 1990), medications and special procedures (Brooten et al., 1991; Gennaro, York & Brooten, 1990) and maternal infant attachment (Goodman & Sauve, 1985; Gennaro, York & Brooten, 1990, Kenner, 1990). Infant feeding was emphasized as a concern in a number of studies (Brooten et al., 1989; Goodman & Sauve, 1985; Gehl & Lantzy, 1990) and this highlights the fact that premature infants often have difficulty with oral feeding.

There is debate in the literature as to the best way to meet families' needs around discharge. Some purport that information should be standardized such that

discharge-teaching protocols are systematic and comprehensive (Arenson, 1988; Cagan & Meier, 1979). This would ensure that all families receive the same information, pertinent facts are not overlooked and families are empowered through knowledge acquisition (Arenson, 1988), a means of reducing uncertainty. The notion of "standardized" information has been challenged, in recent years, by the philosophy of family centered care, which recognizes parents as equal partners within the health care team (Horner et al., 1987; Bond et al., 1994). The goal is for parents and professionals to work together to develop an individualized plan of care for the infant, both within the hospital and at home. Vecchi et al. (1996) combined the philosophies of standardized discharge protocols and individualized content to develop the Neonatal Individualized Predictive Pathway (NIPP) to guide discharge teaching and planning. The NIPP tool provides a framework to organize teaching and learning needs. It allows parents the opportunity to have an early, active and ongoing role in their infant's discharge preparation.

Two studies (Drake, 1995; Kenner & Lott, 1990) found that parents and health care professionals had different perceptions of needs and concerns related to discharge. To illustrate, Drake (1995), in a pilot study, utilized the 'card sort' technique with a convenience sample of nurses and parents of stable, uncomplicated NICU infants to elucidate the discharge needs of parents. Ten parents and seven nurses were asked to sort a set of seventeen cards, fourteen with a typical discharge teaching topic and three blank cards, into piles of descending importance in order to identify specific discharge teaching needs.

None of the topics were ranked the same (as indicated by mean scores) by parents and professionals. Parents identified "what to do if their baby stopped breathing" as their top priority whereas nurses identified "how to tell if the baby was sick" as most important. Although the ranked responses of the two groups differed, both parents and nurses felt this technique was a valuable tool to highlight individual priorities related to discharge teaching needs. Drake (1995) asserted that parents might be more receptive to the "standardized" information if they perceive that their identified and individual needs are being addressed in a timely manner. This study is limited by its small sample size but does provide some evidence about differences in discharge information needs of the parents as perceived by parents and professionals.

Sheikh, O'Brien and McCluskey-Fawcett (1993) highlighted a significant discrepancy between what was taught to parents and what was recalled. Parents did not remember learning, or indeed hearing, much of the information that NICU nurses reported had been provided. Information overload and stress (Drake, 1995; Janis, 1982) affect recall, as does the content (Christian, 1996; Kenner & Lott, 1990; Ladden, 1990b). Ladden (1990b) recommends that, in order to increase recall and enhance parental feelings of preparedness, nurses present information in an orderly, sequential fashion, repeated as necessary and that parents be offered opportunities to practice caregiving behaviours.

Butts et al. (1988) investigated parental concerns and found that information related to newborn health issues and normal infant care are the most frequent reasons

for calls to a telephone on-call service for parents of very low birthweight (VLBW) infants. Subsequently, McKim (1993a) surveyed 56 mothers of high-risk premature infants and found that information specific to infant behaviour, infant illness, and prematurity was not provided to them prior to discharge. McKim found that mothers who reported the need for more information on how to care for their premature infant were found to be more anxious and less confident in caring for their infant after discharge. McKim and colleagues (1995) acknowledge that the quest for information is one way to gain mastery or control over an unfamiliar or overwhelming situation.

Brooten et al. (1989) compared the pre- and post-discharge teaching needs of 36 mothers of VLBW infants discharged early from an NICU and followed by a clinical nurse specialist for 18 months after discharge. Identified pre-discharge teaching needs included feeding, prevention and recognition of infection and issues related to growth and development. Post-discharge teaching needs related to feeding, current health problems, growth and development and information relating to community resources and services. Information needs changed as families confronted their infant's unique needs during their transition to home. When compared to pre-discharge teaching, the post-discharge teaching needs more than doubled on the following items: feeding, medications, current health problems, growth and development and managing the health care system. Brooten and colleagues acknowledge that the teaching needs found in their study would not necessarily be the same as needs identified by parents of medically complex infants discharged to home, thus supporting the need for the current

study. Their study subjects were described as poor and with lower than average formal education. Additional research is needed with other populations.

Most discharge planning has focused on the uncomplicated, healthy premature infant. The unique needs of the medically complex infant must also be considered during hospitalization and the road to discharge. Vandenberg (1999) asserts

... we have learned that by integrating developmental and social-interaction interventions into our care during hospitalization, we can help prepare families to take home an infant they have come to know, instead of one they fear and consider a stranger. (p. 57.)

Vandenberg (1999) further emphasizes "...to foster an intimate attachment, we must support parents *daily and early* [italics added] in taking on the care of their newborn and in becoming our partners in their infant's care" (p. 58). Care-by-parent opportunities allow families to simulate to some extent, the reality that will be theirs once at home (Ladden, 1990b). Hands-on experience allows parents to "practice" the skills and utilize the knowledge imparted during discharge teaching sessions. Butts et al. (1988) suggest that parents may not be able to anticipate what they need to know until they get home with their infant. Further, information needs change over time (Brazy et al., 2001).

In summary, parents with a premature or medically complex infant have considerable information needs. They want information about basic infant care, information specific to the premature infant and the skills needed to care for a medically complex infant, as well as signs of changing health status and growth and development. Recall of provided information is variable and influenced by readiness for learning, content and presentation. The use of both standardized discharge-teaching

protocols and diagnosis specific information can assist health care professionals to provide comprehensive and relevant instruction to parents.

Support Needs

Support has been classified as social (Kenner, 1990, Kenner & Lott, 1990) and informational (Kenner, 1990; Kenner & Lott, 1990; McKim, 1993a; McKim et al., 1995). Social support is multifaceted and has long been a focus of nursing inquiry. Stewart (1993) described social support as assistance provided by individuals who are part of one's social network. Social support may moderate the impact of stress and stressors to improve health. Social support may be emotional, instrumental, and informational (House & Kahn, 1985 in Stewart, 1993).

Information was identified as a source of support as it enabled parents to care for their infant (Brazy et al., 2001; Griffin et al., 1998; Kenner & Lott, 1990; McHaffie, 1990; McKim, 1993a; McKim et al., 1995; Miles, Carlson & Brunssen, 1999; Vandenberg, 2000). Parents with infants in the NICU reported receiving support from the nurses (Affleck et al., 1991; Affonso et al., 1992; Brazy et al., 2001; Coffman et al., 1990; Gennaro, 1991; Holditch-Davis & Miles, 2000; Hughes et al., 1994; Kenner, 1990; Ladden, 1990b; Miles et al., 1996; Miles, Carlson & Brunssen, 1999, McKim, 1993a), their significant other (Able-Boone & Stevens, 1994; Coffman et al., 1990; Hughes et al., 1994; Kenner & Lott, 1990; McKim, 1993a, 1993b; McKim et al., 1995; Miles et al., 1996), family members (Able-Boone & Stevens, 1994; Brazy et al., 2001; Hughes et al., 1994; McKim, 1993a, 1993b; McKim et al., 1995; Miles et al., 1996), other health care

providers (Brazy et al., 2001; McKim, 1993a, 1993b; Miles et al., 1996), parents of like children (Roman et al., 1995) and from their faith (Able-Boone & Stevens, 1994; Hughes et al., 1994; Miles et al., 1996). Kenner & Lott (1990) found that parents did not identify friends as a source of support because they had not experienced the birth of a premature or sick child.

Nurses were seen as supportive when they showed concern and caring (Affleck et al., 1991; Gennaro, 1991; Holditch-Davis & Miles, 2000), provided information (Gennaro, 1991; Holditch-Davis & Miles, 2000), promoted the parental role (Holditch-Davis & Miles, 2000; Miles, Carlson & Brunssen, 1999) and provided care in a competent manner (Holditch-Davis & Miles, 2000). Parents reported nurses were not supportive when they acted as a 'gatekeeper' and limited parental interaction with the infant (Kenner, 1990). Coffman et al. (1990) compared personal and professional support afforded to mothers of NICU and healthy newborns. Professional support from nurses influenced the satisfaction with the nurse but did not impact personal outcomes, as measured by life satisfaction and emotional affect (Coffman et al., 1990).

Roman et al. (1995) conducted a study on 58 mothers of premature infants to investigate the benefit of a parent-to-parent support program in the NICU. Mothers in the treatment group (N = 27) received support from trained, experienced volunteer parents for one year after the birth of their infant. Mothers in the comparison group (N = 31) were enrolled prior to the initiation of the parent-to-parent support program and did not receive formalized support from a 'veteran' parent (Roman et al., 1995). Mothers in the treatment group had less anxiety in the first four months after discharge,

increased self-esteem, enhanced maternal-infant interaction and a more nurturing home environment. In another study, Miles, Carlson & Funk (1996) found parents rated support from other parents in the NICU low. The researchers asked participants to rate the 'helpfulness' of individuals within their social network on a 5-point scale (1 = not helpful; 5 = extremely helpful). Mean 'helpfulness' scores for other parents ranged from 2.34 - 2.93 and were consistently among the lowest reported scores.

In summary, there are many sources of support identified in the literature. Two important sources of maternal support are social and informational support. Social support is most often provided by a significant other and informational support is most often provided by a health care professional. Information and support contribute to feelings of competence. Information and support promote maternal confidence, enhance maternal-infant attachment and improve the mother's ability to care for her infant. Discharge of a premature and/or medically complex infant and the transition to home is facilitated when appropriate educational programs and support systems are in place.

Transition to Home and Follow-up

A number of research studies in the United States, Canada and Australia describe the efficacy and safety of early discharge (Brooten et al., 1986; Brooten, Brown, et al., 1988; Casiro et al., 1993; Evanochko et al., 1996; Gamblian et al., 1998; Gershan & Kliegman, 1995; Kotagal, Perlstein, Gamblian, Donovan, & Atherton, 1995; Reiger & Henderson-Smart, 1995). Brooten et al. (1986) and

Gamblian, Hess & Kenner (1998) in particular advocate for early discharge of premature infants with specialized follow-up by clinical nurse specialists. In Canada, Evanochko et al. (1996) demonstrated that implementation of a home gavage program with adjunct follow-up by clinical nurse specialists/neonatal practitioners (CNS/NP) decreased length of hospitalization for premature infants. Raddish and Merritt (1998) acknowledge that the care of technologically dependent infants will likely create greater challenges for the families involved. The issue with the medically complex infant is not so much early but timely discharge. Discharge criteria of the American Academy of Pediatrics (1998) position paper are found in Appendix A.

Brooten and colleagues (1986) in a randomized control trial comparing early discharge and routine care concluded that early discharge with home follow-up by a clinical nurse specialist was a safe and effective alternative to discharge guidelines based solely on weight criteria. Routine care discharge criteria stipulated that the infant was clinically stable, feeding well, had achieved a weight of approximately 2200 grams and did not require home follow-up. Infants in the experimental group were discharged, on average, 11 days earlier, weighed 200 grams less and were two weeks younger than infants in the control group. A mean saving of \$18,500 (American dollars) per infant was realized. There were no significant differences in the number of rehospitalizations, acute care visits or measures of development. Based on the above findings, Brooten, Brown et al. (1988) developed a

comprehensive model of transitional home care by clinical nurse specialists (CNS) or nurse practitioners (NP).

Kotagal et al. (1995) described a program of early discharge from NICU and showed that morbidity was unaltered in conjunction with follow-up assessment and family support. They investigated 257 study infants discharged from a NICU after an early discharge program was implemented. The number of emergency room visits and rehospitalizations were evaluated to identify differences as compared to a group of 477 infants discharged from the same unit prior to the implementation of the early discharge program. Differences were found for both outcome measures. Kotagal et al. (1995) found that 2.7% of study infants versus 8.0% of control infants utilized the services of the emergency department within 14 days of discharge, a statistically significant difference ($p < .01$). Readmission rates were 0.4% of study infants and 0.6% of the control infants. There was also a major difference in costs. Implementation and maintenance of the early discharge program cost \$468.00 per infant, thirty times less than in-patient hospital costs. Reiger and Henderson-Smart (1995) also found a reduction in the use of medical services and cost savings in their evaluation of an early discharge program in Australia.

Affleck et al. (1989) identify an emotional disequilibrium of transition from hospital to home. Many parents of infants admitted to neonatal intensive care units never believed that they would take their baby home (Kenner, 1990; Kenner & Lott, 1990; McKim et al., 1995). Researchers have explored parental feelings related to the transition to home (Kenner, 1990; Kenner & Lott, 1990; McKim et al. 1995) and

have identified the following areas of concern: 1) informational needs, 2) anticipatory grief, 3) parent-child development, 4) stress and coping and finally, 5) social support.

Successful adaptation to the home environment is dependent upon discharge planning, transitional care opportunities and recognition of home care needs (Ladden, 1990b). Zelle (1995) stated "the home has become an extension of the intensive and continuing care nurseries" (p. 5.). Drake (1995) supports the necessity for individualized programs of home follow-up. Zahr and Montigo (1993) state home care can diminish the stress experienced by parents of sick premature infants. Bell (1994) and Christian (1996) reiterate this notion and advocate that advanced practice nurses are optimally qualified to provide case management, to design and to implement programs to meet the needs of the compromised neonate. As Kenner and Lott (1990) assert, the neonatal nurse is in a strategic position to impact upon the lives of medically complex infants and their families even after discharge.

The need for ongoing home follow-up by an expert neonatal nurse is supported in the literature (Brooten et al., 1986; Gamblian et al., 1995; Gennaro, 1991; Sheikh et al., 1993; Teague et al., 1993; von Platen, 2000). Brooten et al. (1989) assert

(c)ontinuity of care for these infants and their families, preferably by personnel familiar with these infants' past progress and health status is needed. Accordingly, follow-up by nurses who specialize in the care and problems of these high-risk infants and their families, and who know the problems specific to this group, the health-care system, the services needed and available, and nurse specialists who will serve as advocates for this client group is needed. (p. 321.)

In an evaluation of the first Neonatal Transitional Care Program (NTCP) in Canada, von Platen (2000) reported a number of important/significant findings. One hundred and thirty five infants were enrolled in this study and randomly assigned to either the intervention (n = 71) or control (n = 64) group. Infants in the intervention group were followed by NTCP personnel (3 clinical nurse specialists with neonatal expertise and public health experience) for four months after discharge from an NICU. Infants in the control group received routine care and had follow up from public health nurses for the same period of time. Outcome measures included: infant growth, feeding patterns, health service utilization, maternal patterns of stress, confidence and concerns pre and post-discharge. Infants in the NTCP 1) received more breastmilk (p = 0.013) and for longer periods; 2) received more appropriate vitamin supplementation after discharge and 3) had fewer unscheduled visits with health care providers (p = 0.015). No weight differences were found between experimental and control groups. Mothers who participated in the NTCP were more knowledgeable about community resources and were more satisfied with the health care system yet mothers in both groups had similar levels of stress.

von Platen (2000) states parents of low birth weight infants (LBW) require uninterrupted support and guidance as they transition from hospital to home. The results of this study suggest that infants with a birth weight \leq 2000 grams benefit from in-home support services by specialized health care professionals, knowledgeable and experienced in the care of LBW infant, and who can provide parents with anticipatory guidance and support. Improved infant and family outcome can be expected when

individualized, continuous and expert support is available in the home. In addition, von Platen (2000) found that a neonatal transitional care program has the potential to reduce demands on the health care system.

In summary, discharge to home, be it early or not, is more successful when parents feel competent to care for their child. Information and support contribute to parental feelings of competency. There is evidence to support the efficacy of transitional care programs as parents assume responsibility for the care of their premature and/or medically complex infant.

Conceptual Framework

Selder's (1989) Life Transition Theory is consistent with the philosophy of holistic health and care and it allows one to conceptualize human response to change. Transition and transitional states have long been a focus of nursing science (Chick & Meleis, 1986; Kenner & Lott, 1990; McKim et al., 1995; Murphy, 1990; Schumacher & Meleis, 1994). Key concepts of Selder's (1989) theory include: 1) reality and its disruption and 2) uncertainty and its reduction.

Transitions may be developmental, situational and health-illness (Chick & Meleis, 1986; Murphy, 1990; Schumacher & Meleis, 1994). Transitions occur over time (Chick & Meleis, 1986; Murphy, 1990; Schumacher & Meleis, 1994), involve movement from one state or reality to another (Chick & Meleis, 1986; Selder, 1989; Schumacher & Meleis, 1994) and imply a change in roles, dynamics of relationships and abilities/responsibilities (Chick & Meleis, 1986; Kenner & Lott, 1990; McKim et

al., 1995; Murphy, 1990; Selder, 1989; Schumacher & Meleis, 1994). Personal (Chick & Meleis, 1986; McKim et al., 1995; Selder, 1989; Schumacher & Meleis, 1994) and environmental factors (Chick & Meleis, 1986; Ladden, 1990a; McKim et al., 1995) affect the transition process. Often new knowledge and/or skills are necessary for transition and may, in fact, ease the transitional effort (Kenner & Lott, 1990; Selder, 1989; Schumacher & Meleis, 1994). Goals of the transitional experience include minimizing uncertainty and restoring equilibrium in one's life (McKim et al., 1995; Selder, 1989; Schumacher & Meleis, 1994).

Reality and Its Disruption

A life transition is initiated when a person's current reality is disrupted. Transition may arise from an unexpected and critical event (birth of a premature or ill infant) or an action on the part of the individual (decision to take the baby home with supportive technology). In a transitional state, individuals seek to diminish uncertainty by confronting the disrupted reality, seeking information related to the new reality and finally, engaging in the transition (Selder, 1989). Parents of a premature and/or medically complex infant find themselves in the midst of numerous transitional states. The first disrupted reality that they must confront is that of parental role. Parents relinquish the reality of the birth of a healthy term infant and acknowledge their new reality as the parent of a premature and/or medically complex infant, with its associated responsibilities, skills and challenges. In addition, parental role, especially maternal attachment, is impacted by the

infant's hospitalization. Mothers must bond and learn how care for their infant despite the disrupted reality of the hospital environment and the infant's medical condition. The long awaited and much anticipated discharge of a premature and/or medically complex infant is one example of a transitional state. Indeed, there are multiple and overlapping transitional experiences after the birth, during the infant's hospitalization and upon discharge to home. As the permanency of the disrupted reality is accepted and assimilated, engagement in transition can begin.

Reduction of Uncertainty

Information can reduce uncertainty (Selder, 1989) as can social or professional support. In the NICU information is an important resource for parents as they cope with their own distress and disrupted reality. Information gathering is integral to the transfer of care from professional to parent and to the discharge process. Individuals attempt to reduce uncertainty, in the midst of a transitional state by "normalizing" the situation. Discharge to home, despite reliance upon assistive technology, is a normalizing event.

Instrumental resources, such as written materials or a number to call and support from family, friends and professionals can mediate successful transition and adaptation. Social and professional support can reduce the stress and uncertainty as parents confront their new reality and engage in the transition process. Transitional activities need to be supported for the finite period of time required for the emergence of a new reality. For the purposes of this inquiry, the

needs in question relate specifically to those identified during the period immediately prior to discharge from an NICU and then again, four weeks post-discharge. These parameters have been selected to allow the researcher an opportunity to identify what the information and support needs of primary caregivers are and which, if any, of the articulated needs change over time.

Summary

A major focus of nursing science rests on assisting individuals and families to adapt to and cope with a critical life event. The birth of a premature or critically ill infant is most certainly a critical life event. The alteration in parental role, a consequence of the infant's condition and hospitalization, is a source of significant and long-lasting stress. Maternal-infant attachment and interaction have significant impact on future infant development and outcome. Knowledge and skills have been identified as resources used by parents to enhance coping (Canam, 1993; Sterling; 1990).

After a review of the literature, the following facts are known about parents, especially mothers, of premature or ill infants: 1) they experience an alteration in the parental role; 2) they encounter stress from a variety of sources; 3) maternal stress can have negative consequences for infant development and 4) information and support can lessen the response to stress. Parents with premature and/or medically complex infants have considerable information and support needs. Information and support promote maternal confidence, enhance maternal-

infant attachment and improve the mother's ability to care for her infant as she confronts her new reality and engages in the transition process.

As most of the reviewed literature is based on research done in the United States, it is unknown if the above factors are the same in Canada, particularly the Ottawa region. As the American and Canadian health care systems are different there is a need to investigate the Canadian situation. There is little research about the information and support needs during the first transitional month at home. In addition, there is little information as to whether families' articulated needs change from before discharge to four weeks hence. Finally, to the author's knowledge, there is no information about the information and support needs of families with medically complex infants in the Ottawa area let alone Canada.

Transition theory was chosen as the conceptual framework as it is consistent with a holistic philosophy of health and provides a context in which to study parents' information and support needs during the transition from hospital to home. Mothers of a premature and/or medically complex infant experience a change in maternal role and maternal-infant attachment as a result of their baby's medical condition. Stress and uncertainty are diminished as mothers acquire the information, skills and support necessary for the emergence of their new reality. Further, transition involves the passage from one condition, place or stage to another. In this study, the transition was twofold – transition from participant observer to primary caregiver as well as the transition from hospital to home. Transition is necessarily time limited and the implied professional support is not

meant to be long term. The support in question is meant to build parental capacity, competence and autonomy.

CHAPTER THREE

Methods

This chapter describes the research design, the setting in which the research was conducted, the participants in the study and the procedures for data collection and analysis.

