PARENTAL NEEDS RATING BY PARENTS AND NURSES: ASSOCIATION WITH ILLNESS SEVERTIY

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ABSTRACT

The purpose of this study was to investigate parents' and nurses' perspectives on the psychosocial needs of parents, the extent to which those needs are viewed as met; and to understand the association between parental needs and the infant's illness severity for parents with preterm infants that are born before 32 weeks gestation, in the first 10 days of hospitalization to the neonatal intensive care unit (NICU).

This cross-sectional, descriptive-correlational, pilot study used the NICU Family Needs Inventory and the modified Needs Met Inventory to rate needs statements on an attitudinal scale. Twenty-four parents of preterm infants and 16 neonatal nurses participated in the study.

The results showed no statistically significant difference in how parents and nurses reported parental needs in terms of importance. Differences were observed between the ratings of the top ten needs that were identified by parents and nurses. Statistically significant differences were observed in the perception of needs that are considered met. No correlation between parental needs and illness severity was detected.

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I ride the waves because it matters.

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CHAPTER ONE

INTRODUCTION

In 2011_2012, of the 373,000 Canadian in-hospital births, 47, 820 (7.8%) were reported as preterm (Canadian Institute for Health Information, 2013).[1] In this same time period, 139,386 live in-hospital births were reported across the province of Ontario, of which an estimated 11,108 (8.0%) were preterm, with 1,627 (1.4%) born before 32 weeks' gestation and requiring Level III hospital care (Better Outcomes Registry & Network [BORN] Ontario, 2013). These statistics indicate that Ontario's preterm birth rate is above the national average in Canada. By definition, an infant born alive before the completion of 37 weeks' gestation is preterm.

The environment of the neonatal intensive care unit (NICU) has been extensively reported as chaotic, stressful, and anxiety-provoking for parents of medically fragile preterm infants (Cleveland, 2008; De Rouck & Leys, 2009; Johnson, 2008, McGrath, 2014). In addition, parents have reported feelings of uncertainty, alienation, helplessness, being in a crisis, frustration, guilt, loss of control, inadequacy, and a sense of unreality (Arockiasamy, Holisti, & Albersheim, 2008; Hollywood & Hollywood, 2011; Jackson, Ternestedt, & Schollin, 2003; Obeidat, Bond, & Callister, 2009; Watson, 2010). The structural environment of the NICU is also identified as a physical and psychological barrier for parents because of its intimidating nature owing to the sights, sounds, and medical equipment as well as the altering of parental roles and exclusion of parents from the infant's care (Johnston, 2008; Pepper, Rempel, Austin, Ceci, & Hendson, 2012; Watson, 2010). Indeed, parents of preterm infants have an increased

[1] An infant born alive before the completion of 37 weeks' gestation is defined as preterm herein.

risk of developing depression due to the higher rates of mortality, morbidity, and health disparities in this patient population, as parents are often unprepared to handle the social, cognitive, and physical strains associated with having a preterm infant (Hollywood & Hollywood, 2011; Lindberg & Öhrling, 2008; Twaddell, 2013). These experiences negatively affect the parent-infant interaction and can result in significant adverse consequences to the infant's health outcome.

Needs of the NICU Parent

Parents of preterm infants are rarely psychologically or physically prepared to handle the diverse and complex challenges associated with parenting a preterm infant (Lindberg & Öhrling, 2008). The unsatisfied needs of parents can have a detrimental impact on the infant's short- and long-term health due to parental stress and anxiety (Heidari, Hasanpour, & Fooladi, 2013). The physiological and psychological needs of parents in the NICU are reported to include the need to: a) receive accurate and comprehensible information, b) be actively involved in their infant's care and have a role in decision making, c) maintain vigilance and oversee their infant's care as a means of protection, d) be engaged in physical contact with their infant, e) be viewed positively by nurses, f) have individualized care, and g) establish and maintain the therapeutic nurse-parent relationship (Cleveland, 2008; McGrath, 2014; Pepper et al., 2012). Being separated from the infant, their clinical presentation, the intimidating nature of the NICU environment, and the nurse-parent relationship are all factors that influence parental needs, adjustment to parenthood, and their readiness and ability to learn. Meeting parents' needs is thus important for promoting parental well-being, providing family-

centered care (FCC), and ensuring the best possible outcome for vulnerable preterm infants and their families.

Studying the relationship between parental needs and illness severity provides a greater awareness of the types of needs parents have and the extent to which the infant's health condition influences these needs. Preterm infants born before 32 weeks gestation are at an increased risk of adverse neurodevelopmental, health, and growth outcomes due to the immaturity of the brain and lungs (Saigal & Doyle, 2008), and immunological system. Hence, parents of preterm infants have unique and individualized psychosocial needs related to the psychosocial support and specific education regarding how to care for their infant effectively.

Nurses also play a vital role in caring for preterm infants and their parents through the provision of holistic FCC to promote the optimal health outcome (Punthmatharith, Buddharat, & Kamlangdee, 2007). Understanding how parents and nurses perceive and prioritize parental needs in relation to the infant's illness severity is important for identifying and developing strategic measures to equip nurses with the knowledge and skills to assess, recognize, and address the needs of parents (Obeisat & Hweidi, 2014; Twaddell, 2013). Nurses are often perceived as the infant's gatekeeper (Latour, Hazelset, Duivenvoorden, & van Goudoever, 2010) and as a potential barrier to parents adapting to their roles due to the nurses' over-involvement and their exhibiting attitudes and behaviors that inhibit parental integration and decision making in the infant's care. This in turn hampers the building of positive, supportive and trusting nurse-parent relationships and fosters mistrust (McGrath, 2014).

To provide quality nursing care and engage with parents, nurses must have a clear understanding of the needs that parents with preterm infants identify as important (Heidari et al., 2013; Ward, 2001). A comparison of the perceptions of needs of parents' and nurses' will provide insight into existing gaps and enhance our understanding of what parents' and nurses' view as important. In addition, studying the difference between the points of view parents' and nurses' also generates the evidence required to support the development and implementation of interventions and resources to meet the needs of NICU parents.

The needs of parents vary during the infant's hospitalization (De Rouck & Leys, 2009). The accurate assessment of parents' needs and priorities can reduce unintentional barriers and negative consequences such as stress and anxiety that can result from nurses and other healthcare providers having an incomplete understanding of parental needs and perceptions (Brooks, Rowley, Broadbent & Petrie, 2012; Sargent, 2009; Twaddell, 2013). Parental needs are not always met by healthcare providers who are not attuned to when and how much information should be provided (Harvey, Nongena, Gonzalez-Cinca, Edwards, & Redshaw, 2013). The needs that nurses and mothers recognize as helping promote satisfaction are most important; however, the priority level assigned to those needs differ (Latour, et al., 2010; Punthmatharith et al., 2007; Scott, 1998). Hence, having clear insight into parental needs is essential to developing and sustaining an effective parent-nurse relationship (Sargent, 2009).

The addressing of needs should be directed by an understanding of the parents' perception of their needs as expressed during an assessment. On identifying the needs viewed as relevant by the parent, nurses should then work collaboratively with parents

to determine the resources that would best support these needs. Evaluating how nurses make sense of parents' needs is crucial because most of the communication and education that parents receive as well as the time spent in the NICU is with the nurse (Twaddell, 2013). Nurses' understanding of parental needs may influence how they engage in patient advocacy, and interact with parents in relation to the relevance, amount, and type of support and education provided, which are central to the delivery of FCC and facilitation of parental empowerment (Higman & Shaw, 2008). In addition, meeting the needs of parents is an important nursing function that helps build parents' confidence, advocacy skills, sense-of-self, and autonomy as they become adjusted to their role in parenting a preterm infant.

Summary

Parents of preterm infants have unique and specific needs that must be addressed by healthcare providers according to the priorities identified by parents, as attempts to support needs that are not a priority to parents will negatively affect their level of satisfaction and result in parents feeling unsupported. The relationship between parents and nurses must thus involve collaboration, respect and the implementation of resources and support directed towards supporting parents' needs. Nurses and other NICU staff must continuously expand their understanding of parental needs and seek to support parents in adapting to their role as parents of a preterm infant. These measures are essential for helping parents tackle the challenges they encounter while promoting them as the infant's most important advocate and a non-modifiable constant in his or her life.

The Problem

There is a gap in the body of research regarding parental needs and priorities in the NICU setting. No studies have exclusively investigated nurses' and parents' perspectives of parents' priority needs or sought to identify the association between parental needs and the infant's illness severity for infants born before 32 weeks gestation, during the initial 10-day period of admission to the NICU. The way in which parents prioritize needs and view them as met or unmet requires further investigation. This can lead to the development of tailored resources that provide relevant support and education (Latour et al., 2010; Obeisat & Hweidi, 2014). Unmet needs can have a significant impact on how parents perceive the education, support, and services they receive, on their adjustment to this distressing, unfamiliar, and un-traditional way of becoming a parent, and ultimately, on the infant's overall health outcome. In addition, unmet parental needs affects their ability to meet the needs of their infant, as both the parent's and the infant's needs are closely connected. Nurses' views of parental needs can influence their involvement in patient advocacy, responsiveness to these needs, and the delivery of support and education, which can in turn affect the infant's health outcome and well-being of the family.

Study Aim and Research Questions

This pilot study was designed to use validated questionnaires prospectively to explore parents' and nurses' perceptions of the important needs and met needs of parents with infants born before 32 weeks gestation as well as explore the association between parental needs and illness severity in the first 10 days of admission to the NICU.

The primary study question is:

1. What are the perceived needs of parents of preterm infants born under 32 weeks' gestation during the first 10 days of admission to an NICU setting?

The secondary questions are:

2. Is there a difference between nurses' perceptions of parents' needs and parents' perceived needs?
3. To what extent are parental needs perceived as met or unmet from parents' and nurses' perspectives?
4. Is there an association between parental needs and illness severity in the initial 10 days in the NICU?

Hypotheses

1. Parents will identify different parental needs as important than nurses.
2. The degree to which NICU parents perceive that their needs are met and unmet differs from that reported by nurses.
3. There is a positive association between parental needs and objective measures of illness severity in the initial 10-day period of the infant's admission to the NICU.

Definitions of Terms

Parent(s): Refers to the biological parent, primary caregiver, or individual that assumes significant responsibilities in caring for the infant during the NICU stay.

Need: A physiological or psychological requirement that is recognized by a parent as vital to the support of their well-being.

Illness severity: “The degree of illness and risk of disease manifested by patient, based on clinical data from the medical records or on hospital discharge” (Stedman’s, 2012, p. 1530).

CHAPTER TWO

LITERATURE REVIEW AND CONCEPTUAL FRAMEWORK

This chapter describes the strategies used in selecting the studies included in this literature review. In addition, studies that addressed certain aspects of parental needs in the NICU, differences in perceived needs among parents and healthcare providers and illness severity as a variable that affects parental well-being during their infant's admission will be presented. Next, a discussion on the current gaps in the literature on parental needs in the NICU is presented. Finally, King's conceptual framework for nursing, the theory that guided this study, is used to explain the intricate relationship between parental needs and the interrelated personal, interpersonal, and social systems in the NICU context.

Search Strategy

This literature review was conducted to identify studies that have evaluated and contributed to the current understanding regarding (i) the needs of NICU parents, and to what extent these needs are perceived to have been met from the parents' and nurses' perspectives and (ii) the relationship between these parental needs and the infant's illness severity. A systematic search of nine electronic databases and two internet search engines was conducted. The academic and non-academic databases used to retrieve the research articles were CINAHL- Cumulative Index to Nursing and Allied Health (EBSCO), Nursing and Allied Health Source (Proquest), Medline (Ovid), Scopus, Medline (PubMed), PsycINFO, Sociology Abstracts, Evidence Based Medicine Reviews (Cochrane DSR, ACP Journal Club, DARE and CCTR), Proquest- Dissertations & Theses, Google Scholar and Google. Databases were searched for studies dating from

January 1980 to September 2014. The search timeframe was kept broad due to the limited amount of research available on this topic and for the inclusion of older foundational studies.

Approximately 1400 titles and abstracts were located using the following medical subject headings and/or keywords used in combination or singly: “neonatal intensive care”, “parent*”, “mother*”, “father*”, “family*”, “needs assessment”, “perceived needs”, “critical care”, “intensive care unit”, “healthcare provider”, “nurse”, “nurse practitioner”, “information needs”, “support needs”, “communication needs”, and “illness severity”. The articles were selected by reading the title and abstract first, to identify their relevance to the research focus. A manual search of the reference lists was also conducted. The articles generated from these searches were selected using the following inclusion criteria: peer-reviewed qualitative or quantitative studies**,** theses and dissertations reporting on parental needs experiences and/or illness severity with a specific focus on the NICU, studies published in English, and the full-text being available. Twenty articles met the selection criteria for inclusion in the literature review.

Introduction to the Literature on Parental Needs in the NICU

A paucity of research explores and compares parents’ and nurses’ points- of - view on the needs of NICU parents, the degree to which these needs are believed to have been met, and the correlation with illness severity. An inadequate understanding of and misconceptions about the needs of parents can result in their needs not being met (Harvey et al., 2013). This fact compounds parental stress and can influence their perception of, and satisfaction with, care, thereby serving as an obstacle to providing FCC and to enhancing parental well-being. No data are available on the impact of the infant’s illness severity on parental needs in the NICU setting. As such, studying

whether illness severity affects parental needs is necessary to gather information on the factors that influence parental needs during their infant's admission. The articles discussed in this review are summarized in Appendix A.

NICU Parents' Needs

This section reviews studies of the perceived needs of NICU parents and discusses the implications of those research findings to the present study. Corliss (1995) conducted an exploratory descriptive study to identify perceived needs and the variables that may influence these needs as identified by parents with critically ill neonates. Participants consisted of mothers (*n* = 29), fathers (*n* = 24), and neonates (*n* = 29). The mean gestational age for neonates in this study was 33 weeks (standard deviation [*SD*] = 4.87 weeks). A modified version of the Critical Care Family Needs Inventory (CCFNI) from which the NICU Family Needs Inventory (NICU FNI) was adapted- and used to conduct interviews with parents during the first or second week of admission to the NICU.[2]

Corliss' (1995) study reported that only increased age influences parental needs (*r* = .2665, *p* = .032), with needs increasing as parental age increased. Fathers and mothers rated the needs differently on the first four items; while, fathers viewed them as very important (100%) mothers did not recognize them as such. Information needs were ranked as the most important by parents, which contrasts with the findings of other researchers (Mundy, 2010; Obeisat & Hweidi, 2014; Sargent, 2009; Ward, 2001). The author did not provide information on the ranking of the remaining four subscales, which

[2] The inventory consists of five subscales of needs: assurance, information, proximity, comfort and support. These subscales comprise 56 needs statements that ask respondents to rate each in terms of importance on the following five-point Likert scale: not important (1); slightly important (2); important (3); very important (4); and not applicable (5).

would be interesting for further comparison with existing studies. One limitation was the study's restricted geographical location. In addition, the small sample size and non-random sampling limited its generalizability.

In a related descriptive study, Ward (2001) investigated the perceived needs of 42 mothers and 10 fathers with infants born between 28 and 41 weeks gestation (mean [*M*] = 34.67 weeks, *SD* = 3.75). This study also used the 56-item NICU FNI to assess parental needs. The length of NICU stay before the completion of the questionnaire ranged from 2 to 30 days (*M* = 6.57 days, *SD* = 6.45). Fifty-three (95%) needs statements were reported as important or very important, and assurance needs were reported as the most important overall for both genders. Further, parents ranked their needs on the subscales from most to least important as follows: assurance, information, no difference between proximity and comfort, and support.

In the study by Ward (2001), fathers rated information and assurance as less important than mothers. Two qualitative studies of fathers' experience in the NICU revealed that the information need was perceived as gaining a sense of control (Arockiasamy et al., 2008; Lindberg, Axelsson & Ohrling, 2007). Parents thus use information seeking to develop the knowledge of how to participate in their infants' care as well as to cope with the uncertainty and distressing experience of having their infant admitted to the NICU (De Rouck & Leys, 2009). Similar to Mundy's (2010) study, fathers rated support needs (*M* = 49.1) as less important than mothers (*M* = 59.38) and both genders reported support as the least important of the five subscales. These observed differences were statistically significant (*p* = .003). Ward (2001) attributed the low ranking of support needs to the absence of a parent support group at the healthcare

center where the research was conducted and to most of the NICU FNIs being completed within the first week of the infant's admission.

In Ward's (2001) and Mundy's (2010) studies, parents with infants across the gestational age groups of 24 to 41 weeks were recruited and their length of time in the NICU differed. Both the age distribution and the timeframe in which the NICU FNI was completed were thus two limitations of Ward's (2001) study since these factors can affect parents' perceptions of parental needs because the level of NICU care that an infant requires changes with age and time. Therefore, the effects of time and gestational age on parental needs require further investigation. The study also had limited generalizability to other NICUs as it was conducted in a single setting, while only 10 of the 52 participants were fathers.

Sargent (2009) examined the relationship between maternal/infant characteristics and mothers' needs. The sample consisted of 46 mothers and data were collected by using the NICU FNI. There were 46 infants in the study with birth weights ranging between 595 to 4525 g (M = 1990.87 g, SD = 931.24), gestational ages between 26 to 40 weeks (M = 33 weeks, SD = 4.13) and lengths of stay between 2 to 78 days (M = 14.15 days, SD = 17.21). Mothers' ranked their needs from highest to lowest in the following order: assurance (M = 3.85, SD = 0.192), information (M = 3.73, SD = 0.307), proximity (M = 3.71, SD = 0.285), comfort (M = 3.33, SD = 0.507), and support (M = 3.26, SD = 0.513), which was similar to Obeisat and Hweidi's (2014) findings. All five subscales demonstrated significantly positive correlations wherein a higher score in one needs area produced increased scores in the remaining subscales. Regression analysis indicated an inverse relationship between a mother's information needs and

her infant's length of stay. This finding was not surprising as the need for information should decrease as the infant matures and his or her their condition stabilizes and as the mother becomes more familiar with the unit's routines and the NICU environment; the finding was also supported by Orfali and Gordon's (2004) ethnographic study of parental experience in the NICU. A positive relationship was also noted between increased household income and maternal need for support. A key limitation to this study was the exclusion of fathers, as they play an essential role in supporting mothers. In addition, the exclusion of mothers with infants whose health conditions were considered to be unstable limited the generalizability of the results, as this group of mothers' may have a different view of their needs.