Research Design

A non-experimental descriptive design was used. Two self-report questionnaires were administered, at two time periods, to a consecutive sample of 30 caregivers of premature and/or medically complex infants admitted to and discharged from a NICU. The first time period was immediately prior to discharge and the second was four weeks after discharge.

Setting

The setting for this study was the NICU of a pediatric teaching hospital affiliated with the University of Ottawa. The NICU has a 20-bed capacity. All infants treated in this setting were born in other centres or locations and transferred to the NICU as a result of their critical medical condition. Many of the infants require surgery, cardiac assessment and/or surgery, management of respiratory distress, and/or investigation of a variety of congenital anomalies and syndromes. A multidisciplinary team approach is practiced and families are included in team

conferences and preparation for discharge. Discharge teaching activities are intended to meet learning needs in an individualized yet comprehensive manner. A standardized NICU discharge-teaching tool is completed for all infants and families (Appendix B). Caregivers are encouraged to participate in the care of their child, as the medical condition allows. Care-by-parent opportunities, including rooming-in, and passes to home are offered and utilized by parents. A list of the various resources used in the discharge planning process is provided in Appendix C.

Sample

All primary caregivers with an infant admitted to the NICU for any length of time, and whose infant met the inclusion criteria were invited to participate in the study if they were discharged between December 2000 and May 2001. The primary caregiver was defined as the person responsible for the majority of the infant's care and was identified by the family.

The inclusion criteria for the primary caregivers were: (1) natural, adoptive or foster parent; (2) ability to read and to comprehend English; (3) have an infant (or infants) imminently ready for discharge who was (were) expected to survive beyond the time frame of the study and (4) have provided written informed consent for participation in the study.

Exclusion criterion included: (1) individuals residing greater than 150 kilometres from the hospital and (2) those with a terminally ill infant discharged

home for palliation. The investigator regularly identified potential study participants in collaboration with NICU staff.

A "premature infant" was defined as an infant born before 37 completed weeks of gestation. A "medically complex infant" was defined as an infant who required ongoing medical support after discharge, including, but not limited to: oxygen therapy; tracheostomy care; suctioning; tube feedings (nasogastric or gastrostomy); apnea monitoring; ostomy care; and/or infants with neurologic compromise secondary to intraventricular hemorrhage (IVH), hypoxic-ischemic encephalopathy (HIE) and/or seizures.

When the study was planned, the number of infants meeting the inclusion criteria in this centre over the four-month period was estimated to be 40 infants. It was anticipated that approximately 10 families would not participate and the final sample would be approximately 30 caregivers.

Primary caregivers of both premature and medically complex infants were included in the sample. This was done in order to facilitate enrolment of sufficient participants and although premature infants and those considered medically complex may have different information and support needs, as a result of prolonged hospitalization and illness, many of the needs would indeed be similar.

Ethical Review and Consent to Participate

Ethical review of the proposal was obtained from the Research Ethics Committee of the Children's Hospital of Eastern Ontario (Appendix D). There was

no known risk associated with study participation. None of the participants found answering the questions distressing. If they had, the investigator would have offered to take a break and would have advised the individual that they could decline to answer that particular or any further questions. The investigator was available for debriefing once the questionnaires were completed. The participants were informed that they could contact the investigator or her supervisor at any time with questions or concerns about their participation in this study.

The researcher obtained written informed consent (Appendix E) from the participants prior to administration of the questionnaires. Participants knew their participation was voluntary. Study participants were assured of confidentiality and anonymity. Names or other identifying labels were not used. Numbers were used to identify questionnaire responses. Data were stored in a secure location and contained no identifying information. The raw data were shared only with the investigator's advisor, a data entry clerk and a statistician.

Data Collection Measures

The following measures were used: 1) Personal Information Questionnaire; 2) McKim Questionnaire – "The Information and Support Needs of Mothers of Healthy, Ill, Term, and Preterm Infants' Questionnaire – Part A & B" and 3) Aylward Questionnaire – "The Information and Support Needs of Parents of Premature and/or Medically Complex Infants Questionnaire – Part A & B". Demographic information was gathered through administration of the "Personal Information

Questionnaire" (Appendix F). This tool was developed by the researcher to obtain demographic data related to family composition/characteristics and infant health status and was based on demographic questionnaires previously used by University of Ottawa nurse researchers.

A search of the literature revealed one published measure of information and support needs related to premature infants and none for the parents of medically complex infants. The tool, "The Information and Support Needs of Mothers of Healthy, Ill, Term, and Preterm Infants' Questionnaire – Part A & B" was developed by McKim (1993a). The tool was used with the author's permission (Appendix G) and is included as Appendix H. The first section (Part A) is comprised of 31 closed-ended questions that assess the information parents receive from nurses before their infants are discharged. Each question has six possible responses. They are: a) yes; b) yes, but I didn't want this information; c) no, but I would have liked this information; d) no, but I didn't want this information; e) don't know/don't remember and f) not applicable. The second section (Part B) is comprised of a combination of 32 open- and closed-ended questions that assess the emotional, material and informational support needs of mothers. Maternal anxiety and confidence were measured on a five-point Likert scale and then correlated with demographic factors and information needs. The current study replicated these analyses.

The content and design of McKim's questionnaire was established through a review of the literature, information received from the parents of premature infants,

by McKim's experience as a mother of a premature infant and consultation with experts in perinatal care and questionnaire development. Content validity was ascertained by a review of the questionnaire by 5 nurses, experts in the care of premature infants and families. A pilot study was conducted and McKim modified the tool. Reliability measures were conducted on Part A of 56 study questionnaires. A Cronbach alpha of 0.85 was obtained, indicating a high level of internal consistency (McKim, 1993a).

The second tool that was used was entitled "The Information and Support Needs of Parents of Premature and/or Medically Complex Infants Questionnaire – Part A & B" (Appendix I). This tool was developed by the researcher and was modeled on McKim's questionnaire. Part A addresses the specific informational needs of families of infants with ongoing complex care. Part B addresses the support needs of these same families. Prior to use of this tool, a panel of experts in the field of neonatology determined its content validity. This panel of five experts included four nurses and one physician. The nurses included a clinical instructor, a CNS/Neonatal Nurse Practitioner and two nurses with Master's Degrees in Education. All nurses had at least 20 years of neonatal nursing experience. Comments provided were reviewed and incorporated into a revised tool.

A pilot of the revised tool was administered to six families prior to their discharge from the NICU and two weeks after discharge. Statistical analysis of internal consistency (Cronbach alpha) was deemed to be inappropriate for such a small sample ($n = 6$) and for a scale of categorical responses, where a summary

score could not be computed. There was evidence of consistency in responses over time (test-retest reliability) as only five of 84 responses (6 participants x 14 questions) changed from Time 1 to Time 2. The results of the pilot are presented in Appendix J.

Data Collection

The researcher introduced herself to prospective participants and described the study to them. Families were asked to consider taking part in the study, with the understanding that care for their infant or themselves would not be affected in any way if they chose not to participate. Families decided who would complete the questionnaires. Signed informed consent was then obtained, usually on the day of discharge but up to one week prior to discharge. Table 1 provides the time line for data collection.

Table 1: Time Line for Data Collection

Time One	Time Two
Prior to Discharge	Four Weeks After Discharge
Consent	
Personal Information Questionnaire	
McKim Questionnaire – Part A	McKim Questionnaire – Part A & B
Aylward Questionnaire – Part A	Aylward Questionnaire – Part A & B

The day of discharge, or the day prior to discharge the primary caregiver completed the following:

- a) Personal Information Questionnaire (Appendix F),
- b) McKim Questionnaire – Part A: The Information and Support Needs of Mothers of Healthy, and Ill, Term and Preterm Infants' Questionnaire (Appendix H) and
- c) Aylward Questionnaire – Part A: The Information and Support Needs of Primary Caregivers of Premature and/or Medically Complex Infants (Appendix I).

Arrangements were made to contact the primary caregiver, about three and a half weeks after discharge, to establish a convenient time and place for completion of the post-discharge questionnaires, the second phase of the study. This meeting took place at a time and location convenient to the participant and researcher, respectively. Due to caregiver preferences, weather conditions and time constraints twelve of the follow-up "visits" were completed over the phone.

Four weeks after discharge to home, the researcher contacted or met with the primary caregiver and administered the following questionnaires:

- a) McKim Questionnaire – Part A & B: The Information and Support Needs of Mothers of Healthy, and Ill, Term, and Preterm Infants' Questionnaire (Appendix H) and,

b) Aylward Questionnaire – Part A & B: The Information and Support Needs of Primary Caregivers of Premature and/or Medically Complex Infants – (Appendix I).

Data Analysis

Descriptive statistics (frequencies, means, standard deviations and percentages) were used to describe both the characteristics of the infants and their families as obtained by the Personal Information Questionnaire.

Descriptive statistics (frequencies and percentages) were used to describe the primary caregivers' perceptions of the information provided by the NICU nurses prior to and after discharge. For ease of analysis, questions in the two study questionnaires were grouped into content areas. The content areas, with the corresponding questions, generated from the McKim questionnaire were as follows: 1) basic infant care (questions 1 – 14, 17 – 20 & 24); 2) infant environment (questions 21 - 23); 3) information specific to the premature infants (questions 26 – 28 & 30) and 4) infant behaviour and development (questions 15, 16, 25, 29 & 31). The themes, with corresponding questions generated from the Aylward questionnaire were: 1) recognition/response to changes in health status (questions 2 - 6) and 2) knowledge/skills necessary for the care of the medically complex infant (questions 1 & 7 - 14). Descriptive statistics were also used to describe the post-discharge informational and emotional support needs identified by the primary caregivers of premature and/or medically complex infants after four weeks at home.

Correlational analyses (Pearson product-moment correlations and cross tabulations) were performed to test relationships between demographic factors, anxiety, confidence, information received and information wanted but not received. McKim used a five-point Likert scale to measure maternal anxiety. The current study replicated her methodology and used the same Likert scale.

In order to analyze the rate of agreement (and rate of change) in participant responses over time, contingency tables were derived for each question on Part A of the McKim and Aylward questionnaires. It was then, possible to derive a value for the rate of change between participants' 'a' (yes) responses prior to and after discharge. For example, prior to discharge, 23 participants responded that they received information about how to breastfeed their baby. Four weeks after discharge, 21 of those 23 participants again responded that they received this information. The rate of change, therefore, was the number of participants who changed their response (e.g. 2), divided by the total number who initially responded in the affirmative (e.g. 23) or 9.5%. The rate of change was calculated for each question on both study questionnaires. The average rate of change was then calculated by adding the rate of change for each question and dividing by the number of questions in each content area. To re-iterate, the content areas derived from the two study questionnaires were: basic infant care (19 questions), infant environment (3 questions), infant behaviour and development (5 questions), information specific to premature infants (4 questions), recognition/response to changes in health status (5 questions) and knowledge/skills necessary to care for

the medically complex infant (9 questions). When considering the information and support needs of primary caregivers of premature and/or medically complex infants two responses are critically important: 1) the information received and 2) the information wanted and not received.

The quantitative data elicited from the above tools and the statistical analyses outlined above were analyzed using the Statistical Package for the Social Sciences software (SPSS-10, Windows version).

CHAPTER FOUR

Results

The data is presented in sections. The first describes the characteristics of the 30 study participants. The subsequent sections address the study's three research questions.

Demographic Characteristics of Study Participants

A consecutive enlistment of participants during the four-month period of data collection resulted in a sample size of 30. Only two individuals who were approached declined to participate in the study, thus the participation rate was 94%. Demographic data are presented in Table 2. Table 3 provides information on the range, mean and standard deviations of maternal and infant characteristics.

Table 2: Demographic Characteristics of Study Participants

Characteristic	N	%
Participants		
Mothers	29	96.7
Fathers	1	3.3
Marital Status		
Married	19	63.3
Common-Law	9	30.0
Single	2	6.7
Sex of Infant		
Female	15	50.0
Male	15	50.0
Parity		
Primipara	20	66.7
Multipara	10	33.3
Education		
< grade 12	2	6.7
High school graduate	5	16.7
Some College/University	6	20.0
College/University Graduate	17	56.7
Income (in dollars)		
<20,000	7	23.3
20,000 – 29,999	1	3.3
30,000 – 39,999	2	6.7
40,000 – 49,999	4	13.3
50,000 – 59,999	3	10.0
60,000 – 69,999	2	6.7
70,000 – 79,999	2	6.7
>80,000	9	30.0

Table 3: Characteristics of Study Participants and Their Infants

Characteristic	N	Range	Mean	Standard Deviation
Maternal Age (years)	29	19 – 41	30.38	6.32
Infant Birth Weight (grams)	30	922 – 4172	2357.97	920.83
Gestational Age (weeks)	30	28-41	34.73	3.94
Length of Stay (days)	30	7-117	33.13	29.05

Twenty-eight (93.3%) of the participants were in a relationship and two participants (6.7%) were single. Maternal age ranged from 19 to 41 years ($M = 30.38$ years, $SD = 6.32$). Two-thirds ($n = 20$) of the women were primiparas; the remaining one-third ($n = 10$) were multiparas. The average family had 1.5 children. The majority of the participants had attended or had completed college/university (76.7%).

Two-thirds ($n = 20$) of the participants reported an annual family income of \$40,000 and above, with nine of the 20 reporting an annual income greater than \$80,000. Seven participants (23.3%) stated their annual income was less than \$20,000. Twenty-six participants (86.7%) reported their income as adequate to meet their family's needs. Nineteen participants (63.3%) indicated that their infant's condition would not create a financial hardship for the family. Eight participants (26.7%) reported that their infant's condition would present somewhat of a financial hardship for the family and one participant (3.3%) did not know the impact their infant's condition would have upon the family.

There were 15 male and 15 female infants. Nine infants were term and 21 were premature, born at less than 37 weeks gestation. Gestational age was significantly correlated with birthweight ($r = .834$; $p < .001$) and length of stay ($r = -.539$; $p = .002$). Nineteen (9 term and 10 premature) infants were medically complex, defined as an infant who required ongoing medical support after discharge including, but not limited to, tube feedings, ostomy care and suctioning. Eleven of the 30 infants were discharged home on prescription medications.

Surgical diagnoses included: bilateral choanal atresia, oomphalocele, gastroschisis, imperforate anus, duodenal atresia, sacral teratoma and inguinal hernia.

Cardiovascular diagnoses included: coarctation of the aorta, atrioventricular canal, truncus and supraventricular tachycardia. Neurologic diagnoses included: hypotonia, birth depression, hydrocephalus, cerebral hemorrhage and infarct.

Genetic diagnoses included: Trisomy 21, Trisomy 22 (mosaic), DiGeorge syndrome and cystic fibrosis. Other diagnoses included: birth trauma (fractured humerus), respiratory distress syndrome, sepsis, reflux, necrotizing enterocolitis and intrauterine growth restriction.

Question 1

What are the primary caregivers' perceptions of the information provided by the NICU nurses related to the care of their infant prior to discharge from the hospital?

The primary caregivers' perceptions of the information provided by the nurses were assessed in Part A of the McKim and Aylward questionnaires (Appendices H and I). The possible responses to each question were: a) yes; b) yes, but I didn't want this information; c) no, but I would have liked this information; d) no, but I didn't want this information; e) don't know/don't remember and f) not applicable.

The results of analyses of the two study questionnaires (McKim and Aylward) are presented separately. Appendices K & L illustrate the percentage of

participants choosing each of the six possible responses on the two study questionnaires prior to discharge. The focus of the ensuing analysis will be on the participants' perceptions of the information provided by NICU nurses ('a' responses = yes) and information wanted and not received ('c' responses = no, but I would have liked that information) as these two options have particular consequences for program planning.

Mckim Questionnaire Part A – Time 1 (Before Discharge)

Basic Infant Care (Questions 1 – 14, 17 – 20 & 24)

Information about 1) how to give medications to their baby; 2) how to recognize if their baby was becoming ill and 3) what to do if they thought their baby was becoming ill was reported as received by 83% of the participants. Ninety percent of the participants reported receiving information about how to take their baby's temperature. Seventy-seven percent of the participants indicated that they received information about how to breastfeed, bathe and care for a diaper rash. Less than 50% of the participants reported having received information about: how to prepare the formula (43.3%); when to start the baby on cereals (30.0%) and what kind of cereal to begin with (20.0%). Between 27% and 40% of respondents reported that information about these items was not applicable to them.

Thirty percent of the participants reported that they wanted but did not receive information about the following items: when to start the baby on cereal;

what kind of cereal to begin with and how to know if the baby's spitting up is normal. Twenty seven percent of participants reported that they wanted but did not receive information about how to know if the baby's bowel movement is normal and whether the baby needs any additional iron, vitamins or fluoride. Information about when to take the baby for his/her immunizations and what to do about the baby's crying was wanted but not received by 24% of the participants. The remaining 12 items were reported as wanted but not received by less than 20% of the participants.

Infant Environment (Questions 21 – 23.)

Sixty seven percent of participants indicated they received information about how warmly to dress their baby. Thirty seven percent of participants reported that they received information about what temperature and humidity to keep the house and 30% of participants reported that they received information about when to take their baby outside. Forty-three percent of the participants reported that they would have liked information about what temperature/humidity to keep their house and when to start taking the baby outside. One participant (3.3%) reported that information about how warmly to dress the baby was wanted and not received.

Infant Behaviour and Development (Questions 15, 16, 25, 29 & 31)

Information related to infant behaviour and/or development was reported by participants to have been provided less often. Fewer than half of the participants

reported receiving information about the following: 1) how to know if their baby had colic (31.0%); 2) what kinds of behaviour to expect from their baby during the first six weeks at home (41.4%); 3) that their baby may have difficulty adjusting to home for the first couple of days (40.0%) and 4) how to get their baby to respond to them (40.0%). Fifty percent of the participants reported receiving information about how to know if their baby's 'fussy periods' were normal. At least 40% of participants reported wanting but not receiving information related to infant behaviour. For example, 41% of the participants reported that they wanted but did not receive information about the kind of behaviour to expect from their baby for the first six weeks at home and 48% of the participants indicated that they wanted but did not receive information that their baby may have trouble adjusting to home for the first couple of days.

Information Specific to Premature Infants (Questions 26 – 28 & 30)

Twenty-one study participants had premature infants. The percentages presented below are calculated on responses from this subset of the sample. Three quarters of the participants (75.0%) indicated that they received information that a premature baby may have an irregular breathing pattern. Fifty percent of participants reported receiving information that premature babies may 'grunt', 'groan', 'sneeze' and 'hiccup' and that 'normal' behaviour and development for a premature baby may be 'different' from a term baby. Forty percent of participants indicated that they received information that noisy breathing was normal for

premature infants. Twenty percent of the participants responded that they would have liked to know that their premature baby may have a slightly irregular breathing pattern and 45% of the participants would have liked to know that noisy breathing, especially at night, is normal for premature babies.

Table 4 provides a rank ordered list of the information that participants reported receiving prior to discharge. Fifteen of the 17 items (88%) ranked in the top ten related to basic infant care. Of those items not ranked in the top ten, 10 of 14 items (71%), related to infant environment, behaviour and development and information specific to premature infants.

Table 4: Ranked Order Percentages of 'Yes' Responses Reported on Part A of the McKim Questionnaire Prior to Discharge (N=30)

Rank	Question	%
1	11. How to take your baby's temperature?	90.0
2	10. How to give medicine (if any) to your baby? 19. How to recognize if your baby is becoming ill? 20. What to do if you think your baby is becoming ill?	83.3
3	24. How long you should expect your baby to sleep between feedings? ^a	82.8
4	1. How to breastfeed your baby? 9. How to give your baby a bath? 13. How to take care of a diaper rash?	76.7
5	28. Whether your premature baby may have a slightly irregular breathing pattern? ^{bc}	75.0
6	5. How to help your baby feed well?	73.3
7	18. How to know if the baby's bowel movement is normal?	70.0
8	2. How to know if your baby is getting enough breastmilk? 22. How warmly to dress your baby?	66.7
9	17. What to do about your baby's crying?	63.3
10	8. Whether the baby needs any additional iron, vitamins, or fluoride? 12. When to take your baby for his/her immunization? 14. How to know if the baby's 'spitting up' is normal?	60.0
11	4. How much formula you should give at each feeding?	56.7
12	16. How to know if your baby's 'fussy' periods are normal? 26. Whether it is normal for a premature baby to 'grunt', 'groan', 'sneeze' and 'hiccup'? ^{bc} 30. Were you told that 'normal' behaviour and development for the premature infant may be 'different' from a term baby? ^{bc}	50.0
13	3. How to prepare the formula?	43.3
14	25. What kinds of behaviour to expect from your baby during his/her first six weeks at home? ^a	41.4
15	29. Were you given information about the possibility your baby may have a little problem adjusting to home for the first couple of days? 31. Were you told how to get your baby to respond to you? 27. Whether noisy breathing, especially at night can be normal for premature babies? ^{bc}	40.0
16	21. What temperature and humidity to keep your house?	36.7
17	15. How to know if your baby has colic? ^a	31.0
18	6. When to start the baby on cereals? 23. When to start to take your baby outside the house?	30.0
19	7. What kinds of cereal to begin with?	20.0

^a n = 29.

^b Results based on responses only from participants with premature infants (n = 21)

^c n = 20.

Table 5 illustrates the ranked percentages of participants who reported that they wanted, but did not receive information on items included in the McKim questionnaire prior to discharge. Eleven of the 18 items (61%) ranked in the top ten that participants reported as wanted but not received related to infant environment, behaviour and development, and information specific to premature infants. Items related to basic infant care comprised 39% (7 of 18 items) of the information wanted but not received. Participants wanted information about environment, infant behaviour and development and information specific to premature infants during the transition to home.