Mundy (2010) conducted a descriptive correlational study to assess the most and least important needs of parents in the NICU at admission and discharge. The NICU FNI was used to conduct interviews. Study participants consisted of mothers (n = 43) and fathers (n = 17) with infants born between 24 and 40 weeks gestation (mean = 32.16 weeks, SD = 4.73). The infant's birth weight (BW) ranged from 520 to 3827 g (M = 1883 g, SD = 983). The mean length of stay for infants in this study was 46.37 days. Fifty-two (93%) of the statements on the NICU FNI were reported as important or very important and at least one participant reported that 26 (46%) of the statements were not important (Mundy, 2010). The results of this study indicated that assurance needs (M = 3.89) were rated as the most important, which is similar to the findings of other studies examining parental needs in the NICU (Obeisat & Hweidi, 2014; Sargent, 2009; Ward, 2001). Information needs about the infant were rated as more important by mothers than fathers. This is consistent with the findings of Bialoskurski, Cox, and Wiggins'

(2002) study of the needs of mothers with preterm infants in the NICU. There was also a slight difference in the reporting of support needs with mothers rating (M = 3.36, p = .08) higher than fathers (M = 3.26, p = .08), which was also reported by Ward (2001). On the subscales of needs, both genders ranked the importance of their needs from most to least in the following order: assurance, proximity, information, comfort, and support.

It was not surprising that the parents in Mundy's (2010) study interviewed early in their infant's admission to the NICU reported the need for more information than "veteran" parents at discharge who had familiarity with, and experiences in, the NICU. A similar finding was reported by Sargent (2009), who found that mothers of infants that had been admitted in the NICU for a longer timeframe required less information than newer mothers. From these findings, it is clear that gender differences affect prioritizing parental needs and that a parent's needs should be addressed and met on an individualized basis (Sargent, 2009) to reduce misunderstandings and promote health and well-being.

Mundy's (2010) study suffered from several limitations, which included the potential for parents' responses to be influenced by the interviewer's presence as the questionnaires were administered by interview at admission and discharge. The recruitment strategy was also a limiting factor as parents were interviewed during visits to the NICU; therefore, those absent during the interviewers scheduled appearances were not approached. Moreover, the study did not compare the same parents' responses at admission and discharge nor account for factors that might affect parents' needs including the infant's illness severity, diagnosis, and gestational age at birth.

Finally, the study had limited generalizability due to its small sample size, the use of a single research site, and the under-representation of fathers.

Obeisat and Hweidi (2014) conducted a descriptive correlational study to identify the perceived needs of parents with NICU-admitted infants experiencing a critical illness event. Participants consisted of a convenience sample of 89 (52.4%) fathers and 81 (47.6%) mothers who were required to self-administer the NICU FNI within 72 hours of admission.[3] The authors indicated that a 72-hour time-line was used as previous research had suggested that parents experience significant emotional, psychological and physical distress during this period, after which they enter an adjustment phase wherein their needs vary. The infants of parents in the study had gestational ages that ranged from 27 to 40 weeks (*M* = 35.12 weeks, *SD* = 3.7) and BWs that ranged from 788 to 3847 g, (*M* = 2052 g, *SD* = 19.3).

In this research by Obeisat and Hweidi (2014), parents ranked assurance (*M* = 3.65), information (*M* = 3.05), and proximity (*M* = 2.96) as the most important needs, while rating comfort (*M* = 2.61) and support (*M* = 2.34) as least important. The reporting of assurance and information needs among the needs of greater importance was consistent with the results of Mundy (2010), Sargent (2009) and Ward (2001). Obeisat and Hweidi (2014) also conducted a *t*-test to examine gender differences in perceived needs finding statistically significant differences between mothers' and fathers' perceptions of their needs on the total needs score (*p* = 0.000) and on the support (*p* = 0.000), information (*p* = 0.001), and proximity (*p* = 0.005) subscales as well as on the 23 individual needs statements. Like Mundy (2010) and Ward (2001), the results of this

[3] Parents considered to be illiterate engaged in a 20-30 minute interview instead.

study suggest that factors related to gender and other stressors can influence parental. Therefore, investigating parents' needs in different subgroups of preterm or low BW infants during specific admission periods can provide further clarity on parents' needs during admission. The two key limitations to this study acknowledged by authors were that the diversity in the infant's acuity level and the length of hospitalization may have influenced parents' responses.

Summary. These studies highlight the fact that the needs and priorities of parents during their infant's admission to the NICU cannot be generalized due to the multitude of factors that can affect parental needs. Studies included in this literature review reported that gender differences in needs exist (Corliss; 1995; Mundy, 2010; Obeisat & Hweidi, 2014; Ward, 2001), while factors related to age also play a role (Corliss, 1995). Finally, the accessibility of economic resources and time spent in the NICU influence parental needs (Sargent, 2009).

Differences in Perceived Needs

This section reviews studies that have investigated parents' and healthcare providers' perspectives of parental needs. Harvey et al. (2013) conducted a qualitative study exploring the information and communication needs of parents in the NICU, which revealed that factors related to parental emotional coping strategies, expectations, experience in the NICU, and history influence the manner in which they access information. This study also reported that parental needs are not always met by healthcare providers because of a lack of understanding of the informational needs of parents. Similar findings were reported by Perlman et al. (1991) in a mixed-methods study that described and analyzed the information provided to parents of critically ill

neonates by physicians and the parent's ability to recall the said information. De Rouck and Leys (2009) also noted that the timing and content of the information provision is not always congruent with the parent's needs due to the infant's acuity and the parent's readiness to engage in discussion about the infant's care. Misunderstanding parents' information needs can significantly influence the extent to which parents' view that their needs are met, as they require timely, relevant, and understandable information to make an informed decision about their infants care (De Rouck & Leys, 2009).

Published research comparing nurses' and parents' perceptions of needs is available in pediatric intensive care units (Latour et al., 2010; Scott, 1998). Studies have also analyzed nurses' and family members' perceptions of needs in the adult critical care setting (Maxwell, Stuenkel & Saylor, 2007) and the degree to which these needs are met in adult intensive care unit (Kleinpell & Power, 1992). By contrast, research in the neonatal population is scarce and the available works are unpublished theses that are not in English. Understanding the dynamics and perspectives of parents and nurses on needs importance and the degree to which they are met is important. The more knowledgeable the profession becomes about the needs of parents and nurses' perception of those needs, the more likely it is that interventions can be identified and developed, and practice policies implemented to guide nurses in their roles as advocates, educators, supporters, and facilitators of meeting parental needs. One key limitation to Harvey et al.'s (2013) study was that parents were interviewed while their infant was awaiting discharge to home or transfer to another hospital as their condition had improved, as the passage of time can affect parental views and thus limiting the study's generalizability.

Summary. In order to meet the needs of parents, more information is required on the perspectives of parents and nurses, as this relates to how needs are identified and prioritized. Parents and healthcare providers often have different views of parental needs (Harvey et al., 2013; Latour et al., 2010). Differences in needs identification can lead to unmet and unrealistic expectations, which can be detrimental to a family's health. Further, differences in needs perception can result from the overwhelming experience parents are facing, which speaks of the importance of the on-going assessment of and appropriate response to parental needs.

Illness Severity

This section reviews studies of the effect of the infant's illness severity on parental health and the perception of their infant's health. Illness severity is measured by assessing physiological variables in the initial hours following admission to the NICU (Richardson, Corcoran, Escobar & Lee, 2001).

Mackley, Locke, Spear and Joseph (2010) conducted a prospective study that consisted of a convenience sample of 30 fathers with infants born before the completion of 30 weeks gestation (M = 27 weeks, SD = ±1). The study aimed to evaluate and compare father's perceived levels of stress and the incidence of depressive symptoms at three time periods during admission and to understand how the infant's illness affected paternal stress. In this study, the Score for Neonatal Acute Physiology (SNAP) was used to quantify objective measures of illness severity.

It found no association between paternal stress, depressive symptoms, and the infant's illness severity. This study had limited generalizability due to its small size, the exclusion of mothers, and single NICU setting. This work's main finding consistent with

those of other studies that have assessed the effects of illness severity on parental perceptions of stress, depression, coping and mood alteration (Spear, Leef, Epps, & Locke, 2002); maternal anxiety and mother-infant interactions in very low BW infants weighing less than 1500 g (Zelkowitz, Papageorgiou, Bardin, & Wang, 2009); and maternal stress, illness severity, and the illness perceptions of mothers and healthcare providers (Brooks et al., 2012).

De Wit, Donohue, Sheppard, and Boss (2013) conducted a prospective, mixed-methods study consisting of semi-structured interviews and surveys. To examine mothers' and clinicians' communication in the NICU, a total of 106 mothers and 73 clinicians including nurses, neonatal nurse practitioners, physicians, and a respiratory therapist participated in the study. Maternal interviews were conducted between 48 hours and 15 days after their infant's NICU admission (*M* = 6.2 days). Mothers were asked to identify a clinician that was important to their infant's care and the clinician was contacted for an interview. The time between maternal and clinician interview ranged from 0 to 25 days (*M* = 2.82 days). Altogether, 106 infants were included in the study, of which 17% were very low BW and 44% were stable enough to be transferred to step-down facilities.

The study reported a 45% disagreement on illness severity between mothers and clinicians, while approximately 63% of mothers viewed their infant as less sick than the healthcare provider did. In this study, no objective measure of illness severity was used; the healthcare provider's estimate of the infant's illness severity was used as the "gold standard" (de Wit et al., 2013). Some major limitations to this study are that the infant's illness severity was subject to the healthcare provider's recall bias because only

43% were interviewed on the same day as the mother; further, of the healthcare providers that mothers identified as important to their infant's care, only 48% were interviewed. The omission of fathers from the study also limited the generalizability of the results. Notwithstanding the shortcomings of this study, it does highlight that mothers and healthcare providers may have differing interpretations of an infant's health status despite the appearance of mutual understanding and good communication (de Wit et al., 2013).

Summary. Studies investigating the correlation between illness severity and parental needs are limited. Differences in the perceptions of parents and healthcare providers about the infant's illness severity poses challenges when trying to determine the most effective approach to providing support and counselling to meet the needs of parents. Bridging the understanding between parents and nurses regarding the infant's illness severity is thus important in determining the needs parents have and the resources best suited to addressing them.

Significance

The body of research on parental needs in the NICU in not exhaustive (Cleveland, 2008; Mundy, 2010; Ward, 2001). No study was found that examined the relationship between parental needs, the degree to which those needs are considered to be met, and objective measures of the infant's illness severity from parents' and nurses' perspectives. Examining the association between parental needs and how those needs are perceived as met or unmet in relation to the infant's illness severity is essential to developing nursing interventions during this stressful period. Understanding parental needs and perceptions has implications regarding how strategies for information provision, communication and counseling, and parent support programs are

developed and implemented (Sargent, 2009) to meet the needs of vulnerable infants and their families. The present study bridges the gap in literature by providing evidence about the relationship between parental needs and the infant's illness severity as well as enhancing healthcare providers' knowledge of parental needs, priorities, and expectations and nurses' perspectives which can optimize the care and support that parents receive.

Conceptual Framework

This section highlights the aspects of King's conceptual framework that nurses in the NICU integrate into their practice to meet parental needs.

King's Conceptual Framework for Nurses

The nursing theory that guides this study is King's conceptual systems and theory of goal attainment. King's theory of goal attainment was derived from three open and dynamic interacting systems, namely personal systems (individual), interpersonal systems (groups, either large or small) and social systems (society) (King, 1981, 1992, 1997, 1999). The interaction between the systems' components within their respective internal and external environments is thought to help maintain, promote and restore of health, which is the goal for individuals, groups, and society (George, 2011; Khowaja & Khan, 2006; King, 1992, 1997).

Personal systems contains the concepts of perception, growth and development, body image, learning, time, personal space and coping which provide the foundational knowledge that leads to our understanding of individuals as personal, open, complete and unique systems that engage in continuous and reciprocal interactions with their

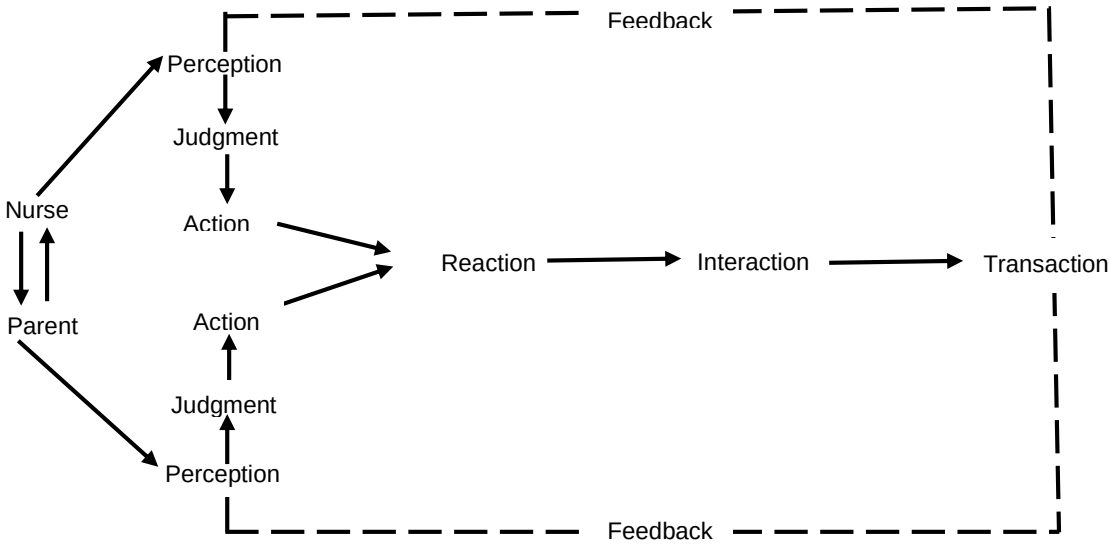

*Figure 1***.** A Model of Nurse-Parent Interactions. Adapted from *A Theory for Nursing: Systems, Concepts, Process*, p. 61, by I. M. King, 1981. Copyright © 1981 by John Wiley & Sons, Inc.

environment (Gunther, 2014; King, 1981). The interactions between individuals form these interpersonal systems, which become more complex as the number of individuals increases. In interpersonal systems, the interaction is occurring between nurses and parents, with communication, role, stress, interaction, transaction, and stressor the key components in understanding the nurse-parent dynamics (George, 2011; Gunther, 2014; King, 1981, see Figure 1). Social systems are represented by a large group that defines, the unique modes, shares common goals and interests, and comprises four elements: organization, authority, power, and decision making (George, 2011; Gunther, 2014; King, 1981). This conceptual system continuously influences an individual throughout his or her life-span and provides a structure and function for nursing (Gunther, 2014).

Theory of Goal Attainment

The theory of goal attainment is formulated from the conceptual framework of interpersonal systems (King, 1981). The theory uses the following 8 concepts to describe the nurse-parent dyad as a type of interpersonal system and the nature of their encounter: interpersonal, perception, interaction, communication, transaction, role, stress/stressor, growth and development (King, 1981, 1992, 1997). All the concepts in the theory are interrelated to the transactions that occur between nurses and parents. However, communication, perception, and interaction are viewed as essential elements in a transaction due to the mental act and personal judgment used while engaging in these processes (King, 1992). Transaction is defined as the observable behaviors/exchanges between an individual and his or her environment (George, 2011; Gunther, 2014). Interaction relates to the verbal and non-verbal goal-directed and observable behaviors that occur in the mutual presence of two or more individuals that facilitate the exchange and interpretation of information (George, 2011; Gunther, 2014; King, 1992). Communication is the processing or exchange of information from one state to another within one self or among several individuals (George, 2011; Gunther, 2014; King, 1981). Perception is the way in which individuals view their reality in relation to how they gain meaning from, organize, translate, store, and transform information gathered from their environment (George, 2011; Gunther, 2014; King, 1981). NICU nurses must apply their knowledge, skills, and judgment when working within these conceptual systems to develop and maintain effective nurse-parent relationships and engage in meaningful transactions that support parental needs and enhance parents' well-being.

Application and Integration of King's Framework and Theory

King's theory and framework were chosen to underpin this research due to the applicability of the concepts within the personal, interpersonal, and social systems in the context of the NICU environment and, more specifically, the nurse-parent relationship. In this environment, the nurse gathers and provides relevant support to meet the needs and goals of parents as they adjust to an un-traditional parenting role. Exploration of needs and perceptions can enhance the standard of care as, nurses expand their understanding of the information, proximity, support, assurance and comfort needs of parents. The interaction and transactions between parents and nurses in the NICU is aligned with King's theory as, during nurse-parent encounters perceptions and judgements regarding needs are developed. Successful engagement in these interrelated processes, the formation of mutual trust and respect, and the on-going evaluation of parental needs and perceptions form the basis for ensuring that parents' needs are met which leads to goal attainment. Nurses are in a unique position to help parents function within the systems, identify parental needs, and support parents in fulfilling their important roles in the infant's development.

CHAPTER THREE

METHOD

This chapter describes the study design including the setting, study population, and instruments. The procedures for recruitment, measures, data collection, and analysis are also provided. Ethical considerations and study limitations inherent to this study are finally reviewed.

Study Design

This was a cross-sectional, descriptive-correlational, pilot study that used validated questionnaires to collect data from parents of preterm infants that were born before 32 weeks gestation during the first 10 days in the NICU, as well as from nurses directly involved in the family's care.

Setting

The study setting was a publicly funded, tertiary-level, university-affiliated, research intensive teaching hospital in the Central East region of Ontario, Canada. The hospital has eight primary care specialty programs including the Women and Babies program, which includes a level 3 NICU. In the NICU, there are 48 beds in single patient rooms and the unit practices family integrated care. A multidisciplinary healthcare team offers support and care for families with premature and critically ill newborns that require medical, surgical, and technological interventions. The NICU offers a parent support program that provides group and individual support as well as information to parents on various topics including breastfeeding, kangaroo care, infant development, medication, and the medical conditions often seen in the preterm infant population.

Participants

The participants in this study were parents of preterm infants born before 32 weeks gestation, which comprise 1.4% of all preterm births in Ontario (BORN, 2013) and face significantly more health challenges over time including sepsis, cardiovascular, respiratory, neurological, and developmental problems when compared to term infants. Nurses were included in this study due to their close working proximity to these parents and infants. Obtaining nurses' perspectives of parental needs and the degree to which they are considered to be met was also required for comparison with parents' feedback. The goal was to determine if parents' and nurses' viewpoints on parental needs corresponded, and to determine if nurses were correctly identifying needs.

Inclusion Criteria

The study's inclusion criteria were as follows.

1. Infants born before the completion of 32 weeks gestation (less than or equal to 31 weeks and 6 days) were eligible to participate.
2. Parents of infants admitted to the unit at the start of the study were eligible to participate if the questionnaires were completed within 10 days of admission.
3. Parents of infants transferred to the research site from another facility were eligible to participate.
4. Nurses were eligible to participate if they provided care to a parent-infant dyad enrolled in the study.
5. The ability to speak and understand English.
6. Both parents were eligible to participate.

Exclusion Criteria

The study's exclusion criteria were as follows:

1. Compassionate care was implemented in anticipation of the infant's death.
2. Parents were unable to speak or understand English.
3. The infant was diagnosed with a life threatening congenital anomaly.

Sampling (Method and Size)

A non-probability convenience sample was recruited by directly approaching participants. The sample size for this pilot study was determined based on Hertzog (2008), who suggested that 10-20 participants in each group would be sufficient to obtain information for a power analysis.

Measures and Instruments

Questionnaires were deemed to an appropriate method of gathering information for identifying and describing parents' and nurses' perceptions of parental needs. As Polit and Beck (2012) indicated, questionnaires are sufficiently flexible to collect data from a large group of participants to examine their perceptions and attitudes.

The research questions were answered by using five instruments to collect quantitative data from participants. Both parents and nurses completed a combined 56-item version of the NICU FNI (Ward, 2001) and a modified version of the Needs Met Inventory (NMI) by Warren (1993) to assess reported needs and the extent to which they are perceived as met. Permission to use and modify the surveys for this study was obtained from the copyright owners and authors of the instruments: K. Ward, J. Leske and N. Warren (see Appendices B, C, and D). Separate demographic tools were developed for, and provided to, the parent and nurse participants to gather descriptive

information. In addition, several open-ended questions were included to capture additional comments or feedback from participants. An infant clinical data sheet (see Appendix E) was developed to collect the physiological measures needed to calculate the infant's illness severity scoring using SNAP II.[4] Permission to use SNAP II was obtained from J. Zupanic (see Appendix F).

NICU FNI

The NICU FNI (Ward, 2001) is a validated instrument that measures the parental importance of needs.[5] This self-reporting instrument was developed with the assistance of NICU nurses to ensure the language and needs statements were reflective of NICU parents' needs. The NICU FNI asked participants to rank needs--based statements in terms of importance on a four-point Likert scale. The 56 needs statements were measured in the following five dimensions: support (18 items), information (11 items), comfort (7 items), proximity (8 items) and assurance (12 items). The internal consistency of the tool was high with a reported Cronbach's (α) alpha of 0.94 (Mundy, 2010), 0.90 (Obeisat & Hweidi, 2014), and 0.91 (Ward, 2001). The internal consistency of the NICU FNI was tested after data collection in this study and the Cronbach's α was 0.93.

[4] The SNAP-II is an objective measure of illness severity that uses six empirical physiologic variables contained in the vital signs and laboratory test results to predict the likelihood of morbidity and mortality in infants across all birth weights (Richardson et al., 2001).

[5] The NICU FNI was modelled on the CCFNI which contained 45 items and which was developed by Leske (1986) in a follow-up study of Molters' (1979) descriptive explorative study that explored and listed the needs of families in the critical care setting (Maxwell et al., 2007). Rigor for the CCFNI has been reported by Leske (1991) to be Cronbach's α = 0.92 after examining the internal validity and consistency of the inventory over a nine-year period through the collection of data from 677 family members of patients that were admitted to critical care units across 14 states.

Needs Met Inventory

The NMI is a validated self-reported tool adapted from the CCFNI that contains the same needs statements and subscales. It is used to determine if needs were met after being identified by families. The main difference between the CCFNI and NMI is that on the NMI parents are asked to rank to what extent they perceived that their needs are met (Mendonca & Warren, 1998). The reliability rating for a 30-item version of the NMI used by Maxwell et al. (2007) yielded a Cronbach's α value of 0.93. For this study, the NMI was modified by adding an additional 26 needs statements to include the same needs statements and number of items in each subscale as the NICU FNI.[6] The 56 needs statements were then ranked by using a four-point Likert scale: 1 (never met), 2 (sometimes met), 3 (usually met), and 4 (always met). The modified NMI had a high level of internal consistency, as data collected from this study yielded a Cronbach's α of 0.95.

Demographic Questionnaires

A demographic tool was used to collect the parent's descriptive information including age, gender, ethnicity, level of education, and marital and employment status. Parents were also asked to describe their baby's current health status and indicate if the infant was born at the research site. One open-ended question, "What helps to meet your needs?", was included to gather additional information not captured in the questionnaires that parents would like to provide.

Nurses were also asked to complete a demographic sheet to gather descriptive information on the number of years working in the NICU, employment title and status,

[6] No previous has used the modified NMI to measure met needs in the NICU setting.

gender, age, ethnicity, and the number of times they had completed the surveys. Two open-ended questions were adapted from Maxwell et al. (2007) to help nurses describe their perceptions of what is being done to help meet parents' needs and to gather any other suggestions on how to help this process. These questions were as follows: "In your opinion, what is being done to help meet the needs of NICU parents?" and "What suggestion(s) do you have on how to help meet the needs of NICU parents?".

An infant clinical data sheet was developed and used by the researcher to collect psychological measures from the infant's chart to calculate the severity of illness score using SNAP-II and to describe participants. The variables used to calculate SNAP-II were collected from data measured over the initial 12 hours of admission and included the lowest mean blood pressure, lowest core body temperature, lowest serum pH, multiple seizures, urine output, and fraction of inspired oxygen (FiO_2/PaO_2) ratio. The scoring range for SNAP-II is 0 (lowest severity) to 115 (highest severity) (Chien et al., 2002). Additional information extracted from the infant's chart included gender, gestational age at birth, length of stay in hospital at the time the information was obtained, birth weight, Apgars at 1 and 5 minutes, diagnosis on admission, transfer from other hospital, ventilation, and singleton status.

Procedures

The researcher reviewed the NICU admissions records and collaborated with the bedside nurse on each site visit to determine which parent-infant dyads were eligible and suitable to approach for study participation. Parents were contacted by the researcher in the infant's room either in person or by using a notice to inform them about the study (see Appendix G). A verbal explanation about the research including

what the parents could expect was provided by the researcher and was guided by a script (see Appendix H). Parents were told that the study was seeking to understand the needs they viewed as important and how those needs were met using a series of needs statements. Copies of the study information letter (see Appendix I) and consent form (see Appendix J) were also provided to parents for review and to determine any additional questions they might have before deciding to participate in the study. Arrangements were made with each parent to determine the next follow-up visit to retrieve the consent form. After reviewing and signing the consent forms, a copy of the survey, which consisted of the NICU FNI and modified NMI (see Appendix K), and a demographic form (see Appendix L) were provided to parents. The infant's health information was obtained from the charts after the parents had signed the consent form. Completed surveys were retrieved by the researcher from the parent's rooms and some parents returned them to the nurses who placed them in the designated survey lockbox.

In-services about the study were provided to 116 nurses by the researcher before recruitment started on eight dates and during different shift periods to inform them about the aim of the study and about how they could get involved. Notices about the study information sessions were posted in the staff lounge, sub-care stations, and change rooms (see Appendix M). Individual nurses were approached to participate in the study after a parent-infant dyad with whom they were working had agreed to complete the surveys. They were informed that the study aimed to understand how the parents with which they worked would indicate that the needs were important and the extent to which they were met. Nurses were provided envelopes containing the study information letter (see Appendix N), consent form (see Appendix O), demographics survey (see Appendix

P), and the combined NICU FNI and modified NMI (see Appendix Q). They were instructed to place the surveys in the locked box placed on the unit by the medication room. The researcher was required to inform the nurse participants that the surveys had to be completed during non-working hours as this was stipulated by the unit administration.

Ethical Considerations

Before initiating data collection, approval to conduct the study was granted by the NICU Neonatal Research Committee, hospital, and university Research Ethics Boards to ensure that no human rights were being violated (see Appendices R, S, and T). In addition, a legal agreement for data transfer was established between the university and research site before any study data were transported from the facility (see Appendix U). The surveys were coded to indicate which had been completed by parents and which by nurses. This process was also necessary to distinguish the mother's responses from those of the father. A record of the parents approached to participate in the study was kept in a confidential log. The study data were stored at the research site in a locked filing cabinet. Each participant completed the surveys in approximately 30 minutes.

Study Benefits and Risks

There were no direct benefits for parents and nurses who participated in the study. The information provided added to the existing body of knowledge on needs importance, the extent to which needs are perceived as met, and the relationship with illness severity. To reduce responder burden, all participants were required to complete questionnaires once. Questionnaires were coded to maintain confidentiality and anonymity. During the study, no parent(s) approached the researcher with concerns

about the care they or their infant had received in the NICU. In the event nurse participants had concerns about how their responses might affect their relationships with the NICU, they were informed that the information provided was confidential and that the study was not a quality improvement and/or performance measure. No financial incentives or gifts were offered to study participants. The results of the study are available to individuals who request a copy of the findings from the researcher.

Data Analysis

The Software Statistical Package for Social Science (SPSS), version 22.0 was used to conduct descriptive and inferential data analyses**.** The quantitative study data were entered into SPSS and the open-ended questions transcribed by the researcher. Descriptive statistics including means, percentages and SDs were generated to describe the study population from the demographic information.

Means and SDs were also used to rank needs importance and needs met. The independent sample *t*-test statistic was used to analyze whether there were statistically significant differences between parents' and nurses' responses. The degree of variance between the groups was determined by conducting Levene's test. The Pearson correlation coefficient was used to determine the association between the subscales means in the NICU FNI and modified NMI and the variable illness severity. The statistical testing for the study was set at an alpha level of $p < .05$.

CHAPTER FOUR

RESULTS

This chapter reports the results of the data that was gathered and analyzed using the methods described in Chapter 3. The data is presented in sections, starting with a description of the participants' characteristics and is followed by addressing the research questions.

Participation in the study was voluntary and recruitment occurred over a two month period between February and April 2015. A total of 37 parents were approached in person by the researcher for participation and twenty-four (65%) completed the surveys. An additional 14 parents that met the study criteria were contacted using the study notices placed in the infant's rooms, of which nine (64%) parents did not respond. Five (36%) parents declined involvement and indicated that they were either "too tired" "too busy" or "not interested". After the first contact, some parents from the initial group of 37 approached to participate were not available during subsequent follow-up visits. Thirty-three nurses were approached, of these, 17 (52%) did not return the surveys. Two nurses declined to participate because they had limited contact with the parents. Several nurses indicated that they were "too busy" due to their patient assignments. There were random missing data for 14 parents and five nurses wherein, a response was not provided to the needs statement and/or "not applicable" was written on the survey. The most data missing from a single respondent were 34 unanswered needs statements. This missing information was replaced by the mean scores, stratified by participant type and gender. According to Kim and Mallory (2014), using the mean score to estimate missing data is the most appropriate approach for this study due to the ease with which the mean value can be determined and the increase in accuracy

compared with using prior knowledge to account for responses not provided by research participants.

Parents' Characteristics

The final study sample included 24 parents which consisted of 14 (58%) mothers and 10 (42%) fathers between 25 and 43 years of age (*M* = 34.75 years, *SD* = 4.82). Their level of education ranged from high school to post graduate. Seventeen (71%) parents were married, five (21%) living with a partner, one (4%) single (never married), and one (4%) widowed. Participants' employment status was reported as being full-time (*n* = 16; 67%), self-employed (*n* = 1; 4%), part-time (*n* = 1; 4%), unemployed (*n* = 1; 4%), parental leave (*n* = 3; 13%), and undeclared (*n* = 2; 8%). The majority of parents (*n* = 17; 71%) stated that this was their first baby. No parent reported that he or she had the opportunity to tour the NICU before their infant's admission. Twenty-one (88%) parents reported having no prior NICU experience. Twenty (83%) parents indicated that their infant's admission was unexpected, whereas for three (13%) it was planned and for one (4%) it was somewhat expected. Five (21%) parents reported their infant's health status as "very stable", while 17 (71%) indicated "stable" and two (8%) said "unstable". English was identified as the primary language for 22 (92%) parents, while one (4%) spoke French and another parent (4%) spoke Japanese. The ethnicity of the majority of participants was Caucasian (*n* = 16; 67%), while the remainder were African American/Black (*n* = 2; 8%), Asian (*n* = 2; 8%), South American (*n* = 2; 8%), West Indian (*n* = 1; 4%), and undeclared (*n* = 1; 4%).

Infants' Characteristics

Fourteen infants were included in the study, nine (64%) females and five (36%)

males with a gestational age ranging from 24 weeks plus 3 days to 31 weeks plus 1 day (*M* = 28 days, *SD* = 2.54). Their birth weights were between 738 to 1640 g (*M* = 1176.64 g, *SD* = 344.38). Eleven (79%) were singletons and three (21%) were twins, as one twin died. Nine (64%) infants were being supported with mechanical ventilation and five (35%) by continuous positive airway pressure. Twelve (86%) were born at the hospital where the study was conducted and the remaining two (14%) were transferred from other regional hospitals to the NICU after birth. The length of time from admission to approach for study consent ranged from 2 to 6 days of life (*M* = 4.75 days, *SD* = 1.22). Consent for study participation was obtained between 5 to 15 days of life (*M* = 7.79 days, *SD* = 3.09). Table 1 presents information on the means and SDs for the infant's weight categories and illness severity measures. The infants' medical diagnoses as documented in the medical records are described in Table 2.

Table 1

Infants' Weight Categories, Apgars and Illness Severity Measures (n = 14)

Variable	*n*	*M*	*SD*
BWs			
Extremely Low BW (less than 1000 g)	5	784	58
Very Low BW (1000 g to less than 1500 g)	5	1275	162
Low BW (1500 g to less than 2500 g)	4	1568	49
Apgars			
@ 1 minute	14	5.29	2.43
@ 5minutes	14	7.14	2.25
Illness severity measures			
Mean blood pressure (mm Hg)	14	27.14	5.99
Lowest temperature (degree Fahrenheit)	14	36.02	1.05
PO_2 (mm Hg)/FiO_2 (%)	14	26.86	14.23
Lowest serum pH	14	7.22	.07
Seizure (multiple, confirmed)	1 = yes 13 = no		

Table 1

Infants' Weight Categories, Apgars and Illness Severity Measures (n = 14) continued

Variable	*n*	*M*	*SD*
Illness severity measures (cont'd)			
Urine output (mL/kg/hr)	14	3.05	1.50
SNAP II Score (0 to 115)	14	32.57	12.09

Note: All illness severity measures were computed from data collected in the first 12 hours of life.

Table 2

Infants' Diagnoses as a Percentage of the Sample (n = 14)

Diagnosis	*n*	Percentage (%)
Birth process		
Prematurity	14	100
Dichorionic diamniotic (DC/DA) twin	2	14
Preterm premature rupture of membranes	1	7
Breech	1	7
Respiratory		
Respiratory distress syndrome	14	100
Apnea of prematurity	3	21
Lung hypoplasia	1	7
Pneumothorax	1	7
Persistent pulmonary tension of the newborn	1	7
Transient tachypnea of the newborn	1	7
Cardiovascular		
Hypotension	2	14
Patent ductus arteriosus	2	14
Hematologic		
Jaundice	4	29
Anemia	3	21
Coagulopathy	2	14
Immunologic		
Sepsis suspected	10	71
Group B Streptococcus positive	1	7
Group B Streptococcus unknown	1	7
Maternal chorioamnionitis	1	7
Topical fungal infection (skin)	1	7
Neurologic		
Intraventricular hemorrhage	3	21

Table 2

Infants' Diagnoses as a Percentage of the Sample (n = 14) continued

Diagnosis	*n*	Percentage (%)
Metabolic		
Metabolic acidosis	2	14
Integumentary		
Wound	2	14
Gastrointestinal		
Abdominal distension	1	7
Genitourinary		
Antenatal left pelviectasis	1	7
Genetics		
Suspected genetic disorder (Trisomy 21)	1	7
Other		
In-utero drug exposure	1	7
Edema	1	7

Nurses' Characteristics

A total of sixteen nurses, all women, participated in the study. There was a 48% survey return rate among nurse participants. The mean age for 14 nurses was 39.64 years (*SD* = 12.18 years), while two nurses did not report their age. The years of NICU experience ranged from 3 to 38 years (*M* = 18 years, *SD* = 12.25). Twelve (75%) of the nurses report that they were employed full-time and four (25%) part-time. Over half reported their ethnicity as Caucasian (*n* = 9; 56%), with the remainder Filipino (*n* = 2; 13%), African American/Black (*n* = 1; 6%), North African (*n* = 1; 6%), and undeclared (*n* = 3; 19%).

Parents' Needs

To test the study hypotheses, an independent sample *t*-test, Levene's test for equality of variance, descriptive statistics in the form of means and SDs, and order of importance were computed to identify the difference between parents' and nurses'

perceptions of needs for the five subscales. The results for needs importance and needs met are presented in the order in which the top 10 needs statements were ranked by parents and nurses to enable comparison between the groups' responses.