Table 5: Ranked Order Percentages of 'No, But I Would Have Liked This Information' Responses Reported on Part A of the McKim Questionnaire Prior to Discharge (N = 30)

Rank	Question	%
1	29. Were you given information about the possibility your baby may have a little problem adjusting to home for the first couple of days? ^a	46.7
2	27. Whether noisy breathing, especially at night can be normal for premature babies? ^{bc}	45.0
3	15. How to know if your baby has colic? ^a	44.8
4	20. What temperature and humidity to keep your house? 23. When to start to take your baby outside the house?	43.3
5	25. What kinds of behaviour to expect from your baby during his/her first six weeks at home? ^a	41.4
6	16. How to know if your baby's 'fussy periods' are normal? 30. Were you told that 'normal' behaviour and development for the premature infant may be 'different' from a term baby? ^{bc}	40.0
7	6. When to start the baby on cereals? 7. What kinds of cereal to begin with? 14. How to know if the baby's 'spitting up' is normal? 26. Whether it is normal for a premature baby to 'grunt', 'groan', 'sneeze' and 'hiccup'? ^{bc}	30.0
8	8. Whether the baby needs any additional iron, vitamins, or fluoride? 18. How to know if the baby's bowel movement is normal?	26.7
9	12. When to take your baby for his/her immunization? 17. What to do about your baby's crying?	23.3
10	28. Whether your premature baby may have a slightly irregular breathing pattern? ^{bc} 31. Were you told how to get your baby to respond to you?	20.0
11	19. How to recognize if your baby is becoming ill?	16.7
12	20. What to do if you think your baby is becoming ill?	13.3
13	24. How long you should expect your baby to sleep between feedings? ^a	10.3
14	4. How much formula you should give at each feeding? 5. How to help your baby feed well?	10.0
15	2. How to know if your baby is getting enough breastmilk? 3. How to prepare the formula?	6.7
16	1. How to breastfeed your baby? 10. How to give medicine (if any) to your baby? 11. How to take your baby's temperature? 13. How to take care of a diaper rash? 22. How warmly to dress your baby?	3.3
17	9. How to give your baby a bath?	0.0

^a n = 29.

^b Results based on responses only from participants with premature infants (n = 21)

^c n = 20.

Aylward Questionnaire Part A – Time 1 (Before Discharge)

The primary caregivers' perceptions of the information provided by the nurses prior to discharge on Part A of the Aylward questionnaire (Appendix I) are described below. The six possible responses ('a' – 'f') to all questions in the Aylward questionnaire are presented in Appendix L.

Recognition/Response to Changes in Health Status (Questions 2 – 6)

As noted in Appendix L, 80% of the participants reported that the nurses offered them an infant cardiopulmonary resuscitation (CPR) course. Seventy percent of participants indicated they received information about how to recognize a change in their baby's colour and 65% reported receiving information about what to do in case of an emergency at home. Less than half of the participants indicated that they received information about what to do if their baby stopped breathing at home (43.3%) or how to recognize changes in their baby's breathing pattern that may mean that he/she is becoming sick (33.3%).

All participants who did not receive information about recognizing changes in breathing patterns that may indicate the baby is becoming sick or recognizing changes in their baby's colour wanted this information (67% and 30%, respectively). Fifty percent of the participants reported that they wanted but did not receive information about what to do if their baby stopped breathing at home and 31% of participants wanted but did not receive information about what to do in case of an emergency at home.

Knowledge/Skills Necessary to Care for the Medically Complex Infant (Questions 1 & 7 – 14)

Information related to the use of assistive technology in the home (e.g. feeding tubes and pumps, ostomies) was reported as received by all of the participants to whom it applied. Seventeen participants had babies who required medication at home. The following results refer to this subset. Forty-seven percent (n= 8) of participants reported that they received information about the side effects of the medications that they would have to give to their babies at home. Twenty-nine percent (n = 5) of the subset reported that they wanted but did not receive this information. The results are presented in Appendix L.

Question 2

What are the informational and support needs identified by the primary caregivers of premature and/or medically complex infants after four weeks at home?

Part A of the two study questionnaires was re-administered after discharge to determine the participants' perceptions of the information provided by the nurses, once they assumed the role of primary caregiver for their infant. In addition, Part B of the McKim and Aylward questionnaires was administered to assess the support needs of the study participants four weeks after discharge (Appendices H and I). To reiterate, the possible responses to each question in Part A were: a) yes; b) yes, but I didn't want this information; c) no, but I would have

liked this information; d) no, but I didn't want this information; e) don't know/don't remember; and f) not applicable.

The results of the two study questionnaires (McKim and Aylward) are presented separately, as before. The six possible responses to all questions, four weeks after discharge, on Part A of the McKim questionnaire are presented in Appendix M.

McKim Questionnaire Part A – Time 2 (Four Weeks After Discharge)

Basic Infant Care (Questions 1 – 14, 17 – 20 & 24)

Eighty-seven percent of the participants reported receiving information about the following: 1) how to bathe their baby; 2) how to give medicine to their baby and 3) how to take their baby's temperature. Eighty percent of the participants reported receiving information about how to recognize and respond if they thought their baby was becoming ill.

Forty percent of participants reported that they wanted but did not receive information about how to know if their baby's 'spitting up' was normal. Thirty seven percent of participants wanted but did not receive information about: 1) how much formula to give at each feed; 2) when to start the baby on cereals; 3) what cereal to begin with and 4) what to do about the baby's crying. Seventeen percent of the participants wanted but did not receive information about: 1) additional vitamins, minerals and fluoride; 2) when to take the baby for his/her immunization; 3) how to

know if the bowel movement was normal; 4) how to recognize if the baby was becoming ill and 5) how long to expect the baby to sleep between feeds. Ten percent or less of the participants reported that they wanted but did not receive information about the following: 1) how to breastfeed (6.7%); 2) how to know if the baby is getting enough breastmilk (10.0%); 3) how to help the baby feel well (6.7%); 4) how to give medicine (3.3%); 5) how to take the baby's temperature (6.7%) and 6) how to care for a diaper rash (6.7%).

Infant Environment (Questions 21 – 23)

Seventy percent of the participants reported receiving information about how warmly to dress their baby. Half of the participants (50.0%) were given information about what temperature and humidity to keep the house and one third (33.3%) reported they were given information about when to start taking their baby outside. Almost half (46.7%) of participants reported not receiving but wanting information about when to start to take the baby outside. Forty percent of the participants wanted but did not receive information about the temperature and humidity to keep the house. Ten percent of the participants reported that they wanted but did not receive information about how warmly to dress their baby.

Infant Behaviour and Development (Questions 15, 16, 25, 29 & 31)

Sixty three percent of the participants reported that they were given information that their baby may have trouble adjusting to the home for the first

couple of days. Fewer than half of the participants reported receiving information on the following items: 1) how to know if their baby had colic (33.3%); 2) how to get the baby to respond to them (36.7%); 3) whether their baby's 'fussy periods' are normal (43.3%) and 4) what kind of behaviour to expect from their infant for the first six weeks at home (46.7%). Information about infant behaviour and development was wanted but not received by a substantial number of participants. Information about the following was wanted and not reported as received: 1) how to know if the baby's 'fussy periods' were normal (50.0%); 2) how to know if the baby has colic (46.7%); 3) what kinds of behaviour to expect during the first six weeks at home (43.3%); 4) how to get the baby to respond (36.7%) and 5) possibility that the baby may have difficulty adjusting to home for the first few days (20.0%).

Information Specific to Premature Infants (Questions 26 – 28 & 30)

Twenty-one participants had a premature infant and the percentages presented below are based on this subset. Over sixty percent (61.9%) of participants indicated they received information that 'normal' behaviour and development of the premature infant may differ from that of a term infant. Fifty two percent of the participants reported that they were given information that it is normal for a premature baby to 'grunt', 'groan', 'sneeze' and 'hiccup' and 48% reported that they received information that noisy breathing is normal for a premature baby and so is a slightly irregular breathing pattern. Of those who had a

premature infant, 38% wanted but did not receive information that noisy breathing, especially at night is normal for a premature baby. Twenty-nine percent of participants with a premature baby wanted but did not receive the following information: 1) that 'normal' behaviour and development may differ from that of a term infant; 2) that premature babies may 'grunt', 'groan', 'sneeze' and 'hiccup' and 3) that premature babies may have a slightly irregular breathing pattern.

Table 6 provides a rank ordered list of the information that participants reported receiving four weeks after discharge. Again, the majority of the items (13 of 17 items or 76%) ranked in the top ten related to basic infant care. Of those items not ranked in the top ten, 57% (8 of 14 items) related to environment, behaviour and development and information specific to premature infants.

Table 6: Ranked Order Percentages of 'Yes' Responses Reported on Part A of the McKim Questionnaire Four Weeks After Discharge (N = 30)

Rank	Question	%
1	9. How to give your baby a bath? 10. How to give medicine (if any) to your baby? 11. How to take your baby's temperature?	86.7
2	19. How to recognize if your baby is becoming ill? 20. What to do if you think your baby is becoming ill?	80.0
3	18. How to know if the baby's bowel movement is normal?	76.7
4	8. Whether the baby needs any additional iron, vitamins, or fluoride?	73.3
5	1. How to breastfeed your baby? 22. How warmly to dress your baby?	70.0
6	5. How to help your baby feed well? 12. When to take your baby for his/her immunization? 13. How to take care of a diaper rash? 24. How long you should expect your baby to sleep between feedings?	66.7
7	29. Were you given information about the possibility your baby may have a little problem adjusting to home for the first couple of days?	63.3
8	30. Were you told that 'normal' behaviour and development for the premature infant may be 'different' from a term baby? ^a	61.9
9	2. How to know if your baby is getting enough breastmilk?	60.0
10	26. Whether it is normal for a premature baby to 'grunt', 'groan', 'sneeze' and 'hiccup'? ^a	52.4
11	14. How to know if the baby's 'spitting up' is normal? 21. What temperature and humidity to keep your house?	50.0
12	27. Whether noisy breathing, especially at night can be normal for premature babies? ^a 28. Whether your premature baby may have a slightly irregular breathing pattern? ^a	47.6
13	3. How to prepare the formula? 25. What kinds of behaviour to expect from your baby during his/her first six weeks at home?	46.7
14	4. How much formula you should give at each feeding? 16. How to know if your baby's 'fussy periods' are normal?	43.3
15	17. What to do about your baby's crying?	40.0
16	31. Were you told how to get your baby to respond to you?	36.7
17	15. How to know if your baby has colic? 23. When to start to take your baby outside the house?	33.3
18	6. When to start the baby on cereals? 7. What kinds of cereal to begin with?	26.7

^a Results based on responses only from participants with premature infants (n = 21)

Table 7 illustrates the ranked percentages of participants who reported that they wanted but did not receive information on items included in the McKim questionnaire four weeks after discharge. Of those 25 items ranked in the top ten, 13 (52%) related to basic infant care and 12 (48%) related to infant environment, behaviour and development and information specific to premature infants.

Table 7: Ranked Order Percentages of 'No, But I Would Have Liked This Information' Responses Reported on Part A of the McKim Questionnaire Four Weeks After Discharge (N = 30)

Rank	Question	%
1	16. How to know if your baby's 'fussy periods' are normal?	50.0
2	15. How to know if your baby has colic? 23. When to start to take your baby outside the house?	46.7
3	25. What kinds of behaviour to expect from your baby during his/her first six weeks at home?	43.3
4	21. What temperature and humidity to keep your house? 14. How to know if the baby's 'spitting up' is normal?	40.0
5	27. Whether noisy breathing, especially at night, can be normal for premature babies? ^a	38.1
6	4. How much formula you should give at each feeding? 6. When to start the baby on cereals? 7. What kinds of cereal to begin with? 17. What to do about your baby's crying? 31. Were you told how to get your baby to respond to you?	36.7
7	26. Whether it is normal for a premature baby to 'grunt', 'groan', 'sneeze' and 'hiccup'? ^a 28. Whether your premature baby may have a slightly irregular breathing pattern? ^a 30. Were you told that 'normal' behaviour and development for the premature infant may be 'different' from a term baby? ^a	28.6
8	3. How to prepare the formula? 29. Were you given information about the possibility your baby may have a little problem adjusting to home for the first couple of days?	20.0
9	8. Whether the baby needs any additional iron, vitamins, or fluoride? 12. When to take your baby for his/her immunization? 18. How to know if the baby's bowel movement is normal? 19. How to recognize if your baby is becoming ill? 24. How long you should expect your baby to sleep between feedings?	16.7
10	2. How to know if your baby is getting enough breastmilk? 20. What to do if your think your baby is becoming ill? 22. How warmly to dress your baby?	10.0
11	1. How to breastfeed your baby? 5. How to help your baby feed well? 11. How to take your baby's temperature? 13. How to take care of a diaper rash?	6.7
12	10. How to give medicine (if any) to your baby?	3.3
13	9. How to give your baby a bath?	0.0

^a n = 29.

^b Results based on responses only from participants with premature infants (n = 21)

As noted in Tables 4 & 6, the majority of the items reported as received related to basic infant care, both prior to and four weeks after discharge (88% and 76%, respectively). The participants' information needs, as illustrated by information wanted but not received, did change over time. Prior to discharge, the majority of the items (11 of 18 items or 61%) reported as wanted but not received related to infant environment, behaviour and development and information specific to premature infants (Table 5). Four weeks after discharge, majority of items reported as wanted but not received related to basic infant care (13 of 25 items or 52%). More information related to basic infant was reported as wanted and not received after discharge.

Information Recall

Participant recall of the information provided by the nurses, before discharge to home, appeared high. This finding is supported by the infrequent selection of the 'don't know/don't remember' option. For example, on the McKim questionnaire, of a possible 930 responses (30 participants x 31 questions) 'don't know/don't remember' was chosen 15 (1.6%) times.

Aylward Questionnaire Part A – Time 2 (Four Weeks After Discharge)

Recognition/Response to Changes in Health Status (Questions 2 – 6)

As illustrated in Appendix N, over 70% of the participants reported receiving information about the following: 1) what to do in case of an emergency at home (76.7%); 2) how to recognize a change in their baby's colour (73.3%) and 3) being offered an infant CPR course (73.3%). Fifty-seven percent of the participants reported receiving information about what to do if their baby stopped breathing at home. Only 23.3% of participants reported receiving information about how to recognize changes in their baby's breathing pattern that may indicate that he/she is becoming ill. Two participants reported that they were not offered an infant CPR course and they would have liked that information and opportunity.

Knowledge/Skills Necessary to Care for the Medically Complex Infant (Questions 1 & 7 – 14)

As reported prior to discharge, all caregivers who required information related to the technology required for the care of the medically complex infant at home, received that information. Seventeen participants had infants who required medication to be given at home. The following results are based on this subset of the study participants. Four weeks after discharge, 59% (n = 10) of participants reported that they received information about the side effects of the medications

that they would have to give their babies at home and 23% (n = 4) that they would have liked this information. The results are presented in Appendix N.

Information Recall

Again, participant recall of information provided by the nurses appeared high. Of a possible 420 responses on the Aylward questionnaire (30 participants x 14 questions) 'don't know/don't remember' was chosen 2 (0.5%) times.

Support Findings

McKim Questionnaire Part B – Time 2 (Four Weeks After Discharge)

Ninety percent (n= 27) of the participants reported that they had help at home. Twenty-five of the participants (83.3%) identified their partner as providing help. Twelve participants (40.0%) reported that their mother provided help and fifteen participants reported that another family member provided help in the home. In eight cases (29.6%), the partner was the sole 'support' provider. Eighteen participants (66.6%) reported receiving help from more than one individual. None of the participants reported receiving help, in the home, from friends or neighbours. Almost three-quarters (73%) indicated that a printed informational booklet would have been helpful. Table 8 illustrates the individual or individuals who provided help in the home. Activities identified as helpful included household chores, care of the newborn or other child(ren) and providing opportunities for the primary caregiver to

rest. Twenty-five (83.3%) participants reported the help they received was adequate.

Table 8: Individual(s) Who Provided Help in the Home as Reported by Study Participants on the McKim Questionnaire (Part B) Four Weeks After Discharge (N=27)

Individual(s) Providing Help in the Home	n	%
Partner	8	29.7
Other Family Member	1	3.7
Partner and Mother	4	14.8
Partner and Other Family Member	6	22.2
Partner, Mother and Other Family Member	7	25.9
Mother, Other Family Member & Housekeeper	1	3.7

Sixteen participants (53.3%) reported that the first week at home was the most difficult. Two-thirds of the participants (n = 20) received a visit from the public health nurse (PHN). Sixty-three percent of these visits occurred during the first week after discharge. Ninety-five percent of participants who received a visit from a PHN found the visit helpful. The PHN answered specific questions (feeding, sleep patterns), ordered equipment (syringes and ostomy supplies) and provided pamphlets and information about community resources.

Aylward Questionnaire (Part B) – Time 2 (Four Weeks After Discharge)

All participants reported they felt comfortable to take their baby home despite the medical condition of their infant. Information provided in hospital, care-by-parent opportunities, passes to home and infant condition were factors that

contributed to the primary caregiver's comfort level. Nineteen participants (63.3%) reported that their infant's condition was not severe and six participants (20.0%) felt that their baby's condition was severe. Twenty-eight participants (93.3%) reported their ability to cope with their infant's medical condition as 'good' or 'very good'.

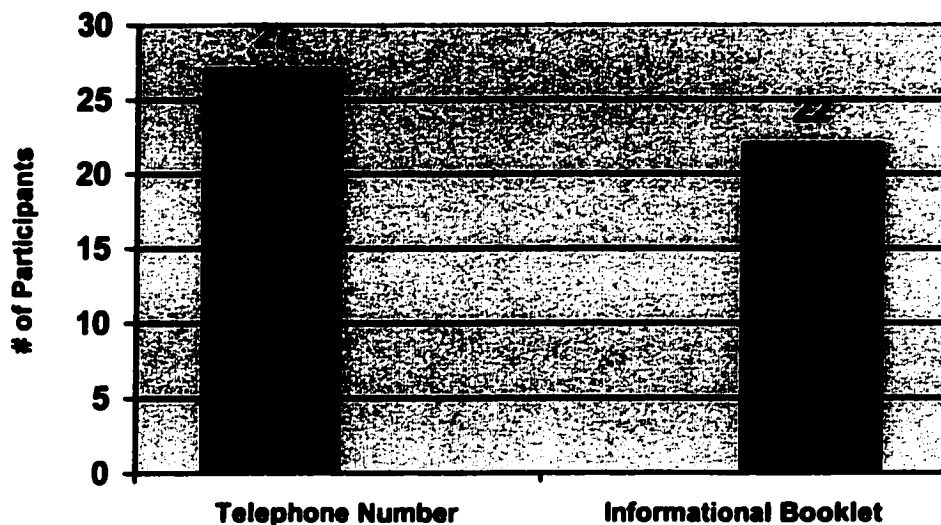
The support needs of study participants are presented in Table 9. Eighty-three percent of participants called for information and support within the first four weeks at home. Participants reported that the number of a place to call and written material(s) would have been supportive (Figure 1). Information lines at CHEO, NICU and Public Health were identified as numbers that participants would have liked.

Table 9: Support Needs as Reported by Primary Caregivers on the Aylward Questionnaire (Part B) Four Weeks After Discharge

Support Need and Source of Support	N	%
After your baby came home from the hospital, did you call for information and support regarding your baby's care?		
Yes	25	83.3
No	5	16.7
If yes, who/where did you call? ^a		
Family Member	15	50.0
Friend	7	23.3
Public Health Nurse	7	23.3
Family Doctor	3	10.0
Pediatrician	9	30.0
NICU	6	20.0
CHEO Information Line	5	16.7
Other	7	23.3
Do you think that parents should be given the phone number of a specific place to call for information and support about their baby's care?		
Yes	27	90.0
No	3	10.0
If yes, where might this place be? ^a		
NICU Information Line	14	46.7
CHEO Information Line	15	50.0
Public Health Information Line	12	40.0
Doctor's Office	6	20.0
Community Drop-In Centre	7	23.3
Other	3	10.0
Who should be available to answer your questions? ^a		
Doctor	9	30.0
Nurse	14	46.7
Public Health Nurse	8	26.7
NICU Nurse	14	46.7
Other	3	10.0

^a More than one option could be selected therefore total response rate is >100%

Figure 1: Resources Reported as Helpful by Study Participants

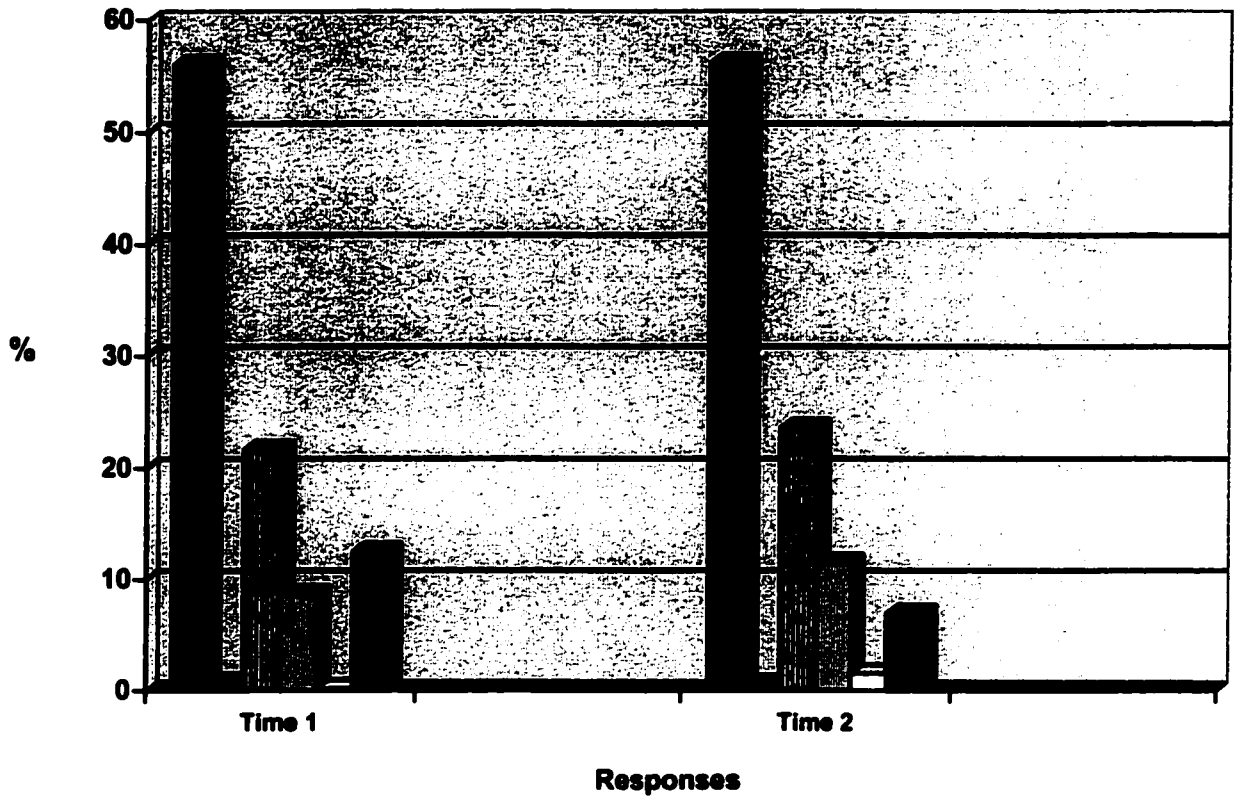


Question 3

Do the primary caregivers' perceptions of the information provided by the NICU nurses change over time?