Needs Importance. The NICU FNI was used to assess parents' and nurses' perceptions of various types of needs using five subscales: *Assurance*, *Information*, *Proximity*, *Comfort* and *Support*. The need statements within each subscale were rated on a 4-point Likert scale as: not important (1), slightly important (2), important (3) and very important (4). Both mothers and fathers ranked *Assurance* as the most important need followed by *Proximity*, *Information, Comfort* and *Support.* The subscales means ranged between 3.34 and 3.89 for mothers and 3.22 and 3.78 for fathers. The results of the independent sample *t*-test showed no significant difference between mothers' and fathers' needs importance for all five subscales: *Assurance*, $t(22) = .840$, $p = .410$; *Proximity*, $t(22) = 1.01$, $p = .323$; *Information*, $t(22) = 1.21$, $p = .241$; *Comfort*, $t(22) = .084$, $p = .933$; and *Support*, $t(22) = .766$, $p = .452$ (see Appendix V).

A comparison of the parents' and nurses' ranking of the importance of these needs revealed some variation in perception as to what was most important. Parents ranked six needs as *very important* (mean scores of 4). The top 10 most important needs identified by parents had mean scores ranging from 3.96 to 4 (see Table 3). Table 4 depicts the top 10 parental needs as identified by nurses with mean scores ranging from 3.81 to 4. The results also indicate that four of the 10 highest ranked important needs were identified similarly by both groups while, three of those needs showed differences in how the groups perceived the needs statements.

Of the 12 statements under the *Assurance* subscale, four were ranked by parents' and five by nurses' in the top 10 needs, and all were rated as either *important* or *very important*. There are 8 needs statements under the *Proximity* subscale, three were ranked by parents' as *important* or *very important*. The nurses' ranked one *Proximity* needs statements, 'to be able to visit my infant at any time', in the top 10 needs and it was rated as *very important*. The *Information* subscale contains 11 needs statements; both parents' and nurses' ranked two statements in the top 10 needs as *important* or *very important*. Of the 18 needs statements in the *Support* subscale; none were ranked by parents' and only one by nurses' in the top 10 needs, and it was rated as *important* or *very important*. The *Comfort* subscale contains 7 needs statements; only one statement was ranked in the top ten needs by both parents' and nurses': 'to see that the NICU staff provide comfort to my infant, such as giving my infant a pacifier, using blankets to support my infant's body, and talking softly to my infant', and it was rated as *important* or *very important*.

Table 3

Parents' Ranking of the 10 Most Important Needs (n = 24)

Item #	Needs Importance Statement	Mean	SD	Percentage of Parents' Response (%)			
				Not Important (1)	Slightly Important (2)	Important (3)	Very Important (4)
1	To know the expected outcome for my infant.* (A)	4.00	.000	0	0	0	100
3	To be able to visit my infant at any time.*, ** (P)	4.00	.000	0	0	0	100

Table 3

Parents' Ranking of the Ten Most Important Needs (n = 24) (continued)

Item #	Needs Importance Statement	Mean	SD	Percentage of Parents' Response (%)			
				Not Important (1)	Slightly Important (2)	Important (3)	Very Important (4)
5	To have questions about my infant answered honestly.* (A)	4.00	.000	0	0	0	100
35	To feel that the hospital personnel care about my infant. (A)	4.00	.000	0	0	0	100
39	To see my infant frequently. (P)	4.00	.000	0	0	0	100
56	To see that the NICU staff provide comfort to my infant, such as giving my infant a pacifier, using blankets to support my infant's body, and talking softly to my infant.* (C)	4.00	.000	0	0	0	100
38	To receive information about my infant at least once a day. (P)	3.96	.204	0	0	4.2	95.8
48	To know why my infant is undergoing certain procedures. (I)	3.96	.204	0	0	4.2	95.8
52	To know that my infant is being handled gently by healthcare providers. (A)	3.96	.204	0	0	4.2	95.8

Table 3

Parents' Ranking of the Ten Most Important Needs (n = 24) (continued)

Item #	Needs Importance Statement	Mean	SD	Percentage of Parents' Response (%)			
				Not Important (1)	Slightly Important (2)	Important (3)	Very Important (4)
53	To know how my infant is being treated medically. (I)	3.96	.204	0	0	4.2	95.8

Notes: * = Needs statements identified by nurses; ** = Needs statements ranked the same by parents and nurses; (A) = Assurance ; (C) = Comfort, (I) = Information; (P) = Proximity; (S) = Support

Parents had higher mean scores than nurses in the *Assurance*, *Proximity*, *Information, and Comfort* subscales. As previously noted, parents viewed their needs in *Assurance* as most important followed by *Proximity*, *Information*, *Comfort*, and *Support*; in contrast, however, nurses ranked their needs in terms of importance, from most to least important as: *Assurance*, *Proximity*, *Information*, *Support*, and *Comfort*. The results of the independent sample *t*-test showed no significant difference between parents' and nurses' needs importance for all five subscales: *Assurance*, $t(38) = -.78$, $p = .442$; *Proximity*, $t(38) = -1.47$, $p = .149$; *Information*, $t(38) = -1.23$, $p = .227$; *Comfort*, $t(38) = -1.37$, $p = .178$; and *Support*, $t(38) = .07$, $p = .946$. Therefore, the null hypothesis of H1 cannot be rejected (see Table 5).

Table 4

Nurses' Ranking of the 10 Most Important Needs (n = 16)

Item #	Needs Importance Statement	Mean	SD	Percentage of Nurses' Response (%)			
				Not Important (1)	Slightly Important (2)	Important (3)	Very Important (4)
3	To be able to visit my infant at any time.*, ** (P)	4.00	.000	0	0	0	100
1	To know the expected outcome for my infant.* (A)	3.94	.250	0	0	6.3	93.8
5	To have questions about my infant answered honestly.* (A)	3.94	.250	0	0	6.3	93.8
10	To be given directions about how I can provide care to my infant in the NICU. (S)	3.94	.250	0	0	6.3	93.8
14	To be assured that the best care possible is being given to my infant. (A)	3.94	.250	0	0	6.3	93.8
34	To receive understandable explanations. (A)	3.94	.250	0	0	6.3	93.8
6	To feel hope about my baby's outcome. (A)	3.88	.342	0	0	12.5	87.5
56	To see that the NICU staff provide comfort to my infant, such as giving my infant a pacifier, using blankets to support my infant's body, and talking softly to my infant.* (C)	3.88	.342	0	0	12.5	87.5

Table 4

Nurses' Ranking of the Ten Most Important Needs (n = 16) (continued)

Item #	Needs Importance Statement	Mean	SD	Percentage of Nurses' Response (%)			
				Not Important (1)	Slightly Important (2)	Important (3)	Very Important (4)
36	To be allowed to help with my infant's physical care. (I)	3.81	.544	0	6.3	6.3	87.5
48	To know why my infant is undergoing certain procedures. (I)	3.81	.544	0	6.3	6.3	87.5

Notes: * = Needs statements identified by parents; ** = Needs statements ranked the same by parents and nurses; (A) = Assurance ; (C) = Comfort, (I) = Information; (P) = Proximity; (S) = Support

Table 5

Parents' and Nurses' Needs Importance Mean Subscales Scores

Needs Importance Variable	Mean	Mean	t-statistics	*p*-value (2-tailed)	*df*
	Parents *n* = 24	Nurses *n* = 16			
Assurance	3.84	3.77	-.778	.442	38
Proximity	3.78	3.63	-1.472	.149	38
Information	3.76	3.63	-1.227	.227	38
Comfort	3.38	3.17	-1.372	.178	38
Support	3.30	3.31	.068	.946	38

Notes: $p < .05$ (2-tailed)

Needs Met. The modified NMI was used to assess parents' and nurses' opinions on the degree to which various types of needs were viewed as met using five subscales: *Assurance*, *Information*, *Proximity*, *Comfort* and *Support*. The statements

comprising each subscale were rated on a Likert scale as: never met (1), sometimes met (2), usually met (3), and always met (4). Both mothers and fathers ranked *Proximity* as the need most frequently met, followed by *Assurance*, *Information, Comfort* and *Support.* The mean of the responses to these subscales ranged between 3.16 and 3.69 for mothers and 3.06 and 3.73 for fathers. The results of the independent sample *t*-test showed no significant difference between mothers' and fathers' needs met for all five subscales: *Proximity*, $t(22) = -.290$, $p = .774$; *Assurance*, $t(22) = -.276$, $p = .785$; *Information*, $t(22) = -.021$, $p = .984$; *Comfort*, $t(22) = .624$, $p = .539$; and *Support*, $t(22) = .544$, $p = .592$ (see Appendix W).

Comparison of the parents' and nurses' ranking of the degree to which needs were met revealed variations in perception. The subscales means ranged between 3.12 and 3.70 for parents and 2.95 and 3.32 for nurses. Both parents and nurses ranked *Proximity* as the highest met need followed by *Assuranc*e, *Information*, *Comfort*, and *Support*. The results of the independent sample *t*-test indicated that statistically significant differences in means existed for the following subscales: *Proximity*, $t(38) = -3.23$, $p = .003$; *Assurance*, $t(38) = -3.2$, $p = .003$; *Information*, $t(38) = -2.68$, $p = .011$; and *Comfort*, $t(38) = -2.95$, $p = .005$. No significant difference between parents and nurses was observed in the means for the variable *Support*, $t(38) = -1.23$, $p = .228$. The null hypothesis for H2 was thus rejected (see Table 6).

The *Proximity* subscale consists of 8 needs statement; parents' and nurses' ranked four statements among the top 15 needs met. One *Proximity* need, 'to hold my infant in my arms and against my skin as soon as I can', was reported as *never met* by one parent. Results from the study data also show that parents universally viewed one

Proximity needs statement as *always met*, -'to see my baby frequently', while nurses did not view any need as such. Of the 12 statements on the *Assurance* subscale, 5 were ranked among the top 15 needs that were reported as met by parents'. One parent indicated that the *Assurance* need, 'to know specific facts concerning my infant's progress', was never met. Four *Assurance* statements were ranking in the top 15 met needs by nurses. Of the 11 items in the *Information* subscale, both parents' and nurses' ranked three in the top 15 needs and those statements were reported as being *sometimes*, *usually* or *always met*. The *Comfort* subscale consists of 7 needs statement; both parents' and nurses' listed two statements among the top 15 needs and they were reported as *sometimes*, *usually* or *always met*. Of the 18 statements in the *Support* subscale, one was ranked by parents', and nurses' listed two in the top 15 needs and they were reported as *sometimes*, *usually* or *always met*. Nine (60%) of the 15 highest met needs were identified by both groups and differences were noted in how each group ranked needs met statements. The mean rank for the 15 highest met needs for parents ranged from 3.75 to 4.00 (see Appendix X) in comparison with nurses at 3.31 to 3.94 (see Appendix Y).

Table 6

Parents' and Nurses' Needs Met Mean Subscales Scores

Needs Met Variable	Mean	Mean	t-statistics	*p*-value (2-tailed)	*df*
	Parents *n* = 24	Nurses *n* = 16			
Proximity	3.70	3.32	-3.232	.003*	38
Assurance	3.65	3.21	-3.196	.003*	38
Information	3.49	3.10	-2.677	.011*	38

Table 6

Parents' and Nurses' Needs Met Mean Subscales Scores

Comfort	3.48	3.05	-2.949	.005*	38
Support	3.12	2.95	-1.226	.228	38

Notes: * = $p < .05$ (2-tailed)

Correlation between Parents' Needs and the Infants' Illness Severity

The Pearson product-moment correlation coefficient was conducted to determine the direction and strength of the correlation between the objective measures of illness severity and the needs importance/needs met variables. The bivariate correlation analysis revealed no significant correlation between the needs importance score and illness severity. However, *Assurance* was significantly correlated with *Information* and *Comfort*. There was also a significant positive correlation between *Proximity* and *Information*, *Comfort*, and *Support*. In addition, *Information* was significantly correlated with *Comfort* and *Support*. A statistically significant correlation was also observed between *Comfort* and *Support*. The correlation coefficients showed no statistical significant correlation between *Assurance* and *Proximity* or *Assurance* and *Support* (see Table 7).

For the needs met analysis, there was a moderately negative correlation between *Assurance* and illness severity, $r(24) = - 0.406$, $p = .049$. However, no significant correlations between *Support*, *Proximity*, *Information*, *Comfort*, and illness severity were observed ($p > .05$). The significantly positive correlations between all five subscales (see Appendix Z) signify that higher mean scores in a subscale are associated with higher mean scores in the other subscales.

Table 7

Correlation Between the infants' Illness Severity and Needs Importance Variables for Parents' (n = 24)

	Illness Severity	Assurance	Proximity	Information	Comfort	Support
Illness Severity	1.00	.195	-.137	.004	.043	.053
Assurance		1.00	.397	.618**	.473*	.261
Proximity			1.00	.820**	.578**	.602**
Information				1.00	.670**	.600**
Comfort					1.00	.603**
Support						1.00

Notes: * = $p < .05$ (2-tailed); ** = $p < .01$ (2-tailed)

Open-Ended Questions

Parents. One open-ended question provided parents with the opportunity to elaborate on their experiences. Nineteen parents responded to the question "what helps meet your needs as a parent with a baby in the NICU?". Several parents identified the breastfeeding consultation, Milk and Cookie social, social workers, and facilities (including the private rooms) as beneficial resources. They also noted that in general staff were "supportive", "approachable", "friendly", "knowledgeable", "level-headed", "incredible", and "had good bedside manners". One parent highlighted that their relationship with the nurse influenced their experience by stating, "*The connection made and caring feeling from the nurses keeps me calm and understanding and limits stress*." Another parent wrote, "*To be given hugs by staff and comforted that it will be alright, he is in the best possible place*." Parents noted that open communication,

frequent updates, honest feedback, and clear explanations on what happened and what to expect without the perception of judgmental interaction as they transition into the NICU environment is needed to reduce confusion. The ability to stay in their infant's room, have unrestricted visits, and the availability of a 24-hour hotline service were also said to decrease parents' anxiety.

Nurses. Nurses were asked two open-ended questions to gain insight into their perspectives on what they believe is being done to meet parental needs and what can enhance current strategies that help this. Fifteen nurses provided feedback, highlighting the availability of private patient rooms, a breast-pumping room, and a family lounge as spaces that help meet parents' needs. Support provided by the parent coordinator as well as the Milk and Cookie social, Father's Pizza Nights, and Mother's Tea on Saturdays that are led by parents with prior experience in the NICU also serve as ways for parents to meet. Several nurses mentioned the interactions between parents, nursing staff, and social workers as helpful. In addition, the ability for parents to join committees, participate in medical rounds, and provide education about the NICU environment, medical equipment, and updates on the infant's health status were also highlighted as factors that meet the needs of parents. The developmental milestone certificates created as the infant experiences various events, such as their first kangaroo care, reaching the 1 kg weight club, having their first bath, or no longer requiring ventilator support, were also reported as helpful.

In regards to additional measures that can aid in meeting the needs of parents, the nurses suggested the creation of more opportunities for primary care teams to maintain continuous care and reduce parental stress through the delivery of information. The

inclusion of a mental health nurse liaison as a part of the healthcare team was also cited as a resource that would be beneficial to parents, especially for individuals not coping with the experience. Facilitating parents' involvement in their infant's care early in admission, respecting their wishes, and encouraging them to ask questions were cited as areas in which meeting parents' needs could be enhanced. Serving the needs of parents for whom English is not their primary language and to whom nurses are unable to communicate effectively is another need that requires further investigation.

CHAPTER FIVE

DISCUSSION AND CONCLUSION

The primary purpose of this study was to gain information on the perceived needs and degree to which the said needs were viewed as met for parents with premature infants born before 32 weeks gestation within the initial 10 days of admission to the NICU, as identified by parents and nurses. The secondary purpose of the study was to ascertain the nature of the relationship between parental needs and objective measures of illness severity. This chapter discusses the study results in relation to previous research findings and King's conceptual framework. The limitations of this study are also reported and suggestions for future research and practice implications presented.

Discussion on Needs Perception

Needs Importance

No study has thus far investigated the relationship between parental needs and objective measures of illness severity in infants, for parents with infants born less than 32 weeks gestation early in the NICU admission, and the degree to which the identified needs are considered to be met by parents and nurses. Thus, there is limited ability for comparison with prior research. The finding that assurance needs were ranked as the most important overall is consistent with the results from several studies that have investigated parents' perceptions of their needs in the NICU (Mundy, 2010; Obeisat & Hweidi, 2014; Sargent, 2009; Ward, 2001). However, this finding is inconsistent with other studies that have reported information needs to be the most important (Bialoskurski et al., 2002; Corliss, 1995). As in Mundy's (2010) study, parents in this

study also ranked the five needs importance subscales from highest to least as assurance, proximity, information, comfort, and support. While in other studies parents have ranked their needs as assurance, information, proximity, comfort, and support (Obeisat & Hweidi, 2014; Ward, 2001). These differences in needs ranking reaffirms that parents' needs must be assessed on an individualized basis to enhance the likelihood of them being addressed effectively (Mundy, 2010), as the needs of no two individuals are the same (Punthmatharith et al., 2007). The reported difference in needs ranking may be influenced by the timing of the data collection, age, gender, family structure, and the targeted research population, with the acuity level, nature, and degree of illness observed in premature infants varying across gestational ages (Corliss, 1995; Mundy, 2010; Obeisat & Hweidi, 2014; Ward, 2001). In addition, the nurses' experience in the NICU might explain some differences in perceptions. Nonetheless, the fact the parents often identify assurance, proximity, and information among the top needs is not surprising. Having information about what they can expect in relation to the short- and long-term outcomes of their infant's health is an important element in their decision-making process (Obeisat & Hweidi, 2014). In addition, being in close proximity to their infant increases a parent's sense of involvement in the infant's care by helping them gain a better sense of the care provided, which could serve as an assurance strategy while building relationships with the nurses.

No published studies have compared nurses' ranking of the five subscales in the NICU FNI. In this study, nurses ranked the subscales in terms of needs importance from highest to lowest as assurance, proximity, information, support, and comfort, which was slightly different from the parents' views. The difference in mean scores between

the groups might be related to the priorities, meanings, and expectations ascribed to comfort and support. Needs prioritization between parents and nurses is also influenced by their experience, which alters their expectations and perceptions (Latour et al., 2010; Obeisat & Hweidi, 2014; Punthmatharith et al., 2007; Scott, 1998), this can influence nurses' ability to engage in care viewed by parents as supportive.