A comparison of the percentages of participants' responses on Part A of the McKim questionnaire prior to (Time 1) and four weeks after discharge (Time 2) is depicted in Figure 2. The pattern is strikingly similar over time. It does not, however, take into account the individual changes in responses prior to and four weeks after discharge. More in-depth analysis shows the differences in responses and will be discussed.

Figure 2: Comparison of the Percentages of Participants' Responses on Part A of the McKim Questionnaire Prior To (Time 1) and Four Weeks After Discharge (Time 2)



■ yes	■ yes, but I didn't want this information
■ no, but I would have liked this information	■ no, but I didn't want this information
□ don't know/don't remember	■ not applicable

McKim Questionnaire Part A – Comparison of Participants' Perceptions of Information Provided by the Nurses Prior to and Four Weeks after Discharge

Appendices O and P provide a comparison of the percentage of participants choosing each of the six possible responses on the two study questionnaires both

prior to (Time 1) and four weeks after discharge (Time 2). The two study questionnaires (McKim and Aylward) will again be presented separately.

Basic Infant Care (Questions 1 – 14, 17 – 20 & 24)

On 12 of 19 questions related to basic infant care, more participants reported receiving information prior to discharge than after four weeks at home. The questions that were answered most consistently addressed the following topics: feeding (including breastfeeding, formula preparation, how to help the baby feed well and introduction of cereals), how to give medication, how to take the baby's temperature, when to take the baby for his/her immunization, how to know if the bowel movement is normal and how to recognize and respond to signs of illness. The percentage of participants who reported they received the above information varied by less than seven percent over time.

After four weeks at home, 73% of the participants reported that they received information about the need for additional vitamins and iron compared to 60% of the participants prior to discharge. When compared to responses reported prior to discharge, an additional ten to thirteen percent of the participants reported receiving information about bathing their infant (76.7% vs. 86.7%) after four weeks at home. Ten percent fewer participants reported receiving information about caring for a diaper rash and how to know whether the baby's 'spitting up' was normal. Sixteen percent fewer participants reported that they knew how long their baby should sleep between feeds after discharge. Twenty-three percent fewer

participants reported receiving information about what to do about their baby's crying than they indicated receiving prior to discharge (63.3% vs. 40.0%).

Infant Environment (Questions 21 – 23)

On each of these three items, more participants reported that they received the information four weeks after discharge than they reported prior to discharge (see Appendix O). For example, an additional thirteen percent of the participants reported receiving information about what temperature and humidity to keep the house (36.6% vs. 50.0%) after four weeks at home.

Infant Behaviour and Development (Questions 15, 16, 25, 29 & 31)

Prior to discharge, 40% of participants responded that they received information that their baby may have difficulty adjusting to the home environment for the first couple of days, after discharge this number increased to 63% of the participants. The remaining four items were answered by similar percentages of participants prior to and after discharge. More participants reported receiving information about how to know if their baby's fussy periods were normal and how to get their baby to respond to them prior to discharge. Prior to discharge, fewer participants reported receiving information about how to know if their baby has colic and what kinds of behaviour to expect from their baby during the first six weeks at home than they reported receiving after discharge.

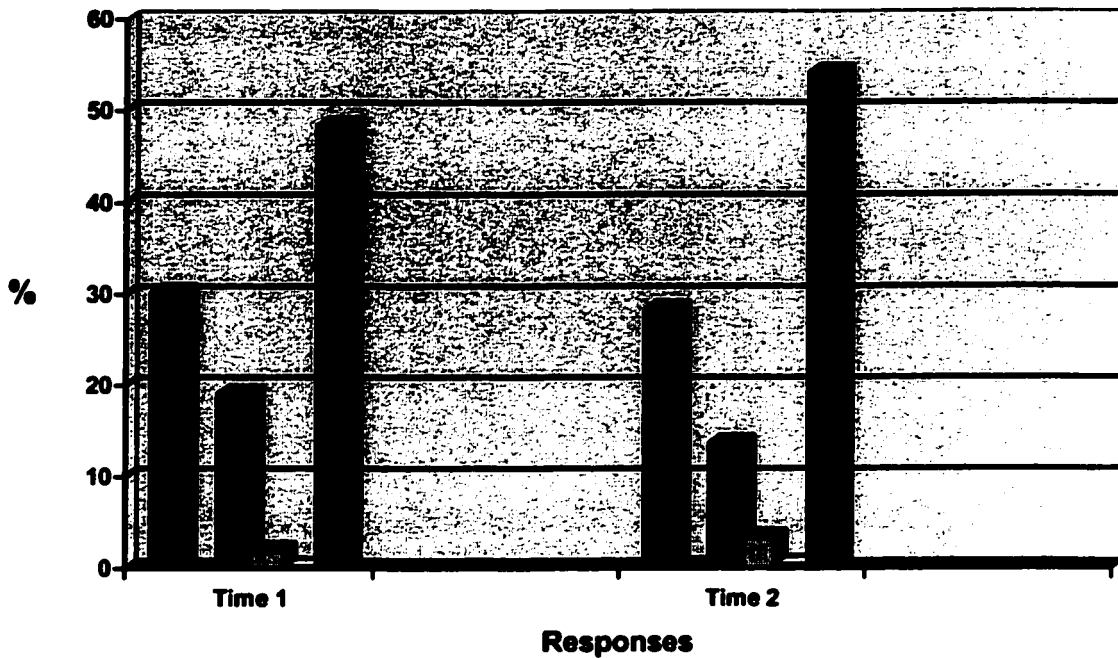
Information Specific to Premature Infants (Questions 26 – 28 & 30)

After four weeks at home, on three of four items, participants reported receiving more information specific to premature infants than prior to discharge. For example, after four weeks at home, an additional 12% of the participants reported receiving information that 'normal' behaviour and development of a premature infant may differ from that of a full term infant (50.0% vs. 61.9%), prior to and four weeks after discharge, respectively. The one item that fewer participants reported receiving information about after discharge, related to premature infants having a slightly irregular breathing pattern (75.0% vs. 47.6%, prior to and four weeks after discharge, respectively).

Aylward Questionnaire Part A – Comparison of Participants' Perceptions of Information Provided by the Nurses Prior To and Four Weeks after Discharge

A comparison of the percentages of participants' responses on Part A of the Aylward questionnaire prior to (Time 1) and four weeks after discharge (Time 2) is depicted in Figure 3. As with the McKim questionnaire, the pattern is strikingly similar over time. Again, it does not take into account individual changes in responses prior to and four weeks after discharge. Further analysis identifies the differences in responses presented in Appendix P and will be discussed further on.

Figure 3: Comparison of the Percentages of Participants' Responses on Part A of the Aylward Questionnaire Prior To (Time 1) and Four Weeks After Discharge (Time 2)



Recognition/Response to Changes in Health Status (Questions 2 – 6)

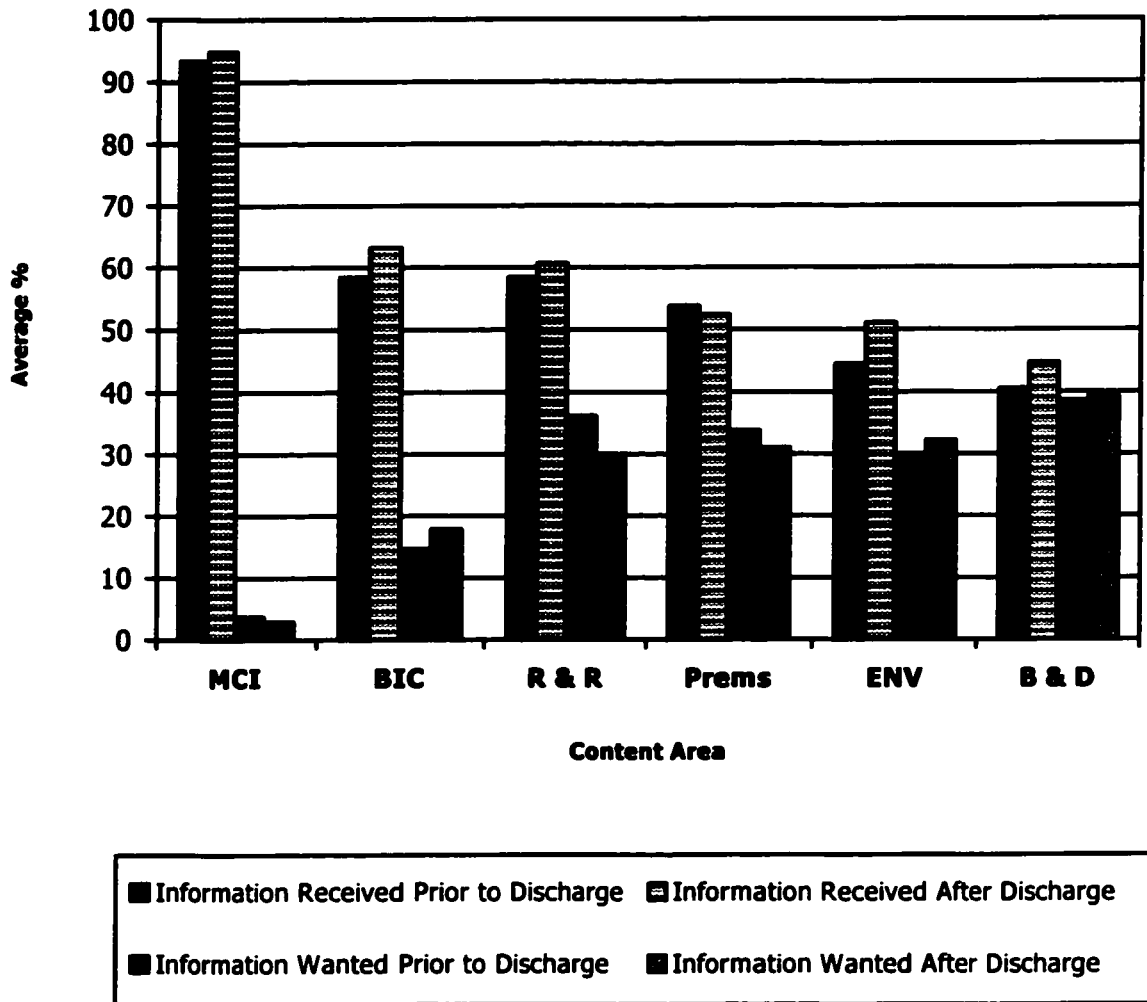
On these five items, three of thirty participants changed their responses at least half of the time. The vast majority of these responses changed (10 of 11) to 'yes' after discharge. There were four of the thirty participants who did not change any of their responses over time. There were no questions to which participants changed their responses more than fifty percent of the time. The greatest

percentage of participants who changed their responses did so on questions related to side effects of medications (43.3%) and how to recognize changes in the baby's breathing pattern that may mean he/she is becoming sick (33.3%).

Four weeks after discharge, there were eight participants who reported they had received more information than they indicated prior to discharge. In 2 of the 5 questions applicable to all, at least 10% more participants reported receiving information after four weeks at home than they reported prior to discharge. For example, after four weeks at home, 76.7% of participants reported receiving information about what to do in case of an emergency at home compared to 65.5% of the participants prior to discharge. Compared to responses reported prior to discharge, an additional 13% of parents reported receiving information about what to do if their baby stopped breathing at home when asked four weeks after discharge (43.3% versus 56.7%). Conversely, ten percent fewer participants recalled receiving information about how to recognize changes in their baby's breathing pattern that may mean that he/she is becoming sick (33.3% versus 23.3%) after four weeks at home.

A comparison of participant reports of information received and information wanted but not received prior to and after discharge on both study questionnaires is presented in Figure 4.

Figure 4: Comparison of the Average Percentage of Participants' Responses of 'Information Received' and 'Information Wanted but Not Received' Prior to (Time 1) and Four Weeks After Discharge (Time 2) by Content Area



LEGEND for CONTENT AREAS

- MCI Knowledge/Skills Necessary to Care for the Medically Complex Infant
- BIC Basic Infant Care
- R & R Recognition/Response to Changes in Health Status
- Prems Information Specific to Premature Infants
- ENV Environment
- B & D Behaviour and Development

Correlations of Study Variables on McKim and Aylward Questionnaires

Pearson product-moment correlation coefficients were calculated on both study questionnaires, on data collected prior to and after discharge for all 30 participants. McKim's (1993a) analyses were replicated. The following items were correlated: maternal age, birth weight, gestational age, number of children, length of stay, percentage of 'a' responses (yes) prior to and after discharge, percentage of 'c' responses (no, but I would have liked that information) prior to and after discharge, level of anxiety (McKim Questionnaire - Part B) and level of confidence (McKim Questionnaire - Part B). The two relationships of particular interest were: 1) information (received or wanted) and anxiety and 2) information (received and wanted) and confidence. In this study, no significant relationships were found between anxiety, confidence and information received or wanted. The findings are presented in Table 10.

Table 10: Summary of Pearson Product-Moment Correlation Coefficients for Study Variables (McKim Questionnaire) Measured Prior to Discharge (Time 1) and Four Weeks After Discharge (Time 2)

	Maternal Age	Birth Weight	GA ^①	# of Children	LOS ^②	Anxiety	Confidence
Maternal Age		-.276	-.240	.440*	.059	.325	.271
BW			.834**	-.304	-.496**	-.077	.063
GA				-.209	-.539**	-.155	.121
# of Children					.100	.022	.359
LOS						.307	-.296
% 'a' (Time 1) ^③	-.015	-.496**	-.459*	-.183	.476**	.352	-.336
% 'c' (Time 1) ^④	-.268	.336	.266	-.373*	-.431*	-.279	.050
% 'a' (Time 2) ^⑤	-.078	-.441*	-.361	-.201	.312	.263	-.251
% 'c' (Time 2) ^⑥	-.238	.262	.095	-.332	-.347	-.309	.036

① gestational age

② length of stay

③ percentage of 'a' responses prior to discharge

④ percentage of 'c' responses prior to discharge

⑤ percentage of 'a' responses four weeks after discharge

⑥ percentage of 'c' responses four weeks after discharge

* p < 0.05

** p < 0.01

The same variables as described previously were correlated for primary caregivers of premature and/or medically complex infants (Aylward Questionnaire – Part A) and the results are presented in Table 11. Identical relationships were found among the demographic variables. There was a significant relationship between anxiety and information received prior to discharge ($r = .461$; $p = .010$). For primary caregivers of premature and/or medically complex infants, anxiety was

positively correlated with the amount of information provided prior to discharge (i.e. the more information that was provided the higher the anxiety level). There were no significant relationships between confidence and information received or not.

Table 11: Summary of Pearson Product-Moment Correlation Coefficients for Study Variables (Aylward Questionnaire) Measured Prior to Discharge (Time 1) and Four Weeks After Discharge (Time 2)

	Maternal Age	Birth Weight	GA ^①	# of Children	LOS ^②	Anxiety	Confidence
Maternal Age		-.276	-.240	440*	.059	.325	.271
Birth Weight			.834**	-.304	-.496**	-.077	.063
GA				-.209	-.539**	-.155	.121
# of Children					.100	.022	.359
LOS						.307	-.296
% 'a' (Time 1) ^③	.044	-.049	-.011	.018	.180	.461*	-.252
% 'c' (Time 1) ^④	-.227	-.014	.140	-.091	-.423*	-.292	.296
% 'a' (Time 2) ^⑤	.332	-.059	-.069	.059	.031	.266	-.296
% 'c' (Time 2) ^⑥	-.500**	.018	.110	-.243	-.028	-.258	.041

① gestational age

② length of stay

③ percentage of 'a' responses prior to discharge

④ percentage of 'c' responses prior to discharge

⑤ percentage of 'a' responses four weeks after discharge

⑥ percentage of 'c' responses four weeks after discharge

* p < 0.05

** p < 0.01

Cross Tabulations on Part A of the McKim and Aylward Questionnaires

In order to analyze the rate of agreement (and rate of change) in participant responses over time, contingency tables were derived for each question on Part A of the McKim and Aylward questionnaires. As discussed in Chapter 3 the rate of change was calculated for each question in Part A of both study questionnaires. The range of change and average rate of change for each content area is presented in Table 12.

Table 12: Rate of Change in 'Yes' Responses Over Time Reported by Content Area on the McKim and Aylward Questionnaires

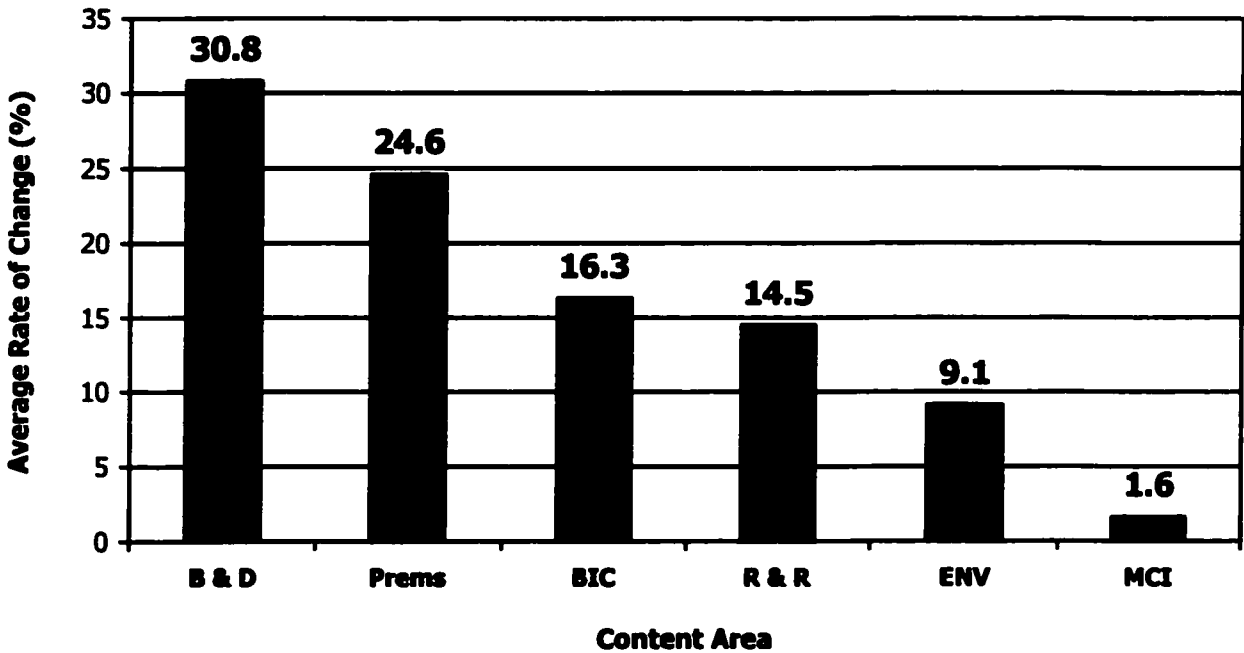
Content Area	Range of Change (%)	Average Rate of Change (%)
McKim Questionnaire		
Basic Infant Care	0.0 – 47.4	16.3
Infant Environment	0.0 – 22.2	9.1
Behaviour and Development	0.0 – 50.0	30.8
Information Specific to Premature Infants ¹	20.0 – 33.3	24.6
Aylward Questionnaire		
Recognition/Response to Changes in Health Status	0.0 – 40.0	14.5
Knowledge/Skills Necessary to Care for the Medically Complex Infant ²	0.0 – 14.3	1.6

¹ Results based on responses only from participants with premature infants (n = 21)

² Results based on responses only from participants for whom the question applied.

The average rate of change was greatest for the following content areas: 1) behaviour and development (30.8%); 2) information specific to premature infants (24.6%); 3) basic infant care (16.3%) and recognition/response to changes in health status (13.7%). The average rate of change was lowest in the following content areas: 1) infant environment (9.1%) and 2) knowledge and skills related to the care of the medically complex infant (1.6%). Figure 5 provides a graphic representation of this data.