In parents' ranking of the top 10 needs, no items were related to the support subscale for which the mean score for nurses was higher than that for parents. Further, only one item related to comfort, namely "to see that the NICU staff provide comfort to my infant, such as giving my infant a pacifier, using blankets to support my infant's body, and talking softly to my infant", was included in the top 10 needs. By contrast, nurses mentioned one item for each subscale as important to parents. These items were "to be given directions about how I can provide care to my infant in the NICU" from the support subscale and "to see that the NICU staff provide comfort to my infant, such as giving my infant a pacifier, using blankets to support my infant's body, and talking softly to my infant" from the comfort subscale. Based on the findings of this study, support and comfort were thus ranked as the least important needs by parents and nurses, which is consistent with the findings of other studies (Bialoskurski et al., 2002; Mundy, 2010; Obeisat & Hweidi, 2014; Ward, 2001), suggesting that during the admission period, less emphasis is placed on these needs.

One interesting point about the ranking of comfort and support by parents is that the facility in which this study was conducted provides several formal and informal support groups for parents. Similar to the findings of other studies (Mundy, 2010; Ward, 2001), these needs were still rated the lowest, indicating that during this period parents

might only be ready to attend to the immediate needs and well-being of their infants and that peer support and their own comfort is less of a priority, or that their needs are being met by informal support resources.

Observing the differences in needs rating between parents and nurses is important for understanding gaps in our knowledge and practice in relation to the ability to identify and meet parental needs (Latour et al., 2010). Despite the difference observed in the means, they were not statistically significant; this might result from the number of participants in the study. The sample may have been too small to detect any statistical significant difference that may exist. It was hypothesized that perceived parental needs were related to the infant's illness severity; however, this was not observed in this study. The nature of the NICU environment including the resources available (breastfeeding consultation, parental involvement in care, access to information) may influence parental needs regardless of the infant's illness severity rating. Based on the results of this study, one could thus postulate that the above-mentioned resources have a positive influence on reducing needs.

Needs Met

In this study, both parents and nurses ranked the subscales in the NMI in the order of proximity, assurance, information, comfort, and support. Statistically significant differences were noted in all subscales, except support. The results for this study are therefore consistent with those of Maxwell et al. (2007), who suggested that nursing interventions related to assurance, proximity, and information are beneficial for meeting the needs of this parent population. This finding may help the unit's administrators and

staff review their current practice, determine the interventions that help meet the needs of parents, and identify existing gaps in needs fulfillment.

The only needs statement reported universally by parents as always met (related to proximity) was “to see my infant frequently”. This result might be attributed to parents having open access to the NICU and their infant at their discretion. Parents identified six needs met to varying degrees that were not highlighted in the top 15 needs by nurses. These six needs were “to know specific facts concerning my infant’s progress, “to hold my infant in my arms and against my skin as soon as I can”, “to know exactly what is being done for my infant”, “to feel that the hospital personnel care about my infant”, “to have the waiting room near the NICU”, and “to be recognized as important to my infant’s recovery”. The discrepancy between parents’ and nurses’ perceptions of met needs warrants further investigation and reinforces the notion that nurses and healthcare professionals require more insight into the factors that influence parents’ needs as well as the practices that support the meeting of these needs. As nurses enjoy a close working proximity with parents, they are in the best position to help meet these needs (Corliss, 1995). For the needs met statements identified by both groups, parents ranked all the items as met to a greater degree in comparison to nurses and this finding was observed throughout the results. This finding suggests that to some extent nurses sense that they are equipped with the knowledge and/or have the capacity to meets specific parental needs, but might be reserved in expressing their perspectives.

Practical Implications and Application to King's Conceptual Framework

While the results obtained from this study cannot be generalized to other NICU settings, the information obtained from the quantitative data and open-ended questions highlight the need for neonatal nurses to implement measures that facilitate open, ongoing, and substantive dialogue with parents on the nature of their infant's health. The importance of comprehendible, honest, and accurate information, willingness to provide assurance, and support of parental involvement were reinforced by the study findings. Encouraging parents to become partners in their infant's care is essential for strengthening nurse–parent relationships and parent–infant interactions, building trust, and reducing parental stress and anxiety. Nurses must continually assess parents' needs on an individual basis by working fluidly with parents between the personal, interpersonal, and social systems of King's conceptual framework.

The health and well-being of NICU parents and their infants are the main focus throughout hospitalization. During the first 10 days of an infant's admission to the NICU, nurses critically think about and are aware of parents' important needs. They use this awareness during interactions with parents to help them learn ways to adjust to their roles in the NICU. The results of this research suggest that, through their interactions and transactions with parents, NICU nurses are able to accurately assess the top priority needs of parents on all five needs-importance subscales, based on the mean scores and the fact that no significant difference was observed between the two groups' perceptions of parents' needs. Of the needs-met statements, only the *Support* subscale showed no statistically significant difference ($p = .228$). The findings from the needs-met subscales of *Proximity*, *Assurance*, *Information*, and *Comfort* show that nurses

underestimate their influence on and the effectiveness of their interactions with parents. Meeting parents' needs is a complex challenge that requires continuous and purposeful interactions between parents and nurses. The NICU nurses' perceptions of the needs met and important needs are influenced by their collective experience of working in the NICU environment, their educational training, need to provide services to others, sense of reality, and empathy (King, 1981).

The demonstration of empathy and advocacy is essential for meeting the needs and goals of parents as they transition and grow into their new roles, without feeling that they are being judged, pressured, or discriminated against. Learning and the timing of educational moments should be adapted to the parent's needs and preferences. This is a time for collaboration and parental empowerment. Parents must understand, be shown, and made to feel that they are recognized, respected, and valued for their position in the infant's life, which is best demonstrated through a caring and compassionate approach to the delivery of nursing care.

The complexities of the infant's health condition in the NICU environment undoubtedly result in parents and infants interacting with multiple healthcare providers throughout their admission. This can lead to role confusion and a perception of power imbalance as parents seek assurance and information about their infant's health. Parents may encounter situations that challenge their confidence and leave them with questions about the care provided and the nurse's competence, leading to the need for additional information and assurance, to remain close to the infant, and to assert more control. This requires nurses assume a more supportive role and become an information resource and counselor to help increase parents' ability to make effective

decisions and become more involved in their infant's care. Some nurses may not be comfortable in assuming these roles, as they do not have the technical skills or experience to engage with parents at this level, which can be perceived by parents as information being withheld. In such instances, the nurse needs to seek the assistance of more expert team members to support parents and limit the erosion of trust, reduce parental stress, and keep the lines of communication open.

The integration of nursing staff's developmental initiatives geared towards educating and preparing nurses to evaluate, recognize, and address the diverse needs of parents is vital. The presence of a mental health nurse liaison as part of the healthcare team can benefit parents that require additional support not within the scope of the NICU nurse's training, including the exacerbation of pre-existing or the emergence of impaired psychological health outcomes. The use of a simulation training program and open dialogue between parents with infants previously admitted to the NICU and nurses to help raise awareness of the nursing actions/interventions and attitudes that help guide and support parents during this period is needed. This program would provide nurses with the consistent, vetted, and relevant foundational knowledge needed to care for infants and their families in this clinical setting.

Implementing case conferences for parents with all members of the multidisciplinary team may strengthen parents' decision making and enhance the fulfillment of their needs by giving them the opportunity to review and discuss aspects of their infant's care without the time restraints encountered during rounds. The integration of frequent family assessments starting from the point of admission can also provide nurses with valuable information on the needs of parents over the course of

admission. In addition, nurses can use their knowledge of a parent's perception of their needs to explain that the needs are not met in isolation and that meeting all their needs is a priority for promoting the infant's health and development. One parent commented, when asked if any additional needs should be considered, "Intake needs assessment for each couple – formal/informal – in first week of NICU stay with follow-up." The nursing administration is responsible for helping nurses meet the needs of each parent. The meeting of needs is best accomplished when nurses have the resources and time required to complete a comprehensive needs assessment and work with parents to plan how to meet the identified needs.

Limitations

The study findings cannot be generalized beyond this research population due to the small (16 nurses and 24 parents), non-randomized, and homogeneous nature of the sample. In addition, the use of predominantly parent–infant dyads might have contributed to the finding of no significant difference between the mothers' and fathers perspectives on parental needs importance and needs met. A practical consequence of having a group of 14 infants was that, the small sample size with variability in the gestational ages limited the ability to identify statistically significant correlation between the parents' needs and the infants' illness severity. As parents completed the surveys without supervision, they might have communicated and thus influenced each other, possibly resulting in little variation among responses. Another limitation was that 66% of the parent respondents were Caucasians, the outcomes may be different when studying the opinions of a more ethnically diverse population. The results were also limited by the fact that the parent-nurse interaction might have being impacted by the

timing of the data collection wherein, the nurses may not have had considerable experience working with the parents to determine if their needs were met. Nurses in the study were asked to complete the questionnaires independently; however, communication among nurses might have also influenced their responses. The study is also limited as participants' perspectives were only captured at one moment in time, which does not account for changes in perception over time. The use of a single research site is another limitation as it reduces diversity in the research population for both parent and nurse participants. Indeed, in this study, only female nurses participated.

Recommendations for Future Research

This is the first study known to have used the 56-item NICU FNI and modified NMI in combination with this study population. Hence, research involving a larger sample size is needed to determine the validity and reliability of these combined tools. In addition, a larger sample may identify a level of statistical significance not detectable in small samples. The use of multiple research centers in different geographical locations, within various organizations and among diverse groups of participants, would also increase the generalizability of the results. Future research should also consider using the combined NICU FNI and modified NMI instrument to assess needs perception over different periods of time during admission. This approach could provide information on how specific interventions or practice changes influence both parents' and nurses' perceptions of needs and the extent to which they are considered to be met. The concurrent measurement of other variables that might influence parental needs such as the presence of cognitive disturbances related to stress, anxiety, depression, post-

traumatic stress, and other forms of mood disorders, gender, age, and socioeconomic status could further be investigated while administering the combined NICU FNI and modified NMI to provide more data on the reliability and validity of the instrument.

Summary and Conclusion

This study provides preliminary information on the relationship between objective measures of illness severity in premature infants born before 32 weeks gestation, perceived parental needs, and the needs viewed as met. It reveals that factors unrelated to the infant's illness severity affect parents' perceptions of their needs. The findings also highlight differences in parents' and nurses' perceptions of parental needs and show that parents require ongoing assurance about their infant's outcome and care. These results provide nurses and other healthcare providers with insight into areas of care where parents require additional support and interventions to meet their needs. Knowing the needs of parents is an essential step to understanding how to respond to those needs. Collaborating with individual parents to identify their specific needs and tailoring interventions to support their needs would thus be the optimal approach to practicing FCC.

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Appendix A

Summary: Parental needs, difference in needs perception and illness severity articles

Author, year and country	Study design, sampling strategy, methodology, use of theory	Participants	Constructs measured/described, instrument used	Reliability and validity	Strength(s)
NICU Parents' Needs					
Arockiasamy et al., (2008), Canada	Qualitative Purposive sampling Audiotaped, semi-structured interview by physician	*n* = 16 fathers	Explore the experiences of fathers in the NICU with very ill infants and/or preterm infants and their need for support 6 interview questions related to the research focus	3 researchers handed coded the transcripts using constant comparative analysis	Provides evidence on the unique aspects of fathers' experience in the NICU
Bialoskurski, et al., (2002), UK	Quantitative, self-report Survey Convenience sample	*n* = 209 mothers Preterm and very ill infants; no other descriptors reported	Investigate the nature of mother's needs, how needs are distinguished and prioritized Critical Care Maternal Needs Inventory, 39 items, which was modified and renamed from the Critical Care Family Needs Inventory	Content validity established with 4 in-depth interview Revised instrument pilot tested twice, *n* = 10 mothers and *n* = 20 mothers Cronbach α = 0.86	Provides insight into the priorities of NICU mothers' as it relates to their needs and well-being, and the infant's health

Corliss (1995), USA	Exploratory, descriptive Stress theory (Miles & Carter, 1983)	*n* = 53 parents *n* = 29 neonates Mean gestational age = 33 weeks	Identify parental needs during admission to the neonatal intensive care Modified version on the Critical Care Family Needs Inventory (CCFNI)	Cronbach α = 0.90	Provides evidence on the impact of increased age on parental needs in the NICU Compares mothers' and fathers; perception of their needs during their infant's admission to the NICU
De Rouck & Leys (2009), Belgium	Literature review	78 articles	Review the information needs and communication needs of parents in the NICU; and parents sources of information in relation to the infants illness trajectory	No applicable	Synthesized scientific knowledge on the information needs of parents in the NICU Reviewed parents' information needs across the infants' health trajectory i.e. from the pre-admission to downward/death phase Highlights gap in research on intervention strategies to manage information and communication needs

Lindberg et al., (2007), Sweden	Qualitative Narrative interview Thematic analysis	*n* = 8 fathers Infants' gestational age = 25 to 34 weeks	Describe fathers experience with having an infant in the NICU	Authors read and judge sections of the transcripts independently for credibility	Provides fathers' perspective on their need for support and to be understood while their infant is admitted to in the NICU
Mundy, (2010), USA	Descriptive correlation design Convenience sample Survey interview, 5-30 minutes	*n* = 60 parents (*n* = 43 mothers; *n* = 17 fathers) # of infants not reported Infants' gestational age = 24 to 40 weeks	Evaluated parental needs related to information, proximity, assurance, comfort and support. Neonatal Intensive Care Unit Family Needs Inventory, 56 items	Cronbach α = 0.94	Provides evidence on the needs of parents in the NICU
Obeisat & Hweidi, (2014), Jordan	Descriptive correlational design Convenience sample Survey interview, 20-30 minutes; interpreter for one interview	*n* = 170 parents (*n* = 89 fathers and 81 mothers) *n* = 170 infants (50 percent female) Infants' gestational age = 27 to 40 weeks	Evaluated parental needs related to information, proximity, assurance, comfort and support. NICU Family Needs Inventory, 56 items	Cronbach α = 0.90 Cronbach α = 0.83 (reworded version as per 6 parent feedback, post translation)	Sample size, *n* = 170 Eighty-nine fathers participated which represents 52% of the parent sample Provides information on the reliability of the instrument in a non-Western culture

Orfali & Gordon (2004), France & USA	Theoretical approach Comparative ethnographic	*n* = 75 mothers	Comparison of parental experience, preference and choice with neonatal care units in the context of French and American culture	Not Applicable	Provides cross-cultural perspective (France vs. USA) on parents experience with decision-making and coping in the NICU
Sargent, (2009), USA	Descriptive study Survey	*n* = 46 mothers *n* = 46 infants Infants gestational age = 26 to 40 weeks	Assessed hierarchy of maternal needs and determined the effects ethnicity, income, length of stay and infant weight on needs. Modified version of the NICU Family Needs Inventory, 56 items	Cronbach α = 0.61 to 0.87 (for subscales)	Provides information on the impact of socioeconomic resources such as annual household income on maternal support needs Investigates the relationship between the infants' length of hospitalization and mothers' information needs
Ward, (2001), USA	Descriptive study Convenience sample	*n* = 52 parents (*n* = 42 mother; *n* = 10 fathers) *n* = 52 infants Infants gestational age = 28 to 41 weeks	Identify the perceived need of parents by evaluating parental needs related to information, proximity, assurance, comfort and support NICU Family Needs Inventory, 56 items modified from Critical Care Family Needs Inventory	Instrument reviewed by 6 NICU nurses Cronbach α = 0.91	Mothers' and fathers' perception of their needs were compared

Differences in Perceived Needs					
Harvey et al., (2013), UK	Exploratory qualitative Grounded theory Semi-structured interviews	*n* = 18 parents (*n* = 13 mothers & *n* = 5 fathers) *n* = 15 infants (*n* = 7 females & *n* = 8 males) Infants gestational age = 23^{+2} to 32^{+3} weeks	Explore the information and communication needs and experiences of parents in relation to brain imaging, neurological prognosis	Rigour = trustworthiness One team member led analysis- increases internal consistency Team agreed upon final coding and themes	Provides insight in parents' perspective on their information needs and communication with different members of the healthcare team Highlights parents' need for involvement in all aspect of decision-making in relation to their infants' care and on-going dialogue medical professionals
Kleinpell & Power (1992), USA	Family Systems Theory	*n* = 64 family members *n* = 40 patients *n* = 58 nurses	Compare family members' and nurses' perception of the patient's illness and the reported needs of the family; determine family members level of satisfaction with how needs were met; determine the needs of families Critical Care Family Needs Inventory, 45 items APACHE II severity of disease classification	Cronbach α = 0.95 (adapted satisfaction version of the CCFNI) Cronbach α = 0.93 (CCFNI)	Provides a comparison of how family members' and nurses' view needs as important and the level of reported satisfaction with the needs been met.

			Satisfaction Survey (Not specified)		
Latour et al., (2011), Netherlands	Two-round Delphi Empiric survey	*n* = 218 nurses *n* = 46 physicians *n* = 559 parents	To determine difference in practice perception between caregivers and medical staff Questionnaire assessing satisfaction with care, 74 items	Cronbach's α = 0.74 and 0.94 (6 subscales)	Research design Provides insight on parents' and medical professionals' perspective on satisfaction with care
Perlman et al., (1991), Canada	Mixed methods Neonatologists -parent conference (audiotaped) Neonatologists questionnaire Investigator parent-interview (audiotaped)	*n* = 61 parents *n* = 43 neonates *n* = 3 physicians	Analysis and description of information content that is recalled by parents, in comparison to the information that was provided by the neonatologists		Provides insight into parents' information needs, their ability to remember and interpret the information that was communicated during the acute phase of their infants' NICU admission
Maxwell et al., (2007), USA	Descriptive, exploratory design Self-reported surveys	*n* = 20 family members *n* = 30 critical care nurses	Compare difference in nurses' and family members' perception of the needs importance and to identify the needs that were met in an adult intensive care unit	Cronbach α = 0.93 (NMI)	Provides information on how family members' and nurses' view needs and extent to which the identified needs were deemed as met.

			Norris and Grove 30-item version of the Critical Care Family Needs Inventory Warren's Needs Met Inventory (NMI), 30 items		
Scott (1998), USA	Descriptive, comparative Non-probability convenience sampling Crisis Theory King's Conceptual Framework for Nurses	*n* = 11 parents or primary caregivers (female) *n* = 17 nurses	Identify and compare the needs of parents, as perceived by parents and nurses in the pediatric intensive care unit Critical Care Needs Inventory modified for the study population, 53 items	Cronbach α = 0.94 (primary caregivers) Cronbach α = 0.93 (nurses)	Differences in perception amongst mothers' and nurses' on maternal needs in investigated.
Illness Severity					
Brooks et al., (2012), New Zealand	Quantitative Consecutive enrolment on admission Semi-structured interviews	*n* = mothers and clinicians of 99 infants	Investigate the relationship mothers' point of view on their infants' illness and objective measures of illness severity Understand the difference between mothers' and clinicians' perception of the infants' illness	Good validity as per the researchers Good test-retest reliability (No value was reported) Good psychometric properties with reliable and valid measures in the	Provides insight on the differences amongst parents' and clinicians' perspectives on health status Study information was obtained between 3 to 5 days after admission

	Leventhal common sense model		Understand the relationship between mothers' perception of the infants' illness and report levels of stress Clinical Risk Index for Babies-II, 6 variables Brief Illness Perception Questionnaire, 9 items Perceived Stress Scale, 10 items	NICU parents population	
de Wit et al., (2013), USA	Prospective Interview Surveys	*n* = 106 mothers *n* = 106 infants *n* = 73 clinicians	Assess mother and clinician perception on the communication related to the infant's health diagnosis, treatment and illness severity. Determine the clinician's views on maternal understanding of their engagement. 12 item, open-ended survey adapted from a previous study	Transcripts coded independently by two researchers	Maternal sample, *n* = 106 A diverse group of healthcare providers were interviewed which included nurses, physicians, nurse practitioners and respiratory therapists
Mackley et al., (2010), USA	Prospective convenience sample	*n* = 35 fathers	Evaluate paternal stress and depressive symptoms	Reliability of the instruments were establish in previous research	Provides evidence about the stress level of fathers in the NICU

	Self-report questionnaires Interview	Mean gestational age = $27^{+/-1}$ week	Center for Epidemiological Studies- Depression Scale, 20 items Parent Stressor Scale: Infant Hospitalization, 22 items Score for Neonatal Physiology (SNAP)		and their increased rate of depression
Zelkowitz et al., (2009), Canada	Self-reporting survey Videotaped mother-infant interactions	*n* = 56 mothers Mean gestational age = 28^{+5} weeks	Evaluated maternal anxiety and infant interaction State-trait anxiety inventory , 40-items Nursery Neurobiological Risk Score, 7 items Emotional Availability Scales (EAS), 6 subscales	33% of the videos were rated by coders using the EAS	Provides evidence on the association between the severity of the infants' illness and maternal anxiety

Appendix B

Instrument use permission: Neonatal Intensive Care Unit Family Needs Inventory

from: **kelley ward** <[redacted]>

to: Kadeen Briscoe <[redacted]>

date: Mon, Aug 4, 2014 at 9:22 AM

subject: RE: Requesting Permission to use the NICU Family Needs Inventory

Hi Kadeen,

You have my permission to modify/adapt the NICU Family Needs Inventory for your research. There is no cost associated with using my inventory. Best wishes in your endeavor.

Kelley Ward, PhD, RN, C

Date: Sun, 3 Aug 2014 21:47:41 -0400
Subject: Requesting Permission to use the NICU Family Needs Inventory
From: [redacted]
To: [redacted]

Hello Ms. Ward,

My name is Kadeen Briscoe and I am a graduate student pursing a master of science in nursing at York University in Toronto, Canada. As part of my studies, I will be engaging in research to assess the Information needs of parents in the neonatal intensive care (NICU). I will also be studying if parents' needs are been met at different points during the infant's admission to the NICU.

I am sending this e-mail to ask your permission to use the NICU Family Needs Inventory (Kelley Ward, 2001) which, was adapted from the Critical Care Needs Inventory, originally developed by Dr. Nancy Molter and Dr. Jane Leske (1983, 1991). Can I please have your permission to use your inventory in my research?

If yes, is there a fee associated with using the tools? If so, how much does it cost?

Can you please guide me to where I may locate the scoring tool and a copy of the inventory?

Thank you for taking the time to review my e-mail and considering my request.

Have a great day,

Kadeen

Appendix C

Instrument use permission: Neonatal Intensive Care Unit Family Needs Inventory

from: **Jane B Leske** <[redacted]>

to: Kadeen Briscoe <[redacted]>

date: Mon, Aug 4, 2014 at 8:52 AM

subject: RE: Requesting Permission to use Inventory

Here is the information you need-there is no cost to the tool use.

Dear Researcher,

Please find enclosed a copy of the *Critical Care Family Needs Inventory*. You have my permission to use and/or translate the tool to meet your research needs as long as credit is referenced in your work. The psychometric properties of the instrument are published in Leske, J.S. (1991). Internal psychometric properties of the Critical Care Family Needs Inventory, Heart & Lung, 20, 236-244. Please do not hesitate to contact me if you have any questions. Best wishes for a successful research project.

Sincerely,
Jane S. Leske PhD, RN, ACNS-BC
Professor
[redacted]

Hello Dr. Leske,

My name is Kadeen Briscoe and I am a graduate student pursing a master of science in nursing at York University in Toronto, Canada. As part of my studies, I will be engaging in research to assess the Information needs of parents in the neonatal intensive care (NICU). I will also be studying if parents' needs are been met during different points in the infant's admission to the NICU.

I am sending this e-mail to ask your permission to use the Neonatal Family Needs Inventory (Kelley Ward, 2001) and the Needs Met Inventory (Norris & Grove, 1986), which were derived from the Critical Care Needs Inventory (1983, 1991) that you and Dr. Nancy Molter had developed. Can I please have your permission to use both inventories in my research?
If yes, is there a fee associated with using the tools? If so, how much does it cost?
Can you please guide me to where I may locate the scoring tools and copies of the inventories?
Thank you for taking the time to review my e-mail and considering my request.
Have a great day,

Kadeen

Appendix D

Instrument use permission: Needs Met Inventory

from: **Nancy Warren** <[redacted]>

to: Kadeen Briscoe <[redacted]>

date: Thu, Aug 7, 2014 at 6:51 PM

subject: RE: Requesting Permission to use the Warren's Needs Met Inventory

Hi Kadeen,
Have attached the Need Met Inventory for you and you may use any way that you wish.
Good luck,
Nancy

from: **Nancy Warren** <[redacted]>

to: Kadeen Briscoe <[redacted]>

date: Wed, Aug 6, 2014 at 11:48 PM

subject: RE: Requesting Permission to use the Warren's Needs Met Inventory

Hello Kadeen,
Thanks for your e-mail. I would be glad to send you a copy of the inventory and it is rated on a Likert Scale with points for scoring. You may have copies of everything that I have and I never charge a fee. I will send when in the office next week.
Also, many students have used the inventory and have sent their thesis to me to prepare in article format and to publish their work. Of course, I always puts the students name as first author. If you are interested in this, just let me know. I have published about 10 students now.
I have traveled a lot in Canada and think it is beautiful. Even learned enough French to get around in Quebec! Spent a lot of time at the University of New Brunswick, St. John.
Best,
Dr. Warren
Cell: [redacted] - may call at any hour

Hello Dr. Warren
My name is Kadeen Briscoe and I am a graduate student pursing a master of science in nursing at York University in Toronto, Canada. As part of my studies, I will be engaging in research to assess the Information needs of parents in the neonatal intensive care (NICU). I will also be studying if parents' needs are been met at different points during the infant's admission to the NICU.
I am sending this e-mail to ask your permission to use the Warren's Needs Met Inventory which was adapted from the Critical Care Needs Inventory, originally developed by Dr. Nancy Molter and Dr. Jane Leske (1983, 1991). Can I please have your permission to use your inventory in my research?
If yes, is there a fee associated with using the tools? If so, how much does it cost?
Can you please guide me to where I may locate the scoring tool and a copy of the inventory?
Thank you for taking the time to review my e-mail and considering my request.
Have a great day,
Kadeen

Appendix E

Infants' Clinical Information Sheet

Date of data collection: _____

Admission date: _____

Admission time: _____

Gender: Male Female

Birth location: In-born Transferred

Gestational age at birth: _____

Birth weight: _____

Singleton status: Single Twin Triplet

Number of hours or days in the NICU: _____

Admission diagnosis:

_____

_____

_____

Ventilation Status: Room Air CPAP Ventilator

Lowest mean blood pressure**:** _____

Lowest mean temperature: _____

PO2 (mmHg)/FIO2 (%): _____

Lowest serum pH: _____

Urine output: _____

Multiple seizures: Yes No

Apgar scores at: 1 minute _____ 5 minutes _____

Appendix F

Instrument use permission: Score for Neonatal Physiology, Version II (SNAP-II)

Hello Kadeen.

Thank you for your interest in SNAP. The consortium of hospitals that previously managed permission for use of the instrument are no longer doing so, so there is no formal process in place. You may go ahead and use the instrument for your work. Let me know if you need any Information. Shoo Lee at U of T (Chief of neonatology at Mt Sinai) was one of the original authors and might also be a resource.

Best of luck with your study.

John Zupancic

[redacted]

Hello Dr Zupanic,

My name is Kadeen Briscoe and I am a graduate student in nursing at York University in Toronto, Canada. As part of my studies, I will be engaging in research to assess parents and nurses perceptions of needs met during the initial hospitalization period and noting if there is any association with illness severity.

I am sending this e-mail to request your guidance as to where I can obtain permission to use the SNAP-II tool to collect objective measure of illness severity.

Who should I contact to obtain permission to use the SNAP II tool in my research?

Thank you for taking the time to review my e-mail and considering my request.

Have a great day.

Kadeen

Appendix G

Study Notice for Parents

Hello, my name is Kadeen Briscoe. I am a registered nurse and have practiced in the neonatal intensive care (NICU) for five years. Currently, I am a graduate student at York University and I am working on a research study that explores the perceived needs of parents in the NICU. I am seeking your participation in the study.

Would you be interesting in learning more about the study?

Yes ☐ No ☐

If you answer 'yes' to the above question. What is the best time and/or days to visit you on in the NICU?

_____

_____

_____

_____

Please leave the notice on the board with your response and I will pick it up during the next visit. Thank you for taking the time to consider this request.

Appendix H

Recruitment Script for Parent Participants

Hello, my name is Kadeen Briscoe. I am a registered nurse and have practiced in the neonatal intensive care for five years. Currently, I am a graduate student at York University and I am working on a research study that explores the perceived needs of parents in the NICU. I am seeking your participation in the study.

Would you be interesting in learning more about the study? This study is not a part of the treatment or care that you and your baby will receive while in the NICU. I have approached you because you and your baby are admitted to the NICU, and I would like to gain your input on the types of needs that you have and how you view them as been met. Again, the research is not included in the care that you and your baby will receive, and you can decide not to participate and decline to hear any more about the study; this will not affect the care that you and your baby receive while in the NICU.

In this study, I would like to recruit 40 parents to participate by filling out three questionnaires once while in the NICU. The questionnaires on the needs you may have while your baby is in the NICU will take approximately 30 minutes to complete. You can decide not to participate at any point. The responses and Information that you provide will be kept confidential.

Do have any questions about this study?

Are you interested in participating? If yes, the consent form will be reviewed. In the event a parent is not interested, the parent will be thanked for the time taken to talk about the study and asked whether he/she would be willing to provide a reason for his/her non-participation.

Would you like some time to decide whether you would like to participate?

Appendix I

INFORMED CONSENT TO PARTICIPATE IN A RESEARCH STUDY - PARENTS

Study Title: Parental Needs Rating by Parents and Nurses: Association with Illness Severity

Principal Investigator: Marion DeLand PCM, RNC-NIC, MN, Sunnybrook Health Sciences Centre, [redacted]

Co-Investigators: Kadeen Briscoe, RN, MScN (candidate), York University, Toronto, ON, [redacted]

Dr. Mina Singh, RN, PhD, Associate Professor, York University, Toronto ON, Tel: [redacted](supervisor)

Dr. Michelle Butt, RN, PhD, Assistant Professor, McMaster University, Hamilton, ON, [redacted]

Dr. Elsabeth Jensen, RN, BA, PhD, Associate Professor, York University, Toronto, ON, Tel: [redacted]

Dr. Tsrong-Yeh Lee, RN, PhD, Associate Professor, York University, Toronto, ON, Tel: [redacted]

INTRODUCTION

You are being asked to consider participating in a study. A research study is a way of gathering Information in order to provide answers about concerns, procedures and treatments that are not well understood.

This form explains the purpose of this research study, provides Information about the possible risks and benefits, and outlines your rights as a participant and the study procedures.

Please read the form carefully and ask any questions that you have. Participation in this study is voluntary and will not affect the care that you and your infant receive. Please make sure all your questions are answered to your satisfaction before deciding whether or not to participate in this research study. If time permits, please feel free to discuss the study with your family and friends. You have the right to withdraw from the study at any time, and this will not impact the care you and your baby receive while being treated by the neonatal intensive care.

WHAT IS THE STUDY ABOUT AND WHY IS IT BEING CONDUCTED?

You are being asked to participate in a study about the needs and perception of parents in the neonatal intensive care with an infant born before 32 weeks gestation. The study will ask parents and nurses to rate several needs statements in terms of importance and to identify how well those needs are met.

The preterm birth of an infant is known to cause stress and anxiety in parents. We also know that parents are the infant's main source of constant Support and primary advocate, so parental needs must be met adequately in order to promote the health and well-being of the family. By understanding the needs of parents and the extent to which those needs are being met, effective suggestions on how to provide care that meets the needs of parents can be made.

WHAT WILL HAPPEN DURING THE STUDY?
If you choose to participate in the study, you will be asked to complete three questionnaires once during the initial 10 days after your infant is admitted to the neonatal intensive care. The researcher will review your baby's medical chart to gather Information about your baby's medical history.

HOW MANY PEOPLE WILL TAKE PART IN THE STUDY?
A total of 80 participants will be recruited: 40 parents of infants born before 32 weeks completed gestation and 40 nurses will be asked to participate.

WHAT ARE THE RISKS OR HARMS OF PARTICIPATING IN THIS STUDY?
There are no risks associated with taking part in this study for you or the baby. You might feel the questionnaires take some time to complete and you may not wish to answer some of the questions. You have the right not to answer any questions or take part in the study.

WHAT ARE THE BENEFITS OF PARTICIPATING IN THIS STUDY?
You and the baby will not benefit directly from participating in this study. The researcher hopes to gain a better understanding of the needs of parents and the relationship between those needs and their infants' health. The results may help healthcare professionals tailor their care to ensure the needs of parents are being met. The results of the study can be made available to you upon request.

WHAT ARE THE COSTS OF PARTICIPATING IN THIS STUDY?
There is no cost associated with participating in this study. You will be required to take a total of 30 minutes to complete the surveys once during the study timeframe.

ARE STUDY PARTICIPANTS PAID TO PARTICIPATE IN THIS STUDY?
You will not be paid to participate in this study.

DO THE INVESTIGATORS HAVE ANY CONFLICT OF INTEREST?
The research team has no direct interest in the outcome of this study.

WHAT ARE THE RIGHTS OF PARTICIPANTS IN A RESEARCH STUDY?
The rights of all research participants are as follows:

1. As a participant in this study, you have the right to have all the study Information explained and provided in a format that you understand.

2. It is your choice to participate in this study, as your participation is voluntary. You have the right not to participate and to stop participating in the study at any time without having to provide a reason. Your decision to stop participating in the study will not affect the care that your baby will receive.

3. You have the right to receive all study Information that may help you decide whether you would like to participate in this study. It is your right to ask questions about the study, your rights as a participant, and to have all your questions answered to your satisfaction before you make any decision. You also have the right to ask questions throughout the study and review the answers that are provided to you. If you have any questions about this study, you may contact the person in charge of this study, Kadeen Briscoe (Principal Investigator), York University [redacted]. If you have questions about your rights as a research participant or any ethical issues related to this study that you wish to discuss with someone not directly involved with the study, you may call Alison Collins-Mrakas, Senior Manager & Policy Advisor, Office of Research Ethics, York University, [redacted] and/or Dr. Brian Murray, Chair of the Sunnybrook Research Ethics Board at [redacted].

4. You have the right to have all Information that is collected, used and disclosed about you and your baby handled in confidential manner.

If you decide to participate in this study, the investigator(s) will look at your baby's personal health Information and collect only the Information needed to fulfill the purposes of this study. Personal health Information is Information that is specific to your baby including the birth weight, temperature, gender, medical diagnosis, gestational age, blood pressure, seizure, urine output, blood pH, ventilation status, and Apgar score.

The following individuals may come to the hospital to look at your baby's records to ensure that the Information collected for this study is correct and that the study follows the required research guidelines and laws. These individuals are: representatives of the Human Participations Review Committee, York University; the Sunnybrook Research Ethics Board, a group of individuals who oversee research that is conducted at Sunnybrook; and members of the York University community.

Members of the research team, including:

- Dr. Mina Singh, RN, PhD, Associate Professor, York University, Toronto ON, Tel: [redacted]
- Dr. Michelle Butt, RN, PhD, Assistant Professor, McMaster University, Hamilton, ON, [redacted]
- Dr. Elsabeth Jensen RN, BA, PhD, School of Nursing, York University, Toronto, ON, [redacted]
- Dr. Tsorng-Yeh Lee RN, PhD, School of Nursing, York University, Toronto, ON, [redacted]

Your baby's personal health Information will be accessed by the Principal Investigator, Kadeen Briscoe, RN, MScN (candidate), York University, Toronto, [redacted].

The investigators and other individuals mentioned in this document will keep the Information they receive about you confidential, to the extent permitted by law. This risk of identifying you and your baby from the study data is very small, but it can never be completely eliminated.

No identifying Information about you or your baby will be disclosed when the study is published.

The Principal Investigator will keep any personal Information about you in a secure and confidential location for five years and then destroy said Information, as required by Sunnybrook and York University policy.