Figure 5: Average Rate of Change in 'Information Received' Responses over Time by Content Area



LEGEND for CONTENT AREAS

- B & D Behaviour and Development
- Prens Information Specific to Premature Infants
- BIC Basic Infant Care
- R & R Recognition/Response to Changes in Health Status
- ENV Environment
- MCI Knowledge/Skills Necessary to Care for the Medically Complex Infant

CHAPTER 5

Discussion

The final chapter examines the results presented in the previous chapter. It provides a discussion of the findings, study limitations, and the implications for practice and further research.

To the author's knowledge this is the first study in the Ottawa area that addressed the immediate information and support needs of families with premature and/or medically complex infants upon their discharge to home. Most studies in the literature excluded families with medically complex infants. When families with a medically complex infant are included, the focus of the inquiry is on family coping and adaptation in the longer term, rather than the immediate information and support needs. This study adds to the body of knowledge about families with premature and/or medically complex children and their needs during transition from hospital to home.

Demographic Factors

Most participants in this study were mothers of a premature and/or medically complex infant, were involved in a relationship and had no other children. Two-thirds had either attended or completed post secondary education and the majority reported a family income greater than \$40,000. Similar to participants in other

studies (Affonso et al., 1992; Hughes et al., 1994; Stephenson, 1999) this was a well-educated, middle class population of non-single Caucasian women. The participants in McKim's (1993a) study were also non-single Caucasian women. McKim (1993a) did not collect data on educational or socio-economic status. Other researchers (Brooten et al., 1989; Brooten et al., 1986; Gennaro, York & Brooten, 1990; Sterling, 1990) reported that their participants were primarily non-white, poorly educated and of low socio-economic status.

Information Needs

Participants reported receiving information in all content areas. Information related to basic infant care was most consistently reported as received by participants both prior to and after discharge. Participants identified information that would have been helpful to them before discharge and during their transition to home. In addition, information needs changed over time as families were discharged from hospital to home and parents transition from participant observer to primary caregiver. It is known that parents want information about basic infant care (Brooten et al., 1989; Brooten et al., 1991; Butts et al., 1988; Gehl & Lantzy, 1990; Goodman & Sauve, 1985; McKim, 1993a; McKim et al., 1995; von Platen, 2000), infant growth and development (Brooten et al., 1989; Gennaro, York & Brooten, 1990; von Platen, 2000), signs of changing health status (Brooten et al., 1989; Brooten et al., 1991; Butts et al., 1988; Gennaro, York & Brooten, 1990) and information about medications and special procedures (Brooten et al., 1991;

Gennaro, York & Brooten, 1990). Parents in this study received information in all these areas plus information relating to the infant's environment and information specific to the premature infant. Both prior to and four weeks after discharge, a greater percentage of participants reported receiving information about basic infant care and the knowledge/skills required to care for a medically complex infant than reported receiving information about infant environment, infant behaviour and development, or information specific to a premature infant. It is noted that Sheikh et al. (1993) found many parents did not recall information about growth and development.

These differences in responses prior to and four weeks after discharge may be attributed to multiple (and additional) sources of information; a readiness for learning; relevance of the material and participant recall. For example, participants may have received information, after discharge, from a public health nurse, the baby's physician or family or friends. In this study, 20 (67%) participants had a visit from the public health nurse, nine (30%) participants had called their pediatrician, 15 (50%) participants had called family members and seven (23%) participants had called a friend. There was no data collected about information that participants found on the Internet or in books and these are two frequently used resources (Brazy et al., 2001).

With respect to relevance, participants with a medically complex child consistently reported that they had received information related to the care of their child. The rate of change in responses was minimal (1.6%) and is an indication that

this information was received and recalled. The author suggests this speaks to the particular relevance of this information. The caregiver needs to know how to insert and care for a nasogastric tube if the baby is discharged home on tube feedings.

Information in the other content areas, although relevant, may not be absolutely essential for the care of the infant. Participants were less consistent in their responses to items related to infant behaviour and development. This may be evident as there is a tendency, for professionals and parents alike, to focus on the medical complexity and physical needs of the infant rather than on facilitating normal growth and development in this population. In addition, participants were less consistent in their responses to items about information specific to the premature infant. The behaviour (noisy breathing at night) or issue (development of a premature infant being different from a term infant) may not have been in question until the infant was at home and the parent(s) had assumed the role of primary caregiver(s). The author suggests information in these areas needs to be reinforced and available to parents as it becomes more relevant to them.

Butts et al. (1988) suggest readiness for learning is heightened when parents assume total care of their infant. Information deemed less relevant prior to discharge may have become more relevant during the four weeks at home. For example, if a woman planned to breastfeed her baby, information about formula preparation would not have been wanted nor provided. However, if after four weeks at home, exclusive breastfeeding was no longer the reality, information about formula preparation and bottle-feeding would now be of relevance. Further,

questions about the introduction of cereal were likely not uppermost in the participants' minds, at the time of discharge, however, after four weeks at home, parents indicated they needed this information. Feeding issues were identified in the literature as a source of concern for parents (Brooten et al., 1989; Goodman & Sauve, 1985; Gehl & Lantzy, 1990). On the Aylward questionnaire, more participants reported receiving information related to the care of the medically complex infant than information about signs of changing health status both prior to and four weeks after discharge. The literature suggests that caregivers wanted to know the signs of illness (Brooten et al., 1989; Brooten et al., 1991; Butts et al., 1988; Gennaro, York & Brooten, 1990). Sheikh et al. (1993) found, however, that many caregivers did not know the general signs of illness.

There are many reasons why participants may not have recalled specific information. Readiness for learning is affected by stress and anxiety (Drake, 1995; Janis, 1982; Sheikh et al., 1993) and can affect one's ability to absorb and remember complicated medical information (Sheikh et al., 1993). It is possible that the information was provided to parents and simply not remembered. Information overload tends to be the norm at this time as parents and health care providers, alike, ensure preparedness for discharge. Finally, a noisy NICU, with its many distractions, is not the most conducive environment for learning.

In this study, parents wanted information specific to the premature infant. Griffin et al. (1998) suggest parents of premature infants require special instruction and informational materials about their infant's needs and behaviour. Brooten et al.,

(1991) and Gennaro, York and Brooten (1990) note that parents wanted information about infant behaviour and temperament. Premature infants are less active and less responsive than term infants (Gennaro, 1991). Premature infants may have challenging temperaments and ongoing medical needs after discharge (Gennaro, 1991). Parents in this study indicated that they would have liked information about infant temperament, specifically information about colic, crying and their baby's fussy periods, both prior to and four weeks after discharge. All participants reported that they felt comfortable to take their baby home in spite of the fact that they indicated they had unmet informational needs.

For primary caregivers of premature and/or medically complex infants anxiety was positively correlated with the amount of information provided prior to discharge. It is possible that the amount of information that primary caregivers received caused an increase in the anxiety or that the more information they received the more questions were generated and the higher the anxiety. Alternatively, anxiety caused primary caregivers to seek more information. It is noted that Gennaro (1985) found that anxiety enabled mothers to mobilize their resources in order that they could care for their infant.

After four weeks at home, those participants who reported receiving less or different information than they reported prior to discharge may have done so for a variety of reasons. Recall of information from one month previous may be unintentionally inaccurate – for the participants it has been an eventful four weeks. Perhaps, participants had felt anxious about the imminent discharge of their infant

and wanted to present the appearance of being knowledgeable and prepared. Now that their baby is home parents can admit that they do not know everything. In addition, participants may have encountered an issue while at home and realized that pertinent information had not been provided. Parents may not be able to anticipate what they need to know until they are home caring for their infant (Butts et al., 1988) and informational needs change over time (Brazy et al., 2001; Brooten et al., 1989; Butts et al., 1988; Gennaro, Zukowsky et al., 1990). Both of these statements speak to the importance of reiteration, reinforcement and availability of information after discharge. In addition to follow-up by the public health nurse, nurses familiar with the baby's hospital course and expertise in neonatal care could provide reinforcement of information, reassurance to the family and assessment of growth and development. The addition of this resource may make it possible to provide in-home support to more than the two-thirds of families that reported receiving a visit from the public health nurse.

In summary, reasons for changes in participants' responses may be attributable to recall related to the passage of time, the amount of information received and their readiness for learning. Certain information may have become more important and relevant as participants assumed total responsibility for the care of the child, once at home. In addition, certain information may not have been emphasized or pertinent at the time of discharge but became so with the passage of time and infant development. Finally, there are multiple sources of information that participants may have accessed including public health nurses, physicians,

family members, friends, Internet and books. Perhaps, participants acknowledged having the information but may have incorrectly credited the neonatal nurse with its provision.

Support Needs

In this study and others (Affleck et al, 1991; McKim, 1993a) a majority of the participants had at least one individual that provided help once at home. Most often it was the participant's partner, another family member or the participant's mother (Affleck et al., 1991; McKim 1993a). Contrary to findings reported in the literature (Kenner & Lott, 1990), participants in this study did telephone friends for information and support. Most study participants felt the help they had was adequate.

Although caregivers reported that they felt comfortable to take their baby home and that they had adequate support once there, the vast majority of the participants in this study wanted a place to call for information and support, a finding similar to that of McKim (1993a). A majority of participants had already called for information and support during the transition to home and had accessed both the NICU and the CHEO Information Line. The CHEO Information Line is now defunct. These findings support the need for the creation of a program of formalized telephone follow-up.

Informational support is documented in the literature (Kenner, 1990; Kenner & Lott, 1990; McKim, 1993a; McKim et al., 1995). The majority of participants in

support in the form of written reference material. In this study, topics found to need reinforcement after discharge were: feeding (method and introduction of cereals, formula preparation and bottle feeding); infant environment (temperature to keep the house, how warmly to dress the baby, when to start to take the baby outside); infant behaviour and development (issues of colic and 'fussy periods', adjustment to home); information specific to premature infants (breathing patterns/noises, development different than term infant) and recognition of changing health status (signs of illness, response to emergency situations). In addition, numbers for various community resources could be included as well as recommended Internet sites. Brazy et al. (2001) acknowledge that parents use the Internet to gather information about their baby's condition – it would be advisable therefore to provide a listing of recommended and reliable sites. In addition, to the information needs found in this study, the discharge package could include written information specific to the infant's diagnosis (e.g. cystic fibrosis, gastroschisis or cardiac anomaly). In this manner, the discharge package could be both comprehensive and individualized.

The public health nurse was the only source of professional support in the home for two-thirds of the participants. The majority of the participants found the visit helpful. Reasons cited for this included: provision of information (verbal and written); ongoing monitoring of growth (weight) and development; identification of community resources; ordering of necessary supplies (ostomy and suction) and providing reassurance to caregiver. It is of note, that although the majority of the

participants reported they felt comfortable to take their baby home, had adequate support once at home and were satisfied with the visit by the public health nurse, the vast majority had accessed additional sources of support and expressed a desire for a telephone number of a specific place to call for information and support and an informational booklet to which to refer once they were home.

In response to the above, a nurse with neonatal expertise, familiar with the infant and family, could provide information and support during the transition to home. Researchers in the United States and Canada have found that early discharge with follow-up by neonatal nurses is safe and effective and has significant differences in outcomes for the infants and mothers (Brooten et al., 1986; Brooten, Brown, et al., 1988; Casiro et al., 1993; Evanochko et al., 1996; Gamblian et al., 1998; Kotogal et al., 1995, von Platen, 2000).

It is difficult to reconcile who is best prepared to provide information and support to these families upon discharge from the NICU. The issue of continuity of care and the seamless transition to home is fraught with challenges and debate. The benefits of having in home follow-up provided by a neonatal nurse include: nursing expertise specific to the physical and psychosocial concerns of the infant and family, familiarity with the infant and his or her course in hospital and the element of trust that results from the established and ongoing relationship between health care professional and family. Within the current health care system, the limitations of implementing such a program in the Ottawa area and elsewhere relate to cost, time and personnel commitments. Follow-up by public health nurses,

experts in primary care and community resources, is the current reality and as noted above, is appreciated by families. In response to this conundrum, the author would suggest that a randomized control trial to compare current practice (public health nurse follow-up) and an in-home transitional care program with follow-up by an expert neonatal nurse be undertaken. Results would guide program development, care delivery and the organization of professional support during the transition to home.

Implications for Nursing

Before discharge teaching is started it is important to assess a parent's learning needs as well as readiness for learning. Exploration of educational level, learning style and information wanted should accompany an assessment of their level of stress and their motivation to learn. Current discharge teaching includes information from the six content areas addressed in this study. Based on findings from this study, content about infant behaviour and development, infant environment, information specific to the premature infant and recognition of changing health status need to be added to the discharge-teaching tool. Nurses need to address these topics as part of a comprehensive discharge teaching program and document that this teaching was done. Unfortunately, study methodology did not include a chart audit as a means to verify the information that nurses documented as having provided. As a result, there was no way to corroborate or refute participant's responses. Further, documentation will

underscore the information that was provided, a necessary facet of a quality assurance program.

Implications for the Advanced Practice Nurse

As a clinical expert, the Advanced Practice Nurse (APN) shares information with families and nurses alike. Results of this study must be disseminated to the nurses in the NICU and shared with the unit manager in order that changes to current practice can be considered.

This study identified gaps in the current discharge-teaching program. Topics related to infant environment, behaviour and development and the premature infant need to be added to the discharge-teaching tool. Information about the above is also needed to reinforce information provided by the NICU nurses. Multiple strategies can ensure information is provided, recalled or at least made available. Pamphlets, videos, an Internet site and a nursing visit are ways to facilitate access to this information. The APN can co-ordinate efforts to develop these resources. In addition, the APN can develop a proposal for a formalized telephone follow-up program. Program evaluation and continuous quality improvement initiatives, including chart reviews and tool audits are subsumed in the advanced practice role.

Further, the APN may assume the role of case manager for families with complicated discharge needs and thus ensure that information and support needs are identified prior to discharge. He or she would have a pivotal role in the multidisciplinary discharge planning team. The APN may be the person responsible

for the development of creative programming to facilitate successful transition to home. One such endeavour could be the development of a program of transitional home care.

A formal program of information exchange between health care sectors should be contemplated. The APN could take a leadership role in the advancement of this network. To facilitate consistent delivery of this information after discharge, a core group of public health nurses with maternal and neonatal expertise should be developed. Neonatal nurses need to liaise with public health nurses prior to the discharge of these families. Finally, the results of this study should be disseminated within the community and to other units in the city who care for premature infants and their families.

Transition Framework

Changes in roles, responsibilities and abilities are key factors in transitional theory. This study sought to identify the informational and support needs of participants after the birth of a premature and/or medically complex infant. Participants in this study experienced many transitional events. All participants experienced a role transition as they relinquished the birth of a 'healthy' newborn and became parents of a premature and/or medically complex infant. Participants experienced the transition from participant observer to primary caregiver. The information needs of participants changed as they made the transition to home. This finding has implications for discharge planning as well as the type and delivery

of ongoing support – professional, informational or instrumental. Kenner and Lott (1990) state that transition to parenthood may not occur until after discharge and the assumption of total responsibility of care, when parents come to fully appreciate what they need to know to care for their baby.

Limitations of the Study

This study had a number of limitations. It was a small non-random sample of 30 primary caregivers of premature and/or medically complex infants. Participants were primarily Caucasian, English-speaking, almost exclusively female, well educated and in a relationship. It is difficult to generalize the findings to other populations based on the limited sample size and the demographic characteristics of study participants.

The researcher developed one of the study tools. The tool was piloted and revised prior to use. Content validity and test-retest reliability measures were ascertained. However, since this was the first time the tool was administered to a study population, no comparisons with other research projects using the tool can be made and therefore additional refinements to the tool may be necessary. In order to further examine the psychometric properties of the Aylward questionnaire, the following should be considered: 1) repeat the test-retest for tool reliability and accuracy with a larger sample (e.g. 12 participants); 2) conduct the retest within 2 – 4 days in order to avoid the effects of rapidly changing information and support needs. It is acknowledged however that participants may remember their initial

responses when the test is repeated at such a close interval. Finally, one could examine construct validity through comparison of results with other tools that measure the same concepts. Convergence of results, when similar concepts are measured with different instruments would support construct validity and reliability.

The use of a self-report questionnaire raises concerns about self-report bias, including social desirability (Streiner & Norman, 1995) and recall. Participants are expected to provide accurate responses and to acknowledge when they don't remember a particular point. However, the methodology of this study did not provide a means to assess and validate the accuracy of the participants' responses and recall through observation or documentation of the discharge teaching by the nurses. It is possible that some information was not provided but there is also the possibility that information was provided by the nurses and simply not recalled – limitations of human memory. Alternately, some information may have been provided by an individual other than the NICU nurse and attributed to him or her. The limitation becomes the inability to differentiate between these scenarios.

Four weeks after discharge, the administration of the questionnaires was to take place at a mutually agreed upon location, as per the consent. The intent was for this location to be the participant's home. In some instances the most convenient 'location' was the telephone. In order not to jeopardize recruitment, telephone administration of the questionnaires was done.

Finally, there were challenges incurred with the use of the McKim questionnaire. Analysis may be facilitated if only three response options were

offered – a) yes; b) no, but I would have liked this information and c) not applicable. The author suggests that participants may have considered 'no, but I didn't want this information' and 'not applicable' to mean the same thing.

Measures of anxiety and the infant's medical condition, although reflective of individual participant's appraisal, were garnered from responses on the same Likert-type scale used in the McKim (1993) questionnaire. The use of standardized tools to measure any of these variables would add objectivity and validity to the findings. In addition, another study, with a larger sample size is required to further investigate the relationship between variables.

Strengths of the Study

In the present study, none of the participants were lost to attrition. There was little missing data. Participation rate was high – 30 of 32 individuals approached agreed to participate in this study. This fact speaks to the importance of the issue under investigation. The results from the current study add to the existing body of knowledge about the information and support needs of mother's of premature and term infants. The findings from both study questionnaires identified gaps in current knowledge and highlighted areas in which additional information is needed. These findings will be the basis of recommendations for nursing practice and future research. The development of a new tool was also a positive feature of the study. If the Aylward questionnaire can be utilized in other centres and have its

reliability confirmed it may provide a means to generate additional knowledge specific to the population of medically complex infants.

Recommendations for Future Research

First, the current study should be repeated with a larger sample size in order to increase the generalizability of the results. Efforts should be made to include individuals who speak other languages, through translation of the instrument and the aid of an interpreter. It would be valuable to compare the perceptions of both caregivers and nurses related to the information provided prior to discharge. Other researchers (Drake, 1995; Kenner & Lott, 1990) have found that the perceptions of these two groups are different. This type of investigation may provide some insight into whether in fact the information is provided and not recalled or whether it was not provided at all. The study questionnaires could be administered at different centres in the city to assess the information and support needs in their population(s) as well as to evaluate their discharge-teaching program. There would be value in administering the current study questionnaires in conjunction with validated tools that measure such constructs as stress (e.g., Miles et al., 1996), coping (e.g., Lazarus & Folkman, 1984), support (e.g., Miles, Carlson & Brunssen, 1999) and anxiety (e.g., Spielberger, Gorsuch, & Lushene, 1970).

As the pediatric centre in question is the referral centre for a large geographic area it would be of interest to investigate the differences, if any, in the information and support needs as well as the availability of resources for families

who live within the city and those who do not. The author would suggest that a randomized control trial to compare current practice (public health nurse follow-up) and an in-home transitional care program with follow-up by an expert neonatal nurse be undertaken. Results would guide program development, care delivery and the organization of professional support during the transition to home.

Other questions that were generated from this research were as follows:

1. Does length of stay influence the discharge information provided by nurses?
2. What is the impact of distance from the tertiary centre in relation to parental information and support needs?
3. What is the impact of peer support for parents of premature and/or medically complex infants?
4. What is the feasibility of developing a transitional, in-home follow-up program, provided by Advanced Practice Nurses?

Conclusion

Based on this study, parents of premature and/or medically complex infants appear to have obtained and recalled core information about the care of their baby. There appears a greater need to know about infant environment, behaviour and development and recognition of illness once at home. Therefore, a process to deliver and/or reinforce this information should be developed. Recommendations generated from this study include: 1) the development of resources (written, video, web-based) on topics related to environment, infant behaviour and development,

the unique characteristics of the premature infant, and changing health status; 2) development of a telephone follow-up program; and 3) investigation into the feasibility of developing a transitional care program for neonatal clients in the Ottawa area.

References

Able-Boone, H., & Stevens, E. (1994). After the intensive care nursery experience: Families' perceptions of their well being. Children's Health Care, 23(2), 99-114.

Affleck, G., Tennen, H., & Rowe, J. (1991). Infants in crisis: How parents cope with newborn intensive care and its aftermath. New York: Springer-Verlag.

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

Affonso, D.D., Hurst, I., Mayberry, L.J., Haller, L., Yost, K., & Lynch, M.E. (1992). Stressors reported by mothers of hospitalized premature infants. Neonatal Network, 11(6), 63-70.

American Academy of Pediatrics (1998). Hospital discharge of the high-risk neonate: Proposed guidelines. Pediatrics, 102(2), 411-417.

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

Baker, J. (1995). Parents as partners in the NICU. Neonatal Network, 14(1), 9-10.

Barton, L. A., & Lawlor-Klean, P. (1994). Discharge planning and the role of the visiting nurse in the special care nursery. Neonatal Network, 13(6), 77-79.

Bell, P. L. (1994). Neonatal case management: A challenge for advanced practice nurses. Journal of Perinatal and Neonatal Nursing, 8(2), 48-56.

Beveridge, J., Bodnaryk, K., & Ramachandran, C. (2001). Family-centred care in the NICU. Canadian Nurse, 97(3), 14-18.

Blackburn, S. (1995). Problems of preterm infants after discharge. JOGNN, 24(1), 43-49.

Bond, N., Phillips, P., & Rollins, J.A. (1994). Family-centered care at home for families with children who are technology dependent. Pediatric Nursing, 20(2), 123-130.