5. You do not give up your rights by signing this consent form.

6. You have the right to receive a signed copy of the consent form before participating in this study.

7. You have the right to be informed of any new Information that might affect your decision to participate in this study, including Information on the risks and benefits of being a participant in this study.

8. You have the right to access, review and request changes to your personal Information.

9. You have the right to be informed about the results of this study upon the entire study's completion. If you would like to be informed of the results of this study, please contact Kadeen Briscoe, York University, [redacted].

Appendix J

DOCUMENTATION OF INFORMED CONSENT – PARENTS

Full Study Title: Parental Needs Ratings by Parents and Nurses: Association with Illness Severity

Identification Code of Parent: _____

Participant

By signing this form, I confirm that:

- This research study had been fully explained to me and all my questions were answered to my satisfaction.
- I understand the requirements for participating in this research study.
- I have been informed of the risks and benefits, if any, of participating in this research study.
- I have been informed of the alternative to not participating in this study.
- I have been informed of the rights of all research participants.
- I have read each page in this form.
- I authorize access to my infant's medical records and research study data, as explained in this form.
- I have agreed that my baby and I will participate in this study.

Name of Participant/Substitute Decision-Maker (print)	Signature	Date

Person obtaining consent

By signing this form, I confirm that:

- This study and its purpose have been explained to the participant above.
- All questions asked by the participant have been answered.
- I will give a copy of this signed and dated document to the participant.

Name of Person Obtaining Consent (print)	Signature	Date

Statement of Investigator

I acknowledge my responsibility for the care and well-being of the above participant, and I agree to respect the rights and wishes of the participant, as described in this informed consent document, and to conduct this study according to all applicable laws, regulations and guidelines relating to the ethical and legal conduct of research.

Name of Investigator (print)	Signature	Date

ASSISTANCE DECLARATION □ (check here if not applicable)

The participant/substitute decision-maker was assisted during the consent process as follows:

□ The consent form was read to the participant/substitute decision-maker, and the person signing below attests that the study was accurately explained to, and apparently understood by, the participant/substitute decision-maker.

□ The person signing below acted as a translator for the participant/substitute decision-maker during the consent process. He/she attests that he/she has accurately translated the Information for the participant/substitute decision-maker and believes that the participant/substitute decision-maker has understood the Information translated.

Name of Person Assisting (print)	Signature	Date

Appendix K

NICU FAMILY NEEDS INVENTORY & NEEDS MET INVENTORY© - PARENTS

Hello, we are interested in learning about your opinion on the needs of parents in the NICU and how well those needs are met. This questionnaire will take approximately 30 minutes of your time. There are no right or wrong answers and your response will be kept confidential. If you choose not to answer this questionnaire please return it in the envelope provided.

Please circle how **IMPORTANT** each of the following needs is to you.	Please circle how **WELL** each need is being met.

Needs Importance					**Needs Met**			
Not Important	**Slightly Important**	**Important**	**Very Important**	**Statement**	**Never Met**	**Sometimes**	**Usually Met**	**Always Met**
1	2	3	4	To know the expected outcome for my infant.	1	2	3	4
1	2	3	4	To receive a description of the environment before entering the neonatal intensive care unit (NICU) for the first time.	1	2	3	4
1	2	3	4	To be able to visit my infant at any time.	1	2	3	4
1	2	3	4	To talk to the doctor caring for my infant every day.	1	2	3	4
1	2	3	4	To have questions about my infant answered honestly.	1	2	3	4
1	2	3	4	To feel hope about my baby's outcome.	1	2	3	4
1	2	3	4	To have friends/family nearby for Support.	1	2	3	4
1	2	3	4	To have a waiting room for the neonatal unit.	1	2	3	4
1	2	3	4	To have someone to help with transportation.	1	2	3	4
1	2	3	4	To be given directions about how I can provide care to my infant in the NICU.	1	2	3	4
1	2	3	4	To know which staff members could give me Information about my infant's health and general well-being.	1	2	3	4

1	2	3	4	To share my feelings about what is happening.	1	2	3	4
1	2	3	4	To have a specific staff person to call at the hospital when I am unable to visit.	1	2	3	4
1	2	3	4	To be assured that the best care possible is being given to my infant.	1	2	3	4
1	2	3	4	To have a Support group of other families available.	1	2	3	4
1	2	3	4	To have classes about premature infants and their special care needs.	1	2	3	4
1	2	3	4	To have a private place to breastfeed or use a breast pump.	1	2	3	4
1	2	3	4	To help make decisions about my infant's plan of care.	1	2	3	4
1	2	3	4	To have another person with me when visiting the NICU.	1	2	3	4
1	2	3	4	To know exactly what is being done for my infant.	1	2	3	4
1	2	3	4	To have Comfortable furniture in the waiting room.	1	2	3	4
1	2	3	4	To have a pastor, member clergy, or other person from my church visit.	1	2	3	4
1	2	3	4	To be assured that I am permitted to leave the hospital for a period of time.	1	2	3	4
1	2	3	4	To have a telephone near the waiting room.	1	2	3	4
1	2	3	4	To feel accepted by the hospital staff.	1	2	3	4
1	2	3	4	To feel that it is acceptable to cry.	1	2	3	4
1	2	3	4	To be given Information about individuals that could help with problems concerning my situation.	1	2	3	4
1	2	3	4	To have someone show concern for my health.	1	2	3	4
1	2	3	4	To talk to the same nurse most of the time.	1	2	3	4
1	2	3	4	To have a bathroom near the waiting room.	1	2	3	4
1	2	3	4	To talk about the possibility of my infant's death.	1	2	3	4
1	2	3	4	To have Comfortable chairs at my infant's bedside.	1	2	3	4

1	2	3	4	To be given reading material concerning my infant's medical needs.	1	2	3	4
1	2	3	4	To receive understandable explanations.	1	2	3	4
1	2	3	4	To feel that the hospital personnel care about my infant.	1	2	3	4
1	2	3	4	To be allowed to help with my infant's physical care.	1	2	3	4
1	2	3	4	To be told about transfer plans while they are being made.	1	2	3	4
1	2	3	4	To receive Information about my infant at least once a day.	1	2	3	4
1	2	3	4	To see my infant frequently.	1	2	3	4
1	2	3	4	To know specific facts concerning my infant's progress.	1	2	3	4
1	2	3	4	To have the waiting room near the NICU.	1	2	3	4
1	2	3	4	To be recognized as important to my infant's recovery.	1	2	3	4
1	2	3	4	To receive help in responding to the reactions of my infant's siblings.	1	2	3	4
1	2	3	4	To be able to talk to other parents whose infant is in the NICU or who have experienced a similar situation.	1	2	3	4
1	2	3	4	To be allowed to have my infant's siblings visit the infant in the NICU.	1	2	3	4
1	2	3	4	To feel free to choose to stay or leave when my infant is experiencing painful procedures.	1	2	3	4
1	2	3	4	To have a place to sleep near the neonatal intensive care unit.	1	2	3	4
1	2	3	4	To know why my infant is undergoing certain procedures.	1	2	3	4
1	2	3	4	To be called at home about important changes in my infant's condition.	1	2	3	4
1	2	3	4	To know that my infant is being treated for pain.	1	2	3	4
1	2	3	4	To have a place to be alone while in the hospital.	1	2	3	4
1	2	3	4	To know that my infant is being handled gently by healthcare providers.	1	2	3	4
1	2	3	4	To know how my infant is being treated medically.	1	2	3	4

1	2	3	4	To have the neonatal unit quiet and lights dimmed at regular times to let my infant rest.	1	2	3	4
1	2	3	4	To hold my infant in my arms and against my skin as soon as I can.	1	2	3	4
1	2	3	4	To see that the NICU staff provide Comfort to my infant, such as giving my infant a pacifier, using blankets to Support my infant's body, and talking softly to my infant.	1	2	3	4
1	2	3	4	Other:	1	2	3	4

Thank you for taking the time to participate in this study.

Appendix L

Parents' Demographic Information

Please circle or fill in the following Information:

1. Person answering this questionnaire is the:
    - Father
    - Mother
    - Other, please specify: _____

2. How old are you? _____

3. What level of education have you completed?
    - None
    - Grade School
    - Some High School
    - High School
    - Some College
    - College
    - Trade or Technical School
    - Some University
    - University
    - Post Graduate

4. What is your employment status?
    - Homemaker
    - Self-Employed
    - Employed Full-Time
    - Employed Part-Time
    - Unemployed
    - Parental Leave
    - Student

5. What is your primary language?
    - English
    - French
    - Other: (Please Specify)_____

6. What is your marital/family status?
    - Single, Never Married
    - Married
    - Separated
    - Divorced
    - Widowed
    - Living with Partner/ Common-Law

7. How would you describe yourself?
    - Aboriginal
    - African American/Black
    - Asian
    - White/Caucasian
    - Other: (Please Specify) _____

8. Is this your first baby?
    - Yes
    - No

9. Have you ever had a baby in a Neonatal Intensive Care Unit (NICU) before?
   Yes No

10. What is the gender (sex) of your baby? Boy_____ Girl_____

11. Did you have an opportunity to tour the unit before your baby's admission?
   Yes No

12. Was your baby born at this hospital? Yes No

13. How would you describe your baby's current health status?

    Unstable Stable Very Stable I do not know

14. What helps to meet your needs as the parent of a baby in the NICU?

    _____

    _____

    _____

    _____

Appendix M

Study Notice for Nurses

Dear Colleagues,

My name is Kadeen Briscoe and I am currently a graduate student that is working on a research project. I am writing this notice in seeking your assistance to participate in this research. The title of my research is, “Parental Needs Rating by Parents and Nurses: Association with Illness Severity.” This research focuses on assessing the perceived needs of parents with preterm infants born before 32 weeks gestation during the first 10 days of admission, from both the nurses’ and parents’ point-of-view.

Over the upcoming few weeks, I will be visiting the unit to conduct a series pop-up sessions to talk about the project including why you should and how you can get involved. Below are a list of scheduled dates that I will be on unit, the visits will be occurring during different shifts and times to accommodate your schedules. If you have any question/comment about this project, please do not hesitate to contact me at [redacted].

I look forward to talking and working with you!

Kadeen Briscoe, RN, BScN, MScN (candidate)

Research Talk Pop-up Session Dates:

Thursday, January 22nd

Friday, January 23rd

Sunday, January, 25th

Monday, January 26th

Tuesday, January 27th

Thursday, January 29th

Saturday, January 31st

Monday, February 2nd

Appendix N

INFORMED CONSENT TO PARTICIPATE IN A RESEARCH STUDY - NURSES

Study Title: Parental Needs Rating by Parents and Nurses: Association with Illness Severity

Principal Investigator: Marion DeLand PCM, RNC-NIC, MN, Sunnybrook Health Sciences Centre, [redacted]

Co-Investigators: Kadeen Briscoe, RN, MScN (candidate), York University, Toronto, ON, [redacted]

Dr. Mina Singh, RN, PhD, Associate Professor, York University, Toronto ON, Tel: [redacted], (supervisor)

Dr. Michelle Butt, RN, PhD, Assistant Professor, McMaster University, Hamilton, ON, [redacted]

Dr. Elsabeth Jensen, RN, BA, PhD, Associate Professor, York University, Toronto, ON, Tel: [redacted]

Dr. Tsrong-Yeh Lee, RN, PhD, Associate Professor, York University, Toronto, ON, Tel: [redacted]

INTRODUCTION

You are being asked to consider participating in a study. A research study is a way of gathering Information in order to provide answers about concerns, procedures and treatments that are not well understood.

This form explains the purpose of this research study, provides Information about the possible risks and benefits, and outlines your rights as a participant and the study procedures.

Please read the form carefully and ask any questions that you have. Participation in this study is voluntary and will not affect your employment at the hospital. Please make sure all your questions are answered to your satisfaction before deciding whether or not to participate in this research study. You have the right to withdraw from the study at any time without providing a reason.

WHAT IS THE STUDY ABOUT AND WHY IS IT BEING CONDUCTED?

You are being asked to participate in a research study investigating nurses' views on the needs of parents in the neonatal intensive care with an infant born before 32 weeks gestation. The study will ask you to rate several needs statements in terms of importance and to identify how well those needs are met.

The preterm birth of an infant is known to cause stress and anxiety in parents. We also know that parents are the infant's main source of constant Support and primary advocate, so parental needs must be met adequately in order to promote the health and well-being of the family. By understanding the needs of parents and the extent to which those needs are being met, effective suggestions on how to provide care that meets the needs of parents can be made.

WHAT WILL HAPPEN DURING THE STUDY?
If you choose to participate in the study, you will be asked to complete three questionnaires for each parent-infant dyad (enrolled in the study) for whom you are caring.

HOW MANY PEOPLE WILL TAKE PART IN THE STUDY?
A total of 80 participants will be recruited: 40 parents of infants born before 32 weeks completed gestation and 40 nurses will be asked to participate.

WHAT ARE THE RISKS OR HARMS OF PARTICIPATING IN THIS STUDY?
There are no risks associated with taking part in this study. You might feel that the questionnaire takes some time to complete and you may not wish to answer some of the questions. You have the right not to answer the questions and take part in the study.

WHAT ARE THE BENEFITS OF PARTICIPATING IN THIS STUDY?
You will not benefit directly from participating in this study. The researcher hopes to gain a better understanding of the needs of parents and their relationship to the infant's illness severity from the nurses' perspective. The results may help healthcare professionals tailor their care to ensure the needs of parents are being met. The results of the study can be made available to you upon request.

WHAT ARE THE COSTS OF PARTICIPATING IN THIS STUDY?
There is no cost associated with participating in this study. You will be required to spend a total of 30 minutes completing the questionnaires.

ARE STUDY PARTICIPANTS PAID TO PARTICIPATE IN THIS STUDY?
You will not be paid to participate in this study.

DOES (DO) THE INVESTIGATORS HAVE ANY CONFLICT OF INTEREST?
The research team has no direct interest in the outcome of this study.

WHAT ARE THE RIGHTS OF PARTICIPANTS IN A RESEARCH STUDY?
The rights of all research participants are as follows:

1. As a participant in this study, you have the right to have all the study Information explained and provided in a format that you understand.

2. It is your choice to participate in this study, as your participation is voluntary. You have the right not to participate and to stop participating in the study at any time without

having to provide a reason. If you decide to stop participating in the study, it will not interfere with your employment.

3. You have the right to receive all study Information that may help you decide whether you would like to participate in this study. It is your right to ask questions about the study, your rights as a participant, and to have all your questions answered to your satisfaction before you make any decision. You also have the right to ask questions throughout the study and to review the answers that are provided. If you have any questions about this study, you may contact the person in charge of this study, Kadeen Briscoe (Principal Investigator), York University at [redacted]. If you have questions about your rights as a research participant or any ethical issues related to this study that you wish to discuss with someone not directly involved with the study, you may call Alison Collins-Mrakas, Senior Manager & Policy Advisor, Office of Research Ethics, York University, [redacted] and/or Dr. Brian Murray, Chair of the Sunnybrook Research Ethics Board at [redacted].

4. You have the right to have all Information that is collected, used and disclosed about you handled in a confidential manner.

   The following individuals may request the records and contact you to ensure that the Information collected for this study is correct and that the study follows the required research guidelines and laws. These individuals are: representatives of the Human Participations Review Committee, York University; the Sunnybrook Research Ethics Board, a group of individuals who oversee research that is conducted at Sunnybrook; and members of the York University community.

   Members of the research team, including:
   - Dr. Mina Singh, RN, PhD, Associate Professor, York University, Toronto ON, Tel: [redacted]
   - Dr. Michelle Butt, RN, PhD, Assistant Professor, McMaster University, Hamilton, ON, [redacted]
   - Dr. Elsabeth Jensen RN, BA, PhD, School of Nursing, York University, Toronto, ON, [redacted]
   - Dr. Tsorng-Yeh Lee RN, PhD, School of Nursing, York University, Toronto, ON, [redacted]

   The investigators and other individuals mentioned in this document will keep the Information they receive about you confidential, to the extent permitted by law. This risk of identifying you from the study data is very small, but it can never be completely eliminated.

   No identifying Information about you will be disclosed when the study is published.

   The Principal Investigator will keep any personal Information about you in a secure and confidential location for five years and then destroy said Information as required by Sunnybrook and York University policy.

5. You do not give up your right by signing this form.

6. You have the right to receive a signed copy of the consent form before participating in this study.
7. You have the right to be informed of any new Information that might affect your decision to participate in this study, including Information on the risks and benefits of being a participant in this study.

8. You have the right to access, review and request changes to your personal Information.

9. You have the right to be informed about the results of this study upon the entire study's completion. If you would like to be informed of the results of this study, please contact Kadeen Briscoe, York University, [redacted].

Appendix O

DOCUMENTATION OF INFORMED CONSENT – NURSES

Full Study Title: Parental Needs Rating by Parents and Nurses: Association with Illness Severity

Identification Code of Nurse: _____

Participant

By signing this form, I confirm that:

- This research study had been fully explained to me and all my questions were answered to my satisfaction.
- I understand the requirements for participating in this research study.
- I have been informed of the risks and benefits, if any, of participating in this research study.
- I have been informed of the alternative to not participate in this study.
- I have been informed of the rights of all research participants.
- I have read each page in this form.
- I have agreed to participate in this study.

Name of Participant (print)	Signature	Date

Person obtaining consent

By signing this form, I confirm that:

- This study and its purpose have been explained to the participant above.
- All questions asked by the participant have been answered.
- I will give a copy of this signed and dated document to the participant.

Name of Person Obtaining Consent (print)	Signature	Date

Statement of Investigator

I acknowledge my responsibility for the care and well-being of the above participant, and I agree to respect the rights and wishes of the participant as described in this informed consent document, and to conduct this study according to all applicable laws, regulations and guidelines relating to the ethical and legal conduct of research.

Name of Investigator (print)	Signature	Date

ASSISTANCE DECLARATION □ (check here if not applicable)

The participant/substitute decision-maker was assisted during the consent process, as follows:

□ The consent form was read to the participant/substitute decision-maker, and the person signing below attests that the study was accurately explained to, and apparently understood by, the participant/substitute decision-maker.