Brazy, J. E., Anderson, B. M. H., Becker, P. T., & Becker, M. (2001). How parents of premature infants gather information and obtain support. Neonatal Network, 20(2), 41-48.

Brooten D., Brown, L. P., Munro, B. H., York, R., Cohen, S. M., Roncoli, M., & Hollingsworth, A. (1988). Early discharge and specialist transitional care. Image: Journal of Nursing Scholarship, 20(2), 64-68.

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

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

Brooten, D., Gennaro, S., Knapp, H., Jovene, N., Brown, L., & York, R. (1991). Functions of the CNS in early discharge and home followup of very low birthweight infants. Clinical Nurse Specialist, 5(4), 196-201.

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

Brunssen, S. H. & Miles, M.S. (1996). Sources of environmental stress experienced by mothers of hospitalized medically fragile infants. Neonatal Network, 15(3), 88-89.

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

Cagan, J., & Meier, P. (1979). A discharge planning tool for use with families of high-risk infants. JOGNN, May/June, 146-148.

Canadian Pediatric Society (1994). Management of the woman with threatened birth of an infant of extremely low gestational age. A joint statement with the Society of Obstetricians and Gynecologists of Canada. CMAJ, 151(5), 547-551, 553.

Canam, C. (1993). Common adaptive tasks facing parents of children with chronic conditions. Journal of Advanced Nursing, 18, 46-53.

Casiro, O. G., McKenzie, M.E., McFayden, L., Shapiro, C., Seshia, M.M.K., MacDonald, N., Moffatt, M., & Cheang, M.S. (1993). Earlier discharge with community-based intervention for low birth weight infants: A randomized trial. Pediatrics, *92*(1), 128-134.

Chick, N., & Meleis, A. (1986). Transitions: A nursing concern. In P. L. Chinn (Ed.), Nursing research methodology: Issues and implementation (pp. 327-357). Rockville, MD: Aspen.

Christian, A. (1996). Clinical nurse specialists: Creating new programs for neonatal home care. Journal of Perinatal and Neonatal Nursing, *10*(1), 54-63.

Coffman, S., Levitt, M.J., & Deats, C. (1990). Personal and professional support for mothers of NICU and healthy newborns. JOGNN, *20*(5), 406-415.

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

De Simone, L., & Gottlieb, L.N. (1987). Construct validation of the perceived maternal task performance scale. Nursing Papers, *19*(4), 20-35.

Deatrick, J. A., & Knafel, K.A. (1990). Management behaviors: Day-to-day adjustments to childhood chronic conditions. Journal of Pediatric Nursing, *5*(1), 15-22.

Diehl, S. F., Moffitt, K.A., & Wade, S.M. (1991). Focus group interview with parents of children with medically complex needs: An intimate look at their perceptions and feelings. Children's Health Care, *20*(3), 170-178.

Dokken, D. L., & Syndor-Greenberg, N. (1998). Helping families mobilize their personal resources. Pediatric Nursing, 24(1), 66-69.

Drake, E. (1995). Discharge teaching needs of parents in the NICU. Neonatal Network, 14(1), 49-53.

Edwards, K. A., & Allen, M.E. (1988). Nursing management of the human response to the premature birth experience. Neonatal Network, 6(5), 82-86.

Evanochko, C., Boyle, R., Molesky, M., Jancs-Kelley, S., Fox, M., & Byrne, P. (1996). Facilitating early discharge from the NICU: The development of a home gavage program and neonatal outpatient clinic. Neonatal Network, 15(8), 44.

Gale, G., & Franck, L.S. (1998). Toward a standard of care for parents of infants in the neonatal intensive care unit. Critical Care Nursing, 18(5), 62-73.

Gamblian, V., Hess, D. J., & Kenner, C. (1998). Early discharge from the NICU. Journal of Pediatric Nursing, 13(5), 296-301.

Gehl, M. B., & Lantzy, A. (1990). Parents' needs surrounding discharge from the neonatal intensive care unit (NICU). Maternal-Child Nursing Journal, 19(2), 179-180.

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

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

Gennaro, S., Brooten, D., Roncoli, M., & Kumar, S.P. (1993). Stress and health outcomes among mothers of low-birth-weight infants. Western Journal of Nursing Research, 15(1), 97-113.

Gennaro, S., York, R., & Brooten, D. (1990). Anxiety and depression in mothers of low birthweight and very low birthweight infants: Birth through 5 months. Issues in Comprehensive Pediatric Nursing, 13, 97-109.

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

Gershan, L. A., & Kliegman, R.M. (1995). Early discharge of low birth weight infants: An opportunity to evolve and to create partnerships. The Journal of Pediatrics, 127, 272-274.

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

Griffin, T. (1990). Nurse barriers to parenting in the special care nursery. Journal of Perinatal and Neonatal Nursing, 4(2), 56-67.

Griffin, T., Wishba, C., & Kavanaugh, K. (1998). Nursing interventions to reduce stress in parents of hospitalized preterm infants. Journal of Pediatric Nursing, 13(5), 290-295.

Health Canada (1999). Preterm birth. Canadian Perinatal Surveillance System: Ottawa.

Holditch-Davis, D., & Miles, M. S. (2000). Mothers' stories about their experiences in the neonatal intensive care unit. Neonatal Network, 19(3), 13-21.

Horner, M. M., Rawlins, P., & Giles, K. (1987). How parents of children with chronic conditions perceive their own needs. MCN, 12, 40-43.

Hughes, M., McCollum, J., Sheftel, D., & Sanchez, G. (1994). How parents cope with the experience of neonatal intensive care. Children's Health Care, 23(1), 1-14.

Janis, I. L. (1982). Decisionmaking under stress. In L. Goldberger & S. Breznitz, S. (Eds.), Handbook of stress: Theoretical and clinical aspects (pp. 69-87). New York: The Free Press.

Johnston, C. E., & Marder, L. R. (1994). Parenting the child with a chronic condition: An emotional experience. Pediatric Nursing, 20(6), 611-614.

Kenner, C. (1990). Caring for the NICU parent. Journal of Perinatal and Neonatal Nursing, 4(3), 78-87.

Kenner, C., & Lott, J. (1990). Parent transition after discharge from the NICU. Neonatal Network, 9(2), 31-37.

Klein Walker, D., Epstein, S. G., Taylor, A. B., Crocker, A. C., & Tuttle, G. A. (1989). Perceived needs of families with children who have chronic health conditions. Children's Health Care, 18(4), 196-201.

Kotagal, U. R., Perlstein, P.H., Gamblian, V., Donovan, E.F., & Atherton, H.D. (1995). Description and evaluation of a program for the early discharge of infants from a neonatal intensive care unit. The Journal of Pediatrics, 127(2), 285-290.

Ladden, M. (1990a). The impact of preterm birth on the family and society Part 1: Psychologic sequelae of preterm birth. Pediatric Nursing, 16(5), 515-518.

Ladden, M. (1990b). The impact of preterm birth on the family and society Part 2: Transition to home. Pediatric Nursing, 16(6), 620-622, 626.

Leonard, B. J., Brust, J.D., & Nelson, R.P. (1993). Parental distress: Caring for medically fragile children at home. Journal of Pediatric Nursing, 8(1), 22-30.

McGinley, S., Baus, E., Gyza, K., Johnson, K., Lipton, S., Magee, M., Moore, F., & Wojtyak, D. (1996). Multidisciplinary discharge planning: Developing a process. Nursing Management, 27(10), 55-60

McHaffie, H. E. (1990). Mothers of very low birthweight babies: How do they adjust. Journal of Advanced Nursing, 15, 6-11.

McKim, E. (1993a). The information and support needs of mothers of premature infants. Journal of Pediatric Nursing, 8(4), 233-244.

McKim, E. (1993b). The difficult first week at home with a premature infant. Public Health Nursing, 10(2), 89-96.

McKim, E., Kenner, C., Flandermeyer, A., Spangler, L., Darling-Thornburg, P., & Spiering, K. (1995). The transition to home for mothers of healthy and initially ill newborn babies. Midwifery, 11, 184-195.

Miles, M. S., Carlson, J., & Brunssen, S. (1999). The nurse parent support tool. Journal of Pediatric Nursing, 14(1), 44-50.

Miles, M. S., Carlson, J., & Funk, S.G. (1996). Sources of support reported by mothers and fathers of infants hospitalized in a neonatal intensive care unit. Neonatal Network, 15(3), 45-52.

Miles, M. S., Funk, S.G., & Carlson, J. (1993). Parental stressor scale: Neonatal intensive care unit. Nursing Research, 42(3), 148-152.

Miles, M. S., Holditch-Davis, D., Burchinal, P., & Nelson, D. (1999). Distress and growth outcomes in mothers of medically fragile infants. Nursing Research, 48(3), 129-140.

Minde, K., Whitelaw, A., Brown, J., & Fitzhardinge, P. (1983). Effect of neonatal complications in premature infants on early parent-infant interactions. Developmental Medicine & Child Neurology, 25, 763-777.

Moutquin, J.M., & Lalonde A. (1998). The cost of prematurity in Canada. Paper presented at the Preterm Birth Prevention Conference, Ottawa.

Murphy, S. A. (1990). Human responses to transitions: A holistic nursing perspective. Holistic Nursing Practice, 4(3), 1-7.

Patterson, J. M., Leonard, B. J., & Titus, J. C. (1992). Home care for medically fragile children: Impact on family health and well-being. Developmental and Behavioral Pediatrics, 13(4), 248-255.

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

Raddish, M., & Merritt, T.A. (1998). Early discharge of premature infants: A critical analysis. Clinics in Perinatology, 25(2), 499-520.

Ramey, C. T., Bryant, D.M., Wasik, B.H., Sparling, J.J., Fendy, K.H., & LaVange, L.M. (1992). Infant health and development program for low birth weight, premature infants: Program elements, family participation, and child intelligence. Pediatrics, 3, 454-465.

Ray, L. D., & Ritchie, J.A. (1993). Caring for chronically ill children at home: Factors that influence parents' coping. Journal of Pediatric Nursing, 8(4), 217-225.

Rieger, I. D., & Henderson-Smart, D. J. (1995). A neonatal early discharge and home support programme: Shifting care into the community. Journal of Pediatrics and Child Health, 31, 33-37.

Rikli, J. M. (1996). Parenting the premature infant: Potential iatrogenesis from the neonatal intensive care experience. The Online Journal of Knowledge Synthesis for Nursing, 3(Document Number 7)

Ritchie, S. K. (2002). Primary care of the premature infant discharged from the neonatal intensive care unit. MCN, 27(2), 77-85.

Roman, L. A., Lindsay, J. K., Boger, R. P., DeWys, M., Beaumont, E. J., Jones, A. S., & Haas, B. (1995). Parent-to-parent support initiated in the neonatal intensive care unit. Research in Nursing & Health, 18, 385-394.

Scharer, K., & Brooks, G. (1994). Mothers of chronically ill neonates and primary nurses in the NICU: Transfer of care. Neonatal Network, 13(5), 37-47.

Schumacher, K. L., & Meleis, A.I. (1994). Transitions: A central concept in nursing. Image: Journal of Nursing Scholarship, 26(2), 119-127.

- Selder, F. (1989). Life transition theory: The resolution of uncertainty. Nursing & Health Care, 10(8), 437-451.
- Sheikh, L., O'Brien, M., & McCluskey-Fawcett, K. (1993). Parent preparation for the NICU-to-home transition: Staff and parent perceptions. Children's Health Care, 22(3), 227-239.
- Singer, L. T., Salvator, A., Guo, S., Collin, M., Lilien, L., & Baley, J. (1999). Maternal psychological distress and parenting stress after the birth of a very low-birth-weight infant. JAMA, 281(9), 799-805.
- Stephenson, C. (1999). Well-being of families with healthy and technology-assisted infants in the home: A comparative study. Journal of Pediatric Nursing, 14(3), 164-176.
- Sterling, Y. (1990). Resource needs of mothers managing chronically ill infants at home. Neonatal Network, 9(1), 55-59.
- Sterling, Y., Jones, L.C., Johnson, D.H., & Bowen, M.R. (1996). Parents' resources and home management of the care of chronically ill infants. JSPN, 1(3), 103-109.
- Stewart, M.J. (1993). Integrating social support in nursing. Newbury Park: Sage.
- Stewart, M.J. (1995). Social support, coping, and self-care: Public participation concepts. In M.J. Stewart (ed.). Community nursing: Promoting Canadians' health (pp. 89-124). Toronto: Saunders.

Streiner, D.L., & Norman, G. R. (1995). Health measurement scales: A practical guide to their development and use (2nd ed.). Oxford: Oxford University Press.

Teague, B. R., Fleming, J.W., Castle, A., Kiernan, B.S., Lobo, M.L., Riggs, S., & Wolfe, J.G. (1993). "High-tech" home care for children with chronic health conditions: A pilot study. Journal of Pediatric Nursing, 8(4), 226-232.

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

VandenBerg, K. A. (1999). What to tell parents about the developmental needs of their baby at discharge. Neonatal Network, 18(1), 57-59.

VandenBerg, K. A. (2000). Supporting parents in the NICU: Guidelines for promoting parent confidence and competence. Neonatal Network, 19(8), 63-64.

Vecchi, C. J., Vasquez, L., Radin, T., & Johnson, P. (1996). Neonatal individualized predictive pathway (NIPP): A discharge planning tool for parents. Neonatal Network, 15(4), 7-13.

von Platen, A. (2000). Neonatal transitional care program evaluation (Project No. NA1017). Ottawa, ON: Health Transition Fund, Health Canada.

Wereszczak, J., Miles, M.S., & Holditch-Davis, D. (1997). Maternal recall of the neonatal intensive care unit. Neonatal Network, 16(4), 33-40.

Youngblut, J. M., Brennan, P.F., Swegart, L.A. (1994). Families with medically fragile children: An exploratory study. Pediatric Nursing, 20(5), 463-468.

Zahr, L. K., & Montijo, J. (1993). The benefits of home care for sick premature infants. Neonatal Network, 12(1), 33-37.

Zahr, L. K., Parker, S., & Cole, J. (1992). Comparing the effects of neonatal intensive care unit intervention on premature infants at different weights. Developmental and Behavioral Pediatrics, 13(3), 165-172.

Zelle, R. S. (1995). Follow-up of at-risk infants in the home setting: Consultation model. JOGNN, 24(1), 51-55.

Appendix A

American Academy of Pediatrics Guidelines for Early Discharge

Appendix A

American Academy of Pediatrics Guidelines for Early Discharge

The American Academy of Pediatrics (1998) outline the criteria of early discharge as follows:

1. a sustained pattern of weight gain (versus a specific weight criteria)
2. physiologic stability (defined as the ability to suckle feed and to maintain normal body temperature in an open environment)
3. an active program of parental involvement and preparation for post-hospital care
4. a pre-discharge on-site home assessment
5. an active program of parental support after discharge of the very low birth weight infant
6. frequent outpatient follow-up to assure adequate weight gain for the smallest infants in the weeks immediately after discharge and
7. an organized program of post-discharge tracking and surveillance.

Appendix B

NICU Discharge Planning Record

Appendix B

NICU Discharge Planning Record



CHILDREN'S HOSPITAL OF EASTERN ONTARIO
Hôpital Pour Enfants de l'est de l'Ontario

Neonatal Intensive Care Unit
Discharge Planning Record
Fiche de Planification du Congé

Projected Discharge Date: Date prévue du congé:	
Diagnoses: Diagnostic:	Date Initiated: Date de mise en route:

KEY DISCHARGE PERSONNEL/ PERSONNEL CLÉ PARTICIPANT AU CONGÉ

Family Caregivers Aidants naturels _____	Primary Nurses Infirmières de première ligne _____
Neonatologist Néonatalogiste _____	Clinical Nurse Specialist Infirmière de clinique spécialisée _____
Neonatal Advanced Nurse/Resident Infirmière avancée en néonatalogie/résident _____	Social Worker Travailleuse sociale _____
Family Physician Médecin de famille _____	
Public Health Centre de liaison des services communautaires _____	(dd/mm/yy) Form. Completed/Fiche remplie _____ Form. Sent/Fiche envoyée _____
Ontario Health Services Networking Inc. OHSNI _____	
CHEO Discharge Planning Dept. Service de la planification des congés de l'HEEO _____	
Community Care Access Centre (Home Care) CCAC (Soins à domicile) _____	
Other: Autre:	

DISCHARGE FOLLOW UP/SUIVI AU CONGÉ

Clinic / Consultant / Physician Consultation/Consultant/Médecin	Appointment Date (Include Phone #) Date du rendez-vous (inclure le # de téléphone)
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

**Parent Discharge Teaching
Enseignement Aux Parents Au Moment Du Congé**

<p>Bath (initals dd/mm/yy) _____</p> <p>Bain _____</p> <p>Circumcision _____</p> <p>Circoncision _____</p> <p>Clothing _____</p> <p>Vêtements _____</p> <p>Cord Care _____</p> <p>Soin du cordon _____</p> <p>Temperature _____</p> <p>Température _____</p> <p>Immunizations _____</p> <p>Immunisations _____</p> <p>Safety/Sécurité</p> <p>Infant CPR _____</p> <p>RCR Nourissons _____</p> <p>Car Seat Safety _____</p> <p>Sécurité siège de voiture _____</p> <p>Infant Home Safety _____</p> <p>Sécurité du nourisson à la maison _____</p> <p>Car Seat O2 Saturation Monitoring _____</p> <p>Siège auto-surveillance saturation O2 _____</p> <p>Hearing Screening _____</p> <p>Dépistage d'ouïe _____</p>	<p>Breast Feeding Basics (initals dd/mm/yy) _____</p> <p>Basics de l'allaitement maternel _____</p> <p>Expression / Storage _____</p> <p>Expression/conservation du lait _____</p> <p>Bottle Feeding _____</p> <p>Alimentation au biberon _____</p> <p>Formula Preparation _____</p> <p>Préparation du lait maternisé _____</p> <p>Digestion / Elimination _____</p> <p>Digestion/Élimination _____</p> <p>Metabolic Screening/Dépistage métabolique:</p> <p>Ontario PKU _____</p> <p>Quebec PKU _____</p> <p>Urine (day 21) _____</p> <p>Urine (21e jour) _____</p>		
<p>Other (Specialized Teaching and/or Supplies) Autre (fournitures ou enseignement spécialisés)</p> <p>_____</p> <p>_____</p>			
Discharge Medications Médicaments au congé	Teaching Done Enseignement	Pharmacy Contacted Pharmacie contactée	Prescription Given Ordonnance remise
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
<p>Plan: _____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p>			
<p>I have reviewed and understand the above information, and authorize its release to my local Health Department, if appropriate, in order for the Health Department to plan and deliver services for me and my child. J'ai examiné et compris l'information ci-dessus, et j'en autorise la transmission, au besoin, au Service de la Santé local, pour qu'il puisse planifier et dispenser des services à mon enfant ainsi qu'à moi-même.</p>			
<p>X _____ Parent/Guardian Signature Signature du parent/tuteur</p>	<p>X _____ RN Signature Signature de l'infirmière</p>	<p>_____ Date Date</p>	

Appendix C

Current Discharge Planning Resources

Appendix C

Current Discharge Planning Resources

CHEO NICU Discharge Planning Record** (Appendix B)

Ottawa Community Care Access Centre Referral Form

Ottawa-Carleton Health Department Public Health Referral – CHEO Neonatal Unit

CLSC de Hull Referral Form

Information Sheets**

Circumcision

Formula Preparation

Making Your Home Safe for Children

Bathing

Jaundice

** Available in French and English

Appendix D

Research Ethics Board Approval (CHEO)



Appendix D

Research Ethics Board Approval (CHEO)

Children's Hospital of Eastern Ontario
Hôpital pour enfants de l'est de l'Ontario

A University of Ottawa Teaching Hospital / Un Hôpital d'enseignement affilié à l'Université d'Ottawa
401 SMYTH, OTTAWA, ONT. K1H 8L1 TELEPHONE (613) 737-7600

December 11, 2000

Ms. Debbie Aylward
Nursing -NICU
CHEO INTRA

Re: **Proposal OO/46E -Transition to Home: The Informational and Support Needs of
Primary Caregivers of Premature and/or Medically Complex Infants**

Dear Ms. Aylward:

Please accept this letter as written approval from the Research Ethics Committee for the final copy of the questionnaire submitted the week of December 4, 2000 relating to the above-mentioned proposal.

Sincerely,

A handwritten signature in black ink, appearing to read 'D. Palframan'. The signature is fluid and cursive, written over the printed name.

D. Palframan, MD, F.R.C.P.(C)
Chair
Research Ethics Committee

Making a difference in the lives of children and youth

Faire une différence dans la vie des enfants et des adolescents

Appendix E
Study Consent Form

Appendix E

Study Consent Form

STUDY QUESTION: What are the informational and support needs of families with a premature and/or medically complex child discharged from the Neonatal Intensive Care Unit (NICU)?

I _____ consent to participate in a study which will examine the needs of families like mine related to the care of children after discharge from the NICU.

The principal investigator, Debbie Aylward, is a graduate student in the Master's of Science (Nursing) program at the University of Ottawa. It is hoped that information gained from this study will provide insight to help nurses and other health care providers support families through the transition to home after prolonged hospitalization.

Debbie Aylward, the Principle Investigator has explained to me that my participation will involve:

- 1) completing a personal information sheet,
- 2) completing questionnaires about the information I received while my baby was still in hospital,
- 3) completing questionnaires about the different types of support needed by families with a premature and/or medically complex infant after being discharged home, and
- 4) allowing the researcher access my child's medical record to obtain data related to my child's course in hospital.

The primary caregiver and the researcher will mutually agree upon the location for the completion of the questionnaires in item 3). The date will be as near to four weeks after discharge as is convenient for the primary caregiver and the researcher.

The total time required for this study will be approximately 1 hour.

I understand there may be no direct benefits to my child or me by participation in this study but that the information provided may be helpful for other families and health care providers.

I understand that there are no known risks involved in my participation. If I do become distressed, the investigator will assist, as necessary, in arranging counseling for me.

I understand that I have the right to refuse to participate in this study. I may also refuse to answer any specific questions or to withdraw from the study at any time. If I refuse to participate or I withdraw from the study it will not affect the care that my child and I receive at CHEO.

I understand that any information collected about me or my family will remain strictly confidential. No names or identifying features will appear on any data or written or published report.

I understand that all study data will be collected by Debbie Aylward and shared only with her study supervisor, Dr. Denise Alcock.

I understand that I am free to ask any questions regarding the study or my participation by contacting the researcher or study advisor.

You may contact the chair of the Research Ethics Committee for information regarding patient's rights in research studies at 613-738-3272, however, this person cannot provide any medical information with regard to this study.

I acknowledge that the research procedure outlined above has been described to me and that any questions have been answered to my satisfaction.

NAME _____ DATE _____

SIGNATURE _____

I have explained the nature of the study to the parent/primary caregiver and believe that he/she has understood.

NAME Debbie Aylward DATE _____

SIGNATURE _____

Contact numbers: Debbie Aylward 834-2990
Dr. Denise Alcock 562-5432

Appendix F
Personal Information Questionnaire

Appendix G

Permission to use McKim's Tool

Appendix G

Permission to use McKim's Tool

Subj: Re: permission
Date: 28/08/00 12:47:40 PM Eastern Daylight Time
From: emckim@play.psych.mun.ca (Edna McKim)
To: Debaylward@aol.com

To whom it may concern:

I have granted Debbie Aylward permission to use/adapt my questionnaire on the "Information and support needs of mothers of healthy and ill term and preterm infants".

I would request that Ms. Aylward inform me of her findings after the thesis process is completed so that comparison could be made with other studies using this questionnaire.

Edna McKim
Associate Professor
School of Nursing
Memorial University of Newfoundland
St. John's, NF

Appendix H

**The Information and Support Needs of Mothers of Healthy, and Ill, Term, and
Preterm Infants' Questionnaire**

(McKim, 1993)

Appendix H

The Information and Support Needs of Mothers of Healthy, and Ill, Term, and Preterm Infants' Questionnaire

(© Edna McKim: Used with permission)

This questionnaire is to be used to assess the kinds of information and support that you received about caring for your baby both prior to your baby's discharge from hospital and afterwards, when at home. Please do not hesitate to write extra comments on the paper in areas where you feel you want to elaborate.

Part A.

Please circle **one** of options a), b), c), d), e) or f) as your answer to each of the following questions.

DO YOU FEEL THAT, DURING YOUR BABY'S HOSPITALIZATION, THE NURSES GAVE YOU ADEQUATE INFORMATION ABOUT:

1. How to breastfeed your baby?
 - a) yes
 - b) yes, but I didn't want this information
 - c) no, but I would have liked this information
 - d) no, but I didn't want this information
 - e) don't know/don't remember
 - f) not applicable

2. How to know if your baby is getting enough breastmilk?
 - a) yes
 - b) yes, but I didn't want this information
 - c) no, but I would have liked this information
 - d) no, but I didn't want this information
 - e) don't know/don't remember
 - f) not applicable

3. How to prepare the formula?
- a) yes
 - b) yes, but I didn't want this information
 - c) no, but I would have liked this information
 - d) no, but I didn't want this information
 - e) don't know/don't remember
 - f) not applicable
4. How much formula you should give at each feeding?
- a) yes
 - b) yes, but I didn't want this information
 - c) no, but I would have liked this information
 - d) no, but I didn't want this information
 - e) don't know/don't remember
 - f) not applicable
5. How to help you baby feed well, e.g. how to burp him/her, hold him/her and to know when he/she is full?
- a) yes
 - b) yes, but I didn't want this information
 - c) no, but I would have liked this information
 - d) no, but I didn't want this information
 - e) don't know/don't remember
 - f) not applicable

6. When to start the baby on cereals?
 - a) yes
 - b) yes, but I didn't want this information
 - c) no, but I would have liked this information
 - d) no, but I didn't want this information
 - e) don't know/don't remember
 - f) not applicable

7. What kinds of cereal to begin with?
 - a) yes
 - b) yes, but I didn't want this information
 - c) no, but I would have liked this information
 - d) no, but I didn't want this information
 - e) don't know/don't remember
 - f) not applicable

8. Whether the baby needs any additional iron, vitamins, or fluoride?
 - a) yes
 - b) yes, but I didn't want this information
 - c) no, but I would have liked this information
 - d) no, but I didn't want this information
 - e) don't know/don't remember
 - f) not applicable

9. How to give your baby a bath?
- a) yes
 - b) yes, but I didn't want this information
 - c) no, but I would have liked this information
 - d) no, but I didn't want this information
 - e) don't know/don't remember
 - f) not applicable
10. How to give medicine (if any) to your baby?
- a) yes
 - b) yes, but I didn't want this information
 - c) no, but I would have liked this information
 - d) no, but I didn't want this information
 - e) don't know/don't remember
 - f) not applicable
11. How to take your baby's temperature?
- a) yes
 - b) yes, but I didn't want this information
 - c) no, but I would have liked this information
 - d) no, but I didn't want this information
 - e) don't know/don't remember
 - f) not applicable

12. When to take your baby for his/her immunization (needle)?

- a) yes
- b) yes, but I didn't want this information
- c) no, but I would have liked this information
- d) no, but I didn't want this information
- e) don't know/don't remember
- f) not applicable

13. How to take care of a diaper rash?

- a) yes
- b) yes, but I didn't want this information
- c) no, but I would have liked this information
- d) no, but I didn't want this information
- e) don't know/don't remember
- f) not applicable

14. How to know if the baby's "spitting up" is normal?

- a) yes
- b) yes, but I didn't want this information
- c) no, but I would have liked this information
- d) no, but I didn't want this information
- e) don't know/don't remember
- f) not applicable

15. How to know if your baby has colic (crampy tummy pains)?
- a) yes
 - b) yes, but I didn't want this information
 - c) no, but I would have liked this information
 - d) no, but I didn't want this information
 - e) don't know/don't remember
 - f) not applicable
16. How to know if your baby's "fussy periods" are normal?
- a) yes
 - b) yes, but I didn't want this information
 - c) no, but I would have liked this information
 - d) no, but I didn't want this information
 - e) don't know/don't remember
 - f) not applicable
17. What to do about your baby's crying?
- a) yes
 - b) yes, but I didn't want this information
 - c) no, but I would have liked this information
 - d) no, but I didn't want this information
 - e) don't know/don't remember
 - f) not applicable

18. How to know if the baby's bowel movement is normal?

- a) yes
- b) yes, but I didn't want this information
- c) no, but I would have liked this information
- d) no, but I didn't want this information
- e) don't know/don't remember
- f) not applicable

19. How to recognize if your baby is becoming ill?

- a) yes
- b) yes, but I didn't want this information
- c) no, but I would have liked this information
- d) no, but I didn't want this information
- e) don't know/don't remember
- f) not applicable

20. What to do if you think your baby is becoming ill?

- a) yes
- b) yes, but I didn't want this information
- c) no, but I would have liked this information
- d) no, but I didn't want this information
- e) don't know/don't remember
- f) not applicable

21. What temperature and humidity to keep your house?

- a) yes
- b) yes, but I didn't want this information
- c) no, but I would have liked this information
- d) no, but I didn't want this information
- e) don't know/don't remember
- f) not applicable

22. How warmly to dress your baby?

- a) yes
- b) yes, but I didn't want this information
- c) no, but I would have liked this information
- d) no, but I didn't want this information
- e) don't know/don't remember
- f) not applicable

23. When to start to take your baby outside the house?

- a) yes
- b) yes, but I didn't want this information
- c) no, but I would have liked this information
- d) no, but I didn't want this information
- e) don't know/don't remember
- f) not applicable

24. How long you should expect your baby to sleep between feedings?
- a) yes
 - b) yes, but I didn't want this information
 - c) no, but I would have liked this information
 - d) no, but I didn't want this information
 - e) don't know/don't remember
 - f) not applicable
25. What kinds of behaviour to expect from your baby during his/her first six weeks at home?
- a) yes
 - b) yes, but I didn't want this information
 - c) no, but I would have liked this information
 - d) no, but I didn't want this information
 - e) don't know/don't remember
 - f) not applicable
26. Whether it is normal for a premature baby to "grunt" and "groan", "sneeze" and "hiccup"?
- a) yes
 - b) yes, but I didn't want this information
 - c) no, but I would have liked this information
 - d) no, but I didn't want this information
 - e) don't know/don't remember
 - f) not applicable

27. Whether noisy breathing, especially at night, can be normal for premature babies?
- a) yes
 - b) yes, but I didn't want this information
 - c) no, but I would have liked this information
 - d) no, but I didn't want this information
 - e) don't know/don't remember
 - f) not applicable
28. Whether your premature baby may have a slightly irregular breathing pattern?
- a) yes
 - b) yes, but I didn't want this information
 - c) no, but I would have liked this information
 - d) no, but I didn't want this information
 - e) don't know/don't remember
 - f) not applicable
29. Were you given information about the possibility your baby may have a little problem adjusting to home for the first couple of days, since she/he has been used to lights and noise 24 hours a day in hospital?
- a) yes
 - b) yes, but I didn't want this information
 - c) no, but I would have liked this information
 - d) no, but I didn't want this information
 - e) don't know/don't remember
 - f) not applicable

30. Were you told that what is "normal" behaviour and development for the premature infant may be "different" from the behaviour and development of the full-term baby?
- a) yes
 - b) yes, but I didn't want this information
 - c) no, but I would have liked this information
 - d) no, but I didn't want this information
 - e) don't know/don't remember
 - f) not applicable
31. Were you told how to get your baby to respond to you? (smiling, following with eyes, cooing, gurgling)
- a) yes
 - b) yes, but I didn't want this information
 - c) no, but I would have liked this information
 - d) no, but I didn't want this information
 - e) don't know/don't remember
 - f) not applicable

Part B

Please answer the following questions in Section B by writing short answers or by circling one of the options: a), b), c), d), e), f), or g).

1. How many children do you now have?

- a) 1 child
- b) 2 children
- c) 3 children
- d) more than three children

2. What are their ages?

3. When was your baby born?

4. Is your baby a

- (a) boy
- (b) girl

5. How old was your baby when you brought him/her home from the hospital?

Days: _____

Weeks: _____

Months: _____

6. Did you attend prenatal classes?
 - (a) yes
 - (b) no

7. If yes, were these classes helpful?
 - (a) yes
 - (b) no

8. Did you attend the infant care classes during your hospital stay?
 - (a) yes
 - (b) no

9. If yes, were these classes helpful?
 - (a) yes
 - (b) no

10. After leaving hospital, at what time did you find it to be the most difficult in caring for your baby?
 - a) first two days
 - b) after the first two days, but during week one
 - c) week two
 - d) week three to four
 - e) after week four
 - f) no week difficult
 - g) all weeks difficult

11. Why was this time the most difficult?

12. After your baby came home from the hospital, did you have anyone to help you?

(You can circle more than one choice)

- a) no (PLEASE GO TO QUESTION 17)
- b) yes, my husband, boyfriend, partner
- c) yes, a friend or neighbour
- d) yes, my mother
- e) yes, another family member
- f) yes, a house-keeper

13. How did this person (these persons) help you?

14. Was this help adequate?

- (a) yes
- (b) no

15. If no, what kind of help would you have liked?

16. How many times in the last month have you been out to have fun?

GO TO QUESTION 19

IF YOU ANSWERED "NO" TO QUESTION 12, PLEASE ANSWER QUESTIONS 17 & 18.

17. Would you have liked to have had help from family and friends?

- (a) yes
- (b) no

18. What kind of help would you've liked?

19. Did you have a visit from a public health nurse?

- (a) yes
- (b) no

20. If no, would you have liked to have had a visit from the public health nurse?

- (a) yes
- (b) no

21. If yes, how soon after the baby came home did this visit happen?

- a) within 48 hours of discharge
- b) during the first 3 to 6 days after discharge
- c) 7 – 14 days after discharge
- d) more than 15 days

22. Did you find this visit helpful?

- (a) yes
- (b) no

23. If yes, how?

If no, why?

23. When did you first take your baby to your family doctor?

Why?

25. Do you think you should have taken the baby earlier to the doctor's?
- (a) yes
 - (b) no
26. After your baby came home from the hospital, would it have helped if you had a place to call for information and support regarding your baby's care?
- (a) yes
 - (b) no
27. After your baby came home from the hospital, would it have helped if you had had an informational booklet to which to refer?
- (a) yes
 - (b) no
28. After your baby came home from the hospital, how anxious did you feel about caring for your baby? (Please complete this question by circling the point **I** along the line that best describes how you felt).

very anxious I _____ I _____ I _____ I _____ I very comfortable

29. After your baby come home from the hospital, did you feel you had enough information to make you feel

- a) very confident in caring for your baby
- b) had confidence in caring for your baby
- c) slightly confident in caring for your baby
- d) not at all confident in caring for your baby

30. What other information would have been helpful to you?

31. What concerns did you have about your own care and how you felt during this period of time?

32. Did you or do you have any other concerns not already discussed?

I thank you very much for taking the time to complete this questionnaire.

Debbie Aylward, RN, BScN

Appendix I

**The Information and Support Needs of Primary Caregivers of Premature and/or
Medically Complex Infants Questionnaire**

Appendix I

The Information and Support Needs of Primary Caregivers of Premature and/or Medically Complex Infants Questionnaire

(Based on the work of McKim, 1993)

The goal of this questionnaire is to learn 1) what kinds of information and support that you received in the hospital and, 2) what kind of support you received or would have been helpful once you and your baby were at home.

Please do not hesitate to write comments where you feel you want to elaborate.

PART A

Please circle ONE of options a), b), c), d), e) or f).

DURING YOUR BABY'S HOSPITALIZATION, DID THE NURSES GIVE YOU ADEQUATE (ENOUGH) INFORMATION ON THE FOLLOWING TOPICS:

1. How to recognize the side effects of the medications you would have to give to your baby at home?
 - a) yes
 - b) yes, but I didn't want this information
 - c) no, but I would have liked this information
 - d) no, but I didn't want this information
 - e) don't know/don't remember
 - f) not applicable

2. How to recognize changes in your baby's breathing pattern that may mean that he/she is becoming sick?
 - a) yes
 - b) yes, but I didn't want this information
 - c) no, but I would have liked this information
 - d) no, but I didn't want this information
 - e) don't know/don't remember
 - f) not applicable

3. How to recognize a change in your baby's colour?
 - a) yes
 - b) yes, but I didn't want this information
 - c) no, but I would have liked this information
 - d) no, but I didn't want this information
 - e) don't know/don't remember
 - f) not applicable

4. What to do if your baby stopped breathing at home?
 - a) yes
 - b) yes, but I didn't want this information
 - c) no, but I would have liked this information
 - d) no, but I didn't want this information
 - e) don't know/don't remember
 - f) not applicable

5. What to do in case of an emergency at home?
 - a) yes
 - b) yes, but I didn't want this information
 - c) no, but I would have liked this information
 - d) no, but I didn't want this information
 - e) don't know/don't remember
 - f) not applicable

6. Were you offered a cardiopulmonary resuscitation (CPR) course?
 - a) yes
 - b) yes, but I didn't want this information
 - c) no, but I would have liked this information
 - d) no, but I didn't want this information
 - e) don't know/don't remember
 - f) not applicable

7. How to use the suction equipment if you needed it at home?
 - a) yes
 - b) yes, but I didn't want this information
 - c) no, but I would have liked this information
 - d) no, but I didn't want this information
 - e) don't know/don't remember
 - f) not applicable

8. How to know when your baby needed suctioning?
- a) yes
 - b) yes, but I didn't want this information
 - c) no, but I would have liked this information
 - d) no, but I didn't want this information
 - e) don't know/don't remember
 - f) not applicable
9. How to use the oxygen equipment if needed at home?
- a) yes
 - b) yes, but I didn't want this information
 - c) no, but I would have liked this information
 - d) no, but I didn't want this information
 - e) don't know/don't remember
 - f) not applicable
10. How to use the saturation monitor if needed at home?
- a) yes
 - b) yes, but I didn't want this information
 - c) no, but I would have liked this information
 - d) no, but I didn't want this information
 - e) don't know/don't remember
 - f) not applicable

11. How to put in and look after a nasogastric (NG) tube?
 - a) yes
 - b) yes, but I didn't want this information
 - c) no, but I would have liked this information
 - d) no, but I didn't want this information
 - e) don't know/don't remember
 - f) not applicable

12. How to care for a gastrostomy tube (G-tube)?
 - a) yes
 - b) yes, but I didn't want this information
 - c) no, but I would have liked this information
 - d) no, but I didn't want this information
 - e) don't know/don't remember
 - f) not applicable

13. How to use the pump to give tube (ng or g-tube) feedings to your baby?
 - a) yes
 - b) yes, but I didn't want this information
 - c) no, but I would have liked this information
 - d) no, but I didn't want this information
 - e) don't know/don't remember
 - f) not applicable

14. How to care for your baby's ostomy (eg: colostomy, ileostomy, tracheostomy)?

- a) yes
- b) yes, but I didn't want this information
- c) no, but I would have liked this information
- d) no, but I didn't want this information
- e) don't know/don't remember
- f) not applicable

15. Did you take an infant cardiopulmonary resuscitation (CPR) course?

- (a) yes
- (b) no

When?

- (a) before discharge
- (b) after discharge
- (c) other (please specify) _____

16. Did you feel comfortable to take your baby home?

- (a) yes
- (b) no

Why or why not?

PART B

THE FOLLOWING QUESTIONS RELATE TO THE TIME SINCE **DISCHARGE** FROM HOSPITAL.

1. After your baby came home from the hospital, did you call for information and support regarding your baby's care?

- (a) yes
- (b) no

If yes, who/where did you call? (You may choose more than one option.)

- (a) family member
- (b) friend
- (c) public health nurse
- (d) family doctor
- (e) pediatrician
- (f) NICU
- (g) CHEO information line
- (h) other (please specify) _____

2. Do you think that parents should be given the phone number of a specific place to call for information and support about their baby's care?

- (a) yes
- (b) no

If yes, where might this place be?

- (a) NICU Information line
- (b) CHEO Information line
- (c) Public Health Information line
- (d) Doctor's office
- (e) Community Drop-In centres
- (f) Other (please specify) _____

Who should be available to answer your questions?

- (a) a doctor
- (b) a nurse
- (c) a public health nurse
- (d) a NICU nurse
- (e) other (please specify) _____

3. What other support measure (people, resources, and equipment) would have been helpful?

4. How would you describe your child's medical condition?
Please circle the number that best describes your answer.

not severe 1 2 3 4 5 very severe

5. How would you describe your ability to cope with your child's condition?
Please circle the number that best describes your answer.

not good 1 2 3 4 5 very good

6. Any other comments?

Thank you for taking the time to complete this questionnaire.

Debbie Aylward, RN, BScN

Appendix J

**Reliability Analysis of Aylward Pilot Prior to Discharge (Time 1) and After Discharge
(Time 2)**

Appendix J

Reliability Analysis of Aylward Pilot Prior to Discharge (Time 1) and After Discharge (Time 2)

	Participant											
	1		2		3		4		5		6	
Time	1	2	1	2	1	2	1	2	1	2	1	2
Question												
1	A	A	C	C	A	A	F	F	A	A	A	A
2	A	A	C	C	F	F	F	E†	A	A	A	A
3	A	A	A	A	C	C	F	E†	A	A	A	A
4	A	A	C	C	F	F	F	C‡	A	A	A	A
5	A	A	G	C*	A	A	C	C	A	A	A	A
6	A	A	A	A	A	A	F	F	A	A	A	A
7	A	A	F	F	F	F	F	F	F	F	F	F
8	A	A	F	F	F	F	F	F	F	F	F	F
9	A	A	F	F	F	F	F	F	F	F	F	F
10	A	A	F	F	F	F	F	F	F	F	F	F
11	A	A	F	F	F	F	F	F	F	F	F	F
12	F	F	F	F	F	F	F	F	F	F	F	F
13	A	A	F	F	A	F†	F	F	F	F	F	F
14	F	F	F	F	F	F	F	F	F	F	F	F

* originally answered 'yes' but added would have liked more information and at time 2 responded that had not received information but wanted it

† misunderstood the meaning of 'pump' – initially, thought it was the breastpump and not the pump used to administer feeds – question was changed to read "How to use the pump to give tube (ng or g-tube) feedings to your baby?"

‡ allowing for time and memory

Each item had only one response that changed from time 1 to time 2

"at home" added to questions 1, 4, 5, 7, 9 and 10 to specify that these items related to interventions/practices after discharge.

Appendix K

**Participant Responses on the McKim Questionnaire (Part A) Reported Prior to
Discharge by Content Area**

Appendix K

Participant Responses on the McKim Questionnaire (Part A) Reported Prior to Discharge by Content Area

Question	Participant Response (%)					
	a	b	c	d	e	f
Basic Infant Care						
1. How to breastfeed your baby?	76.7	3.3	3.3	6.7	0.0	10.0
2. How to know if your baby is getting enough breastmilk?	66.7	3.3	6.7	6.7	0.0	16.7
3. How to prepare the formula?	43.3	0.0	6.7	10.0	0.0	40.0
4. How much formula you should give at each feeding?	56.7	0.0	10.0	3.3	0.0	30.0
5. How to help your baby feed well?	73.3	0.0	10.0	13.4	0.0	3.3
6. When to start the baby on cereals?	30.0	0.0	30.0	13.3	0.0	26.7
7. What kinds of cereal to begin with?	20.0	0.0	30.0	23.3	0.0	26.7
8. Whether the baby needs any additional iron, vitamins, or fluoride?	60.0	0.0	26.7	0.0	3.3	10.0
9. How to give your baby a bath?	76.7	6.7	0.0	13.3	0.0	3.3
10. How to give medicine (if any) to your baby?	83.3	0.0	3.3	0.0	0.0	13.4
11. How to take your baby's temperature?	90.0	0.0	3.3	3.4	0.0	3.3
12. When to take your baby for his/her immunization?	60.0	0.0	23.3	6.7	0.0	10.0
13. How to take care of a diaper rash?	76.7	3.3	3.3	10.0	0.0	6.7
14. How to know if the baby's 'spitting up' is normal?	60.0	0.0	30.0	3.3	0.0	6.7
17. What to do about your baby's crying?	63.3	0.0	23.3	6.7	0.0	6.7
18. How to know if the baby's bowel movement is normal?	70.0	0.0	26.7	0.0	3.3	0.0
19. How to recognize if your baby is becoming ill?	83.3	0.0	16.7	0.0	0.0	0.0
20. What to do if you think your baby is becoming ill?	83.3	0.0	13.3	3.4	0.0	0.0
24. How long you should expect your baby to sleep between feedings? ¹	82.8	0.0	10.3	6.9	0.0	0.0
Infant Environment						
21. What temperature and humidity to keep your house?	36.7	0.0	43.3	10.0	0.0	10.0
22. How warmly to dress your baby?	66.7	0.0	3.3	20.0	0.0	10.0
23. When to start to take your baby outside the house?	30.0	0.0	43.3	13.4	0.0	13.3

Infant Behaviour and Development						
15. How to know if your baby has colic? ¹	31.0	3.5	44.8	10.4	0.0	10.3
16. How to know if your baby's 'fussy periods' are normal?	50.0	0.0	40.0	0.0	0.0	10.0
25. What kinds of behaviour to expect from your baby during his/her first six weeks at home?	41.4	0.0	41.4	10.3	0.0	6.9
29. Were you given information about the possibility your baby may have a little problem adjusting to home for the first couple of days?	40.0	0.0	46.7	10.0	0.0	3.3
31. Were you told how to get your baby to respond to you?	40.0	0.0	20.0	30.0	0.0	10.0
Information Specific to Premature Infants ²						
26. Whether it is normal for a premature baby to 'grunt', 'groan', 'sneeze' and 'hiccup'? ³	50.0	5.0	30.0	10.0	0.0	5.0
27. Whether noisy breathing, especially at night can be normal for premature babies? ³	40.0	0.0	45.0	10.0	0.0	5.0
28. Whether your premature baby may have a slightly irregular breathing pattern? ³	75.0	0.0	20.0	0.0	0.0	5.0
30. Were you told that 'normal' behaviour and development for the premature infant may be 'different' from a term baby? ³	50.0	0.0	40.0	10.0	0.0	0.0

LEGEND

a = yes

b = yes, but I didn't want this information

c = no, but I would have liked this information

d = no, but I didn't want this information

e = don't know/don't remember

f = not applicable

¹ n = 29.² Results based on responses only from participants with premature infants (n = 21)³ n = 20.

Appendix L

**Participant Responses on the Aylward Questionnaire (Part A) Reported Prior to
Discharge By Content Area**

Appendix L

Participant Responses on the Aylward Questionnaire (Part A) Reported Prior to Discharge By Content Area

Question	Participant Response (%)					
	a	b	c	d	e	f
Recognition/Response to Changes in Health Status						
2. How to recognize changes in your baby's breathing pattern that may mean that he/she is becoming sick?	33.3	0.0	66.7	0.0	0.0	0.0
3. How to recognize a change in your baby's colour?	70.0	0.0	30.0	0.0	0.0	0.0
4. What to do if your baby stopped breathing at home?	43.3	0.0	50.0	3.3	0.0	3.4
5. What to do in case of an emergency at home? ¹	65.5	0.0	31.1	3.4	0.0	0.0
6. Were you offered a cardiopulmonary resuscitation (CPR) course?	80.0	0.0	3.3	13.4	0.0	3.3
Knowledge /Skills Necessary to Care for the Medically Complex Infant ²						
1. How to recognize the side effects of the medications you would have to give to your baby at home? N = 17	47.1	0.0	29.4	0.0	0.0	23.5
7. How to use the suction equipment if you needed it at home? N = 1	100.0	0.0	0.0	0.0	0.0	0.0
8. How to know when your baby needed suctioning? N = 1	100.0	0.0	0.0	0.0	0.0	0.0
9. How to use the oxygen equipment if needed at home? N = 0	0.0	0.0	0.0	0.0	0.0	0.0
10. How to use the saturation monitor if needed at home? N = 1	100.0	0.0	0.0	0.0	0.0	0.0
11. How to put in and look after a nasogastric (NG) tube? N = 3	100.0	0.0	0.0	0.0	0.0	0.0
12. How to care for a gastrostomy tube (G-tube)? N = 2	100.0	0.0	0.0	0.0	0.0	0.0
13. How to use the pump to give tube (NG or G-tube) feedings to your baby? N = 4	100.0	0.0	0.0	0.0	0.0	0.0
14. How to care for your baby's ostomy (eg: colostomy, ileostomy, tracheostomy)? N = 3	100.0	0.0	0.0	0.0	0.0	0.0

LEGEND

a = yes

b = yes, but I didn't want this information

c = no, but I would have liked this information

d = no, but I didn't want this information

e = don't know/don't remember

f = not applicable

¹ n = 29.

² Results based on responses only from participants for whom the question applies. Actual number of participants is listed for each question.

Appendix M

**Participant Responses on the McKim Questionnaire (Part A) Reported Four Weeks
After Discharge by Content Area**

Appendix M

Participant Responses on the McKim Questionnaire (Part A) Reported Four Weeks After Discharge by Content Area

Question	Participant Response (%)					
	a	b	c	d	e	f
Basic Infant Care						
1. How to breastfeed your baby?	70.0	3.3	6.7	16.7	0.0	3.3
2. How to know if your baby is getting enough breastmilk?	60.0	0.0	10.0	16.6	6.7	6.7
3. How to prepare the formula?	46.7	0.0	20.0	16.6	0.0	16.7
4. How much formula you should give at each feeding?	43.3	0.0	36.7	0.0	0.0	20.0
5. How to help your baby feed well?	66.7	0.0	6.7	20.0	3.3	3.3
6. When to start the baby on cereals?	26.7	0.0	36.7	23.3	3.3	10.0
7. What kinds of cereal to begin with?	26.7	0.0	36.7	30.0	0.0	6.6
8. Whether the baby needs any additional iron, vitamins, or fluoride?	73.3	0.0	16.7	10.0	0.0	0.0
9. How to give your baby a bath?	86.7	0.0	0.0	13.3	0.0	0.0
10. How to give medicine (if any) to your baby?	86.7	3.3	3.3	0.0	0.0	6.7
11. How to take your baby's temperature?	86.7	0.0	6.7	6.6	0.0	0.0
12. When to take your baby for his/her immunization?	66.7	0.0	16.7	13.3	3.3	0.0
13. How to take care of a diaper rash?	66.7	0.0	6.7	23.3	0.0	3.3
14. How to know if the baby's 'spitting up' is normal?	50.0	0.0	40.0	6.7	0.0	3.3
17. What to do about your baby's crying?	40.0	3.3	36.7	16.7	3.3	0.0
18. How to know if the baby's bowel movement is normal?	76.7	0.0	16.7	3.3	3.3	0.0
19. How to recognize if your baby is becoming ill?	80.0	0.0	16.7	0.0	3.3	0.0
20. What to do if you think your baby is becoming ill?	80.0	0.0	10.0	6.7	3.3	0.0
24. How long you should expect your baby to sleep between feedings?	66.7	0.0	16.7	16.6	0.0	0.0
Infant Environment						
21. What temperature and humidity to keep your house?	50.0	0.0	40.0	6.7	0.0	3.3
22. How warmly to dress your baby?	70.0	3.3	10.0	16.7	0.0	0.0
23. When to start to take your baby outside the house?	33.3	0.0	46.7	20.0	0.0	0.0

Infant Behaviour and Development						
15. How to know if your baby has colic?	33.3	0.0	46.7	16.7	0.0	3.3
16. How to know if your baby's 'fussy periods' are normal?	43.3	0.0	50.0	6.7	0.0	0.0
25. What kinds of behaviour to expect from your baby during his/her first six weeks at home?	46.7	0.0	43.3	6.7	0.0	3.3
29. Were you given information about the possibility your baby may have a little problem adjusting to home for the first couple of days?	63.3	0.0	20.0	6.7	3.3	6.7
31. Were you told how to get your baby to respond to you?	36.7	0.0	36.7	23.3	3.3	0.0
Information Specific to Premature Infants ¹						
26. Whether it is normal for a premature baby to 'grunt', 'groan', 'sneeze' and 'hiccup'?	52.4	4.8	28.6	9.5	0.0	4.7
27. Whether noisy breathing, especially at night can be normal for premature babies?	47.6	0.0	38.1	0.0	4.8	9.5
28. Whether your premature baby may have a slightly irregular breathing pattern?	47.6	0.0	28.6	4.8	4.7	14.3
30. Were you told that 'normal' behaviour and development for the premature infant may be 'different' from a term baby?	61.9	0.0	28.6	4.8	0.0	4.7

LEGEND

a = yes

b = yes, but I didn't want this information

c = no, but I would have liked this information

d = no, but I didn't want this information

e = don't know/don't remember

f = not applicable

¹ Results based on responses only from participants with premature infants (n = 21)

Appendix N

**Participant Responses on the Aylward Questionnaire (Part A) Reported Four Weeks
After Discharge by Content Area**

Appendix N

Participant Responses on the Aylward Questionnaire (Part A) Reported Four Weeks After Discharge by Content Area

Question	Participant Response (%)					
	a	b	c	d	e	f
Recognition/Response to Changes in Health Status						
2. How to recognize changes in your baby's breathing pattern that may mean that he/she is becoming sick?	23.3	0.0	66.7	3.3	6.7	0.0
3. How to recognize a change in your baby's colour?	73.3	0.0	23.3	3.4	0.0	0.0
4. What to do if your baby stopped breathing at home?	56.7	0.0	33.3	6.7	0.0	3.3
5. What to do in case of an emergency at home?	76.7	0.0	20.0	3.3	0.0	0.0
6. Were you offered a cardiopulmonary resuscitation (CPR) course?	73.3	0.0	6.7	16.7	0.0	3.3
Knowledge/Skills Necessary to Care for the Medically Complex Infant ¹						
1. How to recognize the side effects of the medications you would have to give to your baby at home? n = 17	58.8	0.0	23.5	0.0	0.0	17.7
7. How to use the suction equipment if you needed it at home? n = 1	100.0	0.0	0.0	0.0	0.0	0.0
8. How to know when your baby needed suctioning? n = 1	100.0	0.0	0.0	0.0	0.0	0.0
9. How to use the oxygen equipment if needed at home? n = 0	0.0	0.0	0.0	0.0	0.0	0.0
10. How to use the saturation monitor if needed at home? n = 1	100.0	0.0	0.0	0.0	0.0	0.0
11. How to put in and look after a nasogastric (NG) tube? n = 3	100.0	0.0	0.0	0.0	0.0	0.0
12. How to care for a gastrostomy tube (G-tube)? n = 2	100.0	0.0	0.0	0.0	0.0	0.0
13. How to use the pump to give tube (NG or G-tube) feedings to your baby? n = 4	100.0	0.0	0.0	0.0	0.0	0.0
14. How to care for your baby's ostomy (eg: colostomy, ileostomy, tracheostomy)? n = 3	100.0	0.0	0.0	0.0	0.0	0.0

LEGEND

a = yes

b = yes, but I didn't want this information

c = no, but I would have liked this information

d = no, but I didn't want this information

e = don't know/don't remember

f = not applicable

¹ Results based on responses only from participants for whom the question applies. Actual number of participants is listed for each question.

Appendix O

**Participant Responses on Part A of the McKim Questionnaire Reported Prior To
(Time 1) and Four Weeks After Discharge (Time 2)**

Appendix O

Participant Responses on Part A of the McKim Questionnaire Reported Prior To (Time 1) and Four Weeks After Discharge (Time 2)

Question	Participant Response (%)						
	Time	a	b	c	d	e	f
Basic Infant Care							
1. How to breastfeed your baby?	1	76.7	3.3	3.3	6.7	0.0	10.0
	2	70.0	3.3	6.7	16.7	0.0	3.3
2. How to know if your baby is getting enough breastmilk?	1	66.7	3.3	6.7	6.7	0.0	16.7
	2	60.0	0.0	10.0	16.6	6.7	6.7
3. How to prepare the formula?	1	43.3	0.0	6.7	10.0	0.0	40.0
	2	46.7	0.0	20.0	16.6	0.0	16.7
4. How much formula you should give at each feeding?	1	56.7	0.0	10.0	3.3	0.0	30.0
	2	43.3	0.0	36.7	0.0	0.0	20.0
5. How to help your baby feed well?	1	73.3	0.0	10.0	13.4	0.0	3.3
	2	66.7	0.0	6.7	20.0	3.3	3.3
6. When to start the baby on cereals?	1	30.0	0.0	30.0	13.3	0.0	26.7
	2	26.7	0.0	36.7	23.3	3.3	10.0
7. What kinds of cereal to begin with?	1	20.0	0.0	30.0	23.3	0.0	26.7
	2	26.7	0.0	36.7	30.0	0.0	6.6
8. Whether the baby needs any additional iron, vitamins, or fluoride?	1	60.0	0.0	26.7	0.0	3.3	10.0
	2	73.3	0.0	16.7	10.0	0.0	0.0
9. How to give your baby a bath?	1	76.7	6.7	0.0	13.3	0.0	3.3
	2	86.7	0.0	0.0	13.3	0.0	0.0
10. How to give medicine (if any) to your baby?	1	83.3	0.0	3.3	0.0	0.0	13.4
	2	86.7	3.3	3.3	0.0	0.0	6.7
11. How to take your baby's temperature?	1	90.0	0.0	3.3	3.4	0.0	3.3
	2	86.7	0.0	6.7	6.6	0.0	0.0
12. When to take your baby for his/her immunization?	1	60.0	0.0	23.3	6.7	0.0	10.0
	2	66.7	0.0	16.7	13.3	3.3	0.0
13. How to take care of a diaper rash?	1	76.7	3.3	3.3	10.0	0.0	6.7
	2	66.7	0.0	6.7	23.3	0.0	3.3
14. How to know if the baby's 'spitting up' is normal?	1	60.0	0.0	30.0	3.3	0.0	6.7
	2	50.0	0.0	40.0	6.7	0.0	3.3
17. What to do about your baby's crying?	1	63.3	0.0	23.3	6.7	0.0	6.7
	2	40.0	3.3	36.7	16.7	3.3	0.0
18. How to know if the baby's bowel movement is normal?	1	70.0	0.0	26.7	0.0	3.3	0.0
	2	76.7	0.0	16.7	3.3	3.3	0.0
19. How to recognize if your baby is becoming ill?	1	83.3	0.0	16.7	0.0	0.0	0.0
	2	80.0	0.0	16.7	0.0	3.3	0.0
20. What to do if you think your baby is becoming ill?	1	83.3	0.0	13.3	3.4	0.0	0.0
	2	80.0	0.0	10.0	6.7	3.3	0.0
24. How long you should expect your baby to sleep between feedings?	1 ¹	82.8	0.0	10.3	6.9	0.0	0.0
	2	66.7	0.0	16.7	16.6	0.0	0.0

Infant Environment							
21. What temperature and humidity to keep your house?	1	36.7	0.0	43.3	10.0	0.0	10.0
	2	50.0	0.0	40.0	6.7	0.0	3.3
22. How warmly to dress your baby?	1	66.7	0.0	3.3	20.0	0.0	10.0
	2	70.0	3.3	10.0	16.7	0.0	0.0
23. When to start to take your baby outside the house?	1	30.0	0.0	43.3	13.4	0.0	13.3
	2	33.3	0.0	46.7	20.0	0.0	0.0
Infant Behaviour and Development							
15. How to know if your baby has colic?	1 ¹	31.0	3.5	44.8	10.4	0.0	10.3
	2	33.3	0.0	46.7	16.7	0.0	3.3
16. How to know if your baby's 'fussy periods' are normal?	1	50.0	0.0	40.0	0.0	0.0	10.0
	2	43.3	0.0	50.0	6.7	0.0	0.0
25. What kinds of behaviour to expect from your baby during his/her first six weeks at home?	1	41.4	0.0	41.4	10.3	0.0	6.9
	2	46.7	0.0	43.3	6.7	0.0	3.3
29. Were you given information about the possibility your baby may have a little problem adjusting to home for the first couple of days?	1	40.0	0.0	46.7	10.0	0.0	3.3
	2	63.3	0.0	20.0	6.7	3.3	6.7
31. Were you told how to get your baby to respond to you?	1	40.0	0.0	20.0	30.0	0.0	10.0
	2	36.7	0.0	36.7	23.3	3.3	0.0
Information Specific to Premature Infants ²							
26. Whether it is normal for a premature baby to 'grunt', 'groan', 'sneeze' and 'hiccup'?	1 ³	50.0	5.0	30.0	10.0	0.0	5.0
	2	52.4	4.8	28.6	9.5	0.0	4.7
27. Whether noisy breathing, especially at night can be normal for premature babies?	1 ³	40.0	0.0	45.0	10.0	0.0	5.0
	2	47.6	0.0	38.1	0.0	4.8	9.5
28. Whether your premature baby may have a slightly irregular breathing pattern?	1 ³	75.0	0.0	20.0	0.0	0.0	5.0
	2	47.6	0.0	28.6	4.8	4.7	14.3
30. Were you told that 'normal' behaviour and development for the premature infant may be 'different' from a term baby?	1 ³	50.0	0.0	40.0	10.0	0.0	0.0
	2	61.9	0.0	28.6	4.8	0.0	4.7

LEGEND

a = yes

b = yes, but I didn't want this information

c = no, but I would have liked this information

d = no, but I didn't want this information

e = don't know/don't remember

f = not applicable

¹ n = 29.

² Results based on responses only from participants with premature infants (n = 21)

³ n = 20.

Appendix P

**Participant Responses on Part A of the Aylward Questionnaire Reported Prior To
(Time 1) and Four Weeks After Discharge (Time 2)**

Appendix P

Participant Responses on Part A of the Aylward Questionnaire Reported Prior To (Time 1) and Four Weeks After Discharge (Time 2)

Question	Participant Response (%)						
	Time	a	b	c	d	e	f
Recognition/Response to Changes in Health Status							
2. How to recognize changes in your baby's breathing pattern that may mean that he/she is becoming sick?	1	33.3	0.0	66.7	0.0	0.0	0.0
	2	23.3	0.0	66.7	3.3	6.7	0.0
3. How to recognize a change in your baby's colour?	1	70.0	0.0	30.0	0.0	0.0	0.0
	2	73.3	0.0	23.3	3.4	0.0	0.0
4. What to do if your baby stopped breathing at home?	1	43.3	0.0	50.0	3.3	0.0	3.4
	2	56.7	0.0	33.3	6.7	0.0	3.3
5. What to do in case of an emergency at home?	1 ¹	65.5	0.0	31.1	3.4	0.0	0.0
	2	76.7	0.0	20.0	3.3	0.0	0.0
6. Were you offered a cardiopulmonary resuscitation (CPR) course?	1	80.0	0.0	3.3	13.4	0.0	3.3
	2	73.3	0.0	6.7	16.7	0.0	3.3
Knowledge/Skills Necessary to Care for the Medically Complex Infant ²							
1. How to recognize the side effects of the medications you would have to give to your baby at home? n = 17	1	47.1	0.0	29.4	0.0	0.0	23.5
	2	58.8	0.0	23.5	0.0	0.0	17.7
7. How to use the suction equipment if you needed it at home? n = 1	1	100.0	0.0	0.0	0.0	0.0	0.0
	2	100.0	0.0	0.0	0.0	0.0	0.0
8. How to know when your baby needed suctioning? n = 1	1	100.0	0.0	0.0	0.0	0.0	0.0
	2	100.0	0.0	0.0	0.0	0.0	0.0
9. How to use the oxygen equipment if needed at home? n = 0	1	0.0	0.0	0.0	0.0	0.0	0.0
	2	0.0	0.0	0.0	0.0	0.0	0.0
10. How to use the saturation monitor if needed at home? n = 1	1	100.0	0.0	0.0	0.0	0.0	0.0
	2	100.0	0.0	0.0	0.0	0.0	0.0
11. How to put in and look after a nasogastric (NG) tube? n = 3	1	100.0	0.0	0.0	0.0	0.0	0.0
	2	100.0	0.0	0.0	0.0	0.0	0.0
12. How to care for a gastrostomy tube (G-tube)? n = 2	1	100.0	0.0	0.0	0.0	0.0	0.0
	2	100.0	0.0	0.0	0.0	0.0	0.0
13. How to use the pump to give tube (ng or g-tube) feedings to your baby? n = 4	1	100.0	0.0	0.0	0.0	0.0	0.0
	2	100.0	0.0	0.0	0.0	0.0	0.0
14. How to care for your baby's ostomy (eg: colostomy, ileostomy, tracheostomy)? n = 3	1	100.0	0.0	0.0	0.0	3.3	0.0
	2	100.0	0.0	0.0	0.0	0.0	0.0

LEGEND

a = yes
 b = yes, but I didn't want this information
 c = no, but I would have liked this information

d = no, but I didn't want this information
 e = don't know/don't remember
 f = not applicable

¹ n = 29

² Results based on responses only from participants for whom the question applies. Actual number of participants is listed for each question.