□ The person signing below acted as a translator for the participant/substitute decision-maker during the consent process. He/she attests that he/she has accurately translated the Information for the participant/substitute decision-maker and believes that the participant/substitute decision-maker has understood the Information translated.

Name of Person Assisting (print)	Signature	Date

Appendix P

Nurses' Demographic Questionnaire

1) Have you participated in this study before by completing the questionnaires while working with another family that was enrolled in the study? (Please Circle)

   Yes No

   a. If you answered "**yes"** to the question above, how many times have you completed the questionnaires, including today?

   1 time 2 times 3 times 4 times Other (specify): _____

2) How many year(s) of experience have you had working in the neonatal intensive care?

   _____

3) What is your gender? (Please circle one) Female Male

4) What is your age? _____

5) What is your ethnicity? _____

6) In your opinion what has being done to help meet the needs of parents?

   _____

   _____

   _____

   _____

   _____

   _____

7) What suggestion(s) do you have for how to meet the needs of NICU parents?

   _____

   _____

   _____

   _____

   _____

Appendix Q

NICU FAMILY NEEDS INVENTORY & NEEDS MET INVENTORY© -NURSES

Hello, we are interested in learning about your opinion on the needs of parents in the NICU and how well those needs are met. This questionnaire will take approximately 30 minutes of your time. There are no right or wrong answers and your response will be kept confidential. If you choose not to answer this questionnaire please return it in the envelope provided.

Nurses, in responding to the questionnaire, please consider how the parent(s) of the infant you are caring for would answer these statements.

Please circle how **IMPORTANT** each of the following needs is to you.	Please circle how **WELL** each need is being met.

Needs Importance					**Needs Met**			
Not Important	**Slightly Important**	**Important**	**Very Important**	**Statement**	**Never Met**	**Sometimes**	**Usually Met**	**Always Met**
1	2	3	4	To know the expected outcome for my infant.	1	2	3	4
1	2	3	4	To receive a description of the environment before entering the neonatal intensive care unit (NICU) for the first time.	1	2	3	4
1	2	3	4	To be able to visit my infant at any time.	1	2	3	4
1	2	3	4	To talk to the doctor caring for my infant every day.	1	2	3	4
1	2	3	4	To have questions about my infant answered honestly.	1	2	3	4
1	2	3	4	To feel hope about my baby's outcome.	1	2	3	4
1	2	3	4	To have friends/family nearby for Support.	1	2	3	4
1	2	3	4	To have a waiting room for the neonatal unit.	1	2	3	4
1	2	3	4	To have someone to help with transportation.	1	2	3	4
1	2	3	4	To be given directions about how I can provide care to my infant in the NICU.	1	2	3	4

1	2	3	4	To know which staff members could give me Information about my infant's health and general well-being.	1	2	3	4
1	2	3	4	To share my feelings about what is happening.	1	2	3	4
1	2	3	4	To have a specific staff person to call at the hospital when I am unable to visit.	1	2	3	4
1	2	3	4	To be assured that the best care possible is being given to my infant.	1	2	3	4
1	2	3	4	To have a Support group of other families available.	1	2	3	4
1	2	3	4	To have classes about premature infants and their special care needs.	1	2	3	4
1	2	3	4	To have a private place to breastfeed or use a breast pump.	1	2	3	4
1	2	3	4	To help make decisions about my infant's plan of care.	1	2	3	4
1	2	3	4	To have another person with me when visiting the NICU.	1	2	3	4
1	2	3	4	To know exactly what is being done for my infant.	1	2	3	4
1	2	3	4	To have Comfortable furniture in the waiting room.	1	2	3	4
1	2	3	4	To have a pastor, member clergy, or other person from my church visit.	1	2	3	4
1	2	3	4	To be assured that I am permitted to leave the hospital for a period of time.	1	2	3	4
1	2	3	4	To have a telephone near the waiting room.	1	2	3	4
1	2	3	4	To feel accepted by the hospital staff.	1	2	3	4
1	2	3	4	To feel that it is acceptable to cry.	1	2	3	4
1	2	3	4	To be given Information about individuals that could help with problems concerning my situation.	1	2	3	4
1	2	3	4	To have someone show concern for my health.	1	2	3	4
1	2	3	4	To talk to the same nurse most of the time.	1	2	3	4
1	2	3	4	To have a bathroom near the waiting room.	1	2	3	4
1	2	3	4	To talk about the possibility of my infant's death.	1	2	3	4

1	2	3	4	To have Comfortable chairs at my infant's bedside.	1	2	3	4
1	2	3	4	To be given reading material concerning my infant's medical needs.	1	2	3	4
1	2	3	4	To receive understandable explanations.	1	2	3	4
1	2	3	4	To feel that the hospital personnel care about my infant.	1	2	3	4
1	2	3	4	To be allowed to help with my infant's physical care.	1	2	3	4
1	2	3	4	To be told about transfer plans while they are being made.	1	2	3	4
1	2	3	4	To receive Information about my infant at least once a day.	1	2	3	4
1	2	3	4	To see my infant frequently.	1	2	3	4
1	2	3	4	To know specific facts concerning my infant's progress.	1	2	3	4
1	2	3	4	To have the waiting room near the NICU.	1	2	3	4
1	2	3	4	To be recognized as important to my infant's recovery.	1	2	3	4
1	2	3	4	To receive help in responding to the reactions of my infant's siblings.	1	2	3	4
1	2	3	4	To be able to talk to other parents whose infant is in the NICU or who have experienced a similar situation.	1	2	3	4
1	2	3	4	To be allowed to have my infant's siblings visit the infant in the NICU.	1	2	3	4
1	2	3	4	To feel free to choose to stay or leave when my infant is experiencing painful procedures.	1	2	3	4
1	2	3	4	To have a place to sleep near the neonatal intensive care unit.	1	2	3	4
1	2	3	4	To know why my infant is undergoing certain procedures.	1	2	3	4
1	2	3	4	To be called at home about important changes in my infant's condition.	1	2	3	4
1	2	3	4	To know that my infant is being treated for pain.	1	2	3	4
1	2	3	4	To have a place to be alone while in the hospital.	1	2	3	4
1	2	3	4	To know that my infant is being handled gently by healthcare providers.	1	2	3	4
1	2	3	4	To know how my infant is being treated medically.	1	2	3	4

1	2	3	4	To have the neonatal unit quiet and lights dimmed at regular times to let my infant rest.	1	2	3	4
1	2	3	4	To hold my infant in my arms and against my skin as soon as I can.	1	2	3	4
1	2	3	4	To see that the NICU staff provide Comfort to my infant, such as giving my infant a pacifier, using blankets to Support my infant's body, and talking softly to my infant.	1	2	3	4
1	2	3	4	Other:	1	2	3	4

Thank you for taking the time to participate in this study.

Appendix R

Study Approval: Neonatal Research Committee

November 12, 2014

Ms Kadeen Briscoe
Neonatal Intensive Care Unit
Sunnybrook Health Sciences Centre

Dear Kadeen

Re: Parental Needs Rating by Parents and Nurses: Association with Illness Severity

Thank you for submitting the revised proposal for the above-named project for review by the Neonatal Research Committee. The members of the committee have taken the opportunity to review your project and the letter outlining the changes made in response to the comments provided.

The committee has reviewed your revised protocol and is satisfied with the changes. We are very pleased to inform you that the committee has approved your project both from a scientific content and feasibility perspective.

We will inform Anna Rogowsky, research coordinator for the Women and Babies Program Research Executive Committee, of the committee's decision in order to facilitate completion of the process prior to submission to the Research Ethics Board.

Once you have received approval from the Research Ethics Board, please notify me as soon as possible so that we can ensure a speedy process of start-up.

Thank you

Elizabeth Asztalos

Elizabeth Asztalos MD FRCPC
Chair
Neonatal Research Committee

Appendix S

Study Approval: York University

YORK
UNIVERSITÉ
UNIVERSITY

Certificate #:	**STU 2015 - 024**
Approval Period:	**03/02/15-03/02/16**

Memo

OFFICE OF RESEARCH ETHICS (ORE)

5th Floor,
Kaneff Tower,
4700 Keele St.
Toronto ON
Canada M3J 1P3
Tel 416 736 5914
Fax 416 650 8197
www.research.yorku.ca

To: Kadeen Briscoe, Nursing - Graduate Program, [redacted]

From: Alison M. Collins-Mrakas, Sr. Manager and Policy Advisor, Research Ethics
(on behalf of Denise Henriques, Chair, Human Participants Review Committee)

Date: **Monday, March 02, 2015**

Re: Ethics Approval

Parental Needs Rating by Parents and Nurses: Association with Illness Severity

---

I am writing to inform you that the Human Participants Review Sub-Committee has reviewed and approved the above project.

Should you have any questions, please feel free to contact me at: [redacted] or via email at: [redacted].

Yours sincerely,

Alison M. Collins-Mrakas M.Sc., LLM
Sr. Manager and Policy Advisor,
Office of Research Ethics

Appendix T

Study Approval: Hospital Research Ethics Board

To: Marion DeLand
Neonatal Intensive Care
Room M4 226

From: Dr. Brian J. Murray

Date: January 8, 2015

Subject: **Parental Needs Rating by Parents and Nurses: Association with Illness Severity**

Project Identification Number: 478-2014
Approval Date: January 8, 2015
Expiry Date: January 8, 2016

The Research Ethics Board of Sunnybrook Health Sciences Centre has conducted a Delegated Board review of the research study referenced above and approved the involvement of human participants. Quorum for approval did not involve a member associated with this study.

The approval of this study includes the following documents:

- Protocol dated January 1, 2015
- Appendix A – Recruitment Script for Nursing Participants dated January 1, 2015
- Appendix B – Recruitment Script for Parent Participants dated January 1, 2015
- Appendix C – Study Notice for Parents dated January 1, 2015
- Appendix H – Parents' Demographic Information dated January 1, 2015
- Appendix I – Nurses' Demographic Questionnaire dated January 1, 2015
- Appendix J – NICU Family Needs Inventory Parents dated January 1, 2015
- Appendix K – NICU Family Needs Inventory Nurses dated January 1, 2015
- Appendix L – Infants' Clinical Information Sheet dated January 1, 2015
- Informed Consent Form for Parents Version 2 dated January 1, 2015
- Informed Consent Form for Nurses Version 2 dated January 1, 2015

As Principal Investigator you are responsible for the ethical conduct of this study which may be subject to review by the Quality Assurance and Education Program. The study must comply with current legislation outlined in the Ontario Personal Health Information Protection Act (PHIPA) and all acts, regulations, guidelines and policies that govern this research. The REB requires immediate notification of internal serious adverse events and significant deviations, submission of a renewal form prior to the approval expiry date, and notification of study closure.

The REB and Research Ethics Office are in support of facilitating the progress of ethical research and thank you in advance for your efforts to protect research participants. Best wishes for a successful project.

Brian J. Murray, MD FRCP(C) D,ABSM
Chair, Research Ethics Board

OR

Philip C. Hébert, MD PhD FCFPC
Vice-Chair, Research Ethics Board

/mh

Appendix U

Data Transfer Agreement

DATA TRANSFER AGREEMENT

This Agreement is made by and among:

Sunnybrook Research Institute ("Disclosing Institution ")

Contact information:

Office of Research Administration
Sunnybrook Research Institute
Room S-130, 2075 Bayview Avenue
Toronto, Ontario M4N 3M5
Phone: (416) 480-5720
Fax Number: (416) 480-5814
Attention: Les Boehm, Director of Research Operations & Business Development

and

Marion DeLand, PCM ("Disclosing Investigator" and, together with Disclosing Institution, "Disclosing Party")
With an address at:
2075 Bayview Avenue, Room: M4 226
Toronto, Ontario, M4N 3M5

and

YORK UNIVERSITY ("Receiving Institution")
With an address at:
4700 Keele Street
Toronto, ON
MPJ 1P3

Attention: Director, Innovation York
4700 Keele Street
Toronto, ON
MPJ 1P3
FAX: 416-736-5512

and

Mina Singh, Professor ("Receiving Investigator" and, together with Receiving Institution, "Receiving Party")
With an address at:
4700 Keele Street
Toronto, ON
MPJ 1P3

with respect to data that the Disclosing Party will provide to the Receiving Party for the study entitled: **Parental Needs Rating by Parents and Nurses: Association with Illness Severity** ("the Study").

This Agreement is made in compliance with section 44(5) of the *Personal Health Information Protection Act*, 2004, S.O. 2004, c. 3 ("PHIPA").

The parties hereby agree as follows:

1. **Definitions**. As used in this Agreement, the term "Data" means all personal information (including without limitation medical data and information and other personal health information) that has been collected for the purpose of the Study at Disclosing Party and is provided to the Receiving Party for the purpose of carryingout the Study;

2. **Compliance**. The Disclosing Institution is a Health Information Custodian ("HIC") under PHIPA. As such, this Agreement contains essential provisions in order for the Disclosing Party to remain compliant with PHIPA. In transferring the Data the parties shall comply with all applicable laws, regulations, guidelines and policies ("Applicable Law"). The Disclosing Party will prepare and furnish the Data in accordance with PHIPA including without limitation obtaining all appropriate consents. The Data will not be collected and/or transferred until the Disclosing Party's research ethics board ("REB") and, if applicable the Receiving Party's REB, have: a) approved the Study protocol; and b) approved the Study informed consent forms or waived the requirement to obtain consent. The Disclosing Party retains the right but not the obligation to conduct audits of Receiving Party's compliance with this Agreement upon reasonable advance written notice to Receiving Party and at mutually acceptable times. If there is a breach of the Agreement by Receiving Party, Disclosing Party may require that all Data be returned promptly to Disclosing Party or destroyed in a secure manner at Disclosing Party's option. The Disclosing Party retains the right, acting on reasonable grounds, to refuse the transfer of the Data requested hereunder.

3. **Use of and Disposal of Data.** The Data is for the Receiving Party to use exclusively for the internal development of Disclosing Party and Receiving Party's Study. No other use is permitted under this agreement. The Data will be returned to the Disclosing Party at the earlier of 30 days following the termination of the Study or once the Study has been completed.

4. **Non-Disclosure of Data**. The Receiving Party shall limit access to the Data only to its internal personnel and/or agents who need access for the purposes herein and who are bound by the same confidentiality obligations herein ("Study Staff"). Without limiting the obligation set out in s. 2, the Receiving Party agrees that it/he/she shall, and shall require its/his/her Study Staff, to:
    a) maintain Data in confidence, and not disclose Data except as permitted by this Agreement;
    b) use Data solely for the purposes of the Study or other expressly consented purposes, in compliance with:
        (i) the Study protocol as approved by the Disclosing Party's REB and as

amended from time to time, provided that amendments are approved by the Disclosing Party's REB (the "Protocol");

(ii) any written conditions imposed by the Disclosing Party's or Receiving Party's REB;

(iii) the Study subject's consent consistent with the informed consent form approved by the Disclosing Party's REB (the "Consent") or, if the requirement to obtain consent has been waived, or otherwise determined to be unnecessary, by the Disclosing Party's REB, the waiver of consent given by the Disclosing Party's REB (the "Waiver");

(iv) any other conditions or restrictions imposed by Disclosing Party relating to the use, security, disclosure, return or disposal of the Data as set out in this Agreement.

c) not use the Data to identify any individuals,

d) not transfer the Data to any third parties without the prior written consent of the Disclosing Party and without obligating such third parties to comply with the terms and conditions hereof. Notwithstanding the forgoing, the Receiving Party may transfer the Data:

(i) to regulatory authorities, provided that the Receiving Party gives prior written notice of such intended disclosure to the Disclosing Party;

(ii) as otherwise permitted by the Consent or Waiver; or

(iii) in order to comply with Applicable Law or judicial process, or with a court or regulatory order, provided that the Receiving Party gives prior written notice of such intended disclosure to the Disclosing Party and takes all lawful actions that are reasonable in the circumstances to minimize the extent of such disclosure and obtain confidential treatment for such disclosure.

e) securely destroy the Data as required by the Protocol or instructed by the Disclosing Party and provide a written confirmation of the manner of destruction in a form acceptable to Disclosing Party.

5. **Safeguards and Notification.** The Receiving Party shall use appropriate safeguards (including without limitation with respect to encrypting identifying numbers, linking files, storing and retrieving files from secured locations) to prevent any unauthorized use or disclosure of the Data and shall promptly report to Disclosing Party any unauthorized use or disclosure of which Receiving Party becomes aware.

6. **Contact with Subjects/Individuals.** If identifying information associated with the Data is disclosed, the Receiving Party shall not make contact or attempt to make contact with an identifiable individual unless the Disclosing Party first obtains the individual's consent to be contacted.

7. **Financial Matters and Intellectual Property.** Except as expressly provided herein, no right, title or interest in and to the Data is granted to the Receiving Party or implied hereunder. The Disclosing Party shall own the Data. All other applicable financial matters, if applicable, are attached as Schedule "D" hereto.

8. **Publication.** Receiving Party shall have the right to use a) the analyzed, de-identified data derived from the use of the Data; and b) information and results arising out of analysis of the Data, as part of a publication or presentation of the results of the Study. The Receiving Party shall not include any personally identifying information in any publication or presentation. Disclosing Party's investigator's contribution to the Study shall be acknowledged appropriately in any such publication or presentation in accordance with academic standards.

9. **Study Documents.** The following Study documents are attached hereto and/or incorporated by reference:

Schedule A – Study Protocol	☒ Attached	☐ Incorporated by Reference
Schedule B – Written Conditions of REB	☐ Not Applicable ☒ Attached ☐ Incorporated by Reference	
Schedule C – Consent or Waiver	☒ Attached ☐ Not Applicable	☐ Incorporated by Reference

10. **Term and Termination.** This Agreement will last until the Study is completed or until a Party terminates this agreement. Termination is effective upon thirty (30) days written notice.

11. **Indemnity and Limitation of Liability.** The Receiving Party assumes all liability for damages which may arise from its use, storage or disposal of the Data. The Disclosing Parties will not be liable for any loss, claim, or demand made by Receiving Parties. The Receiving Party will indemnify, defend and hold harmless the Disclosing Parties from any and all claims, liabilities, damages, costs and expenses, including any litigation arising from the Receiving Parties use of the Data. The Disclosing Parties make no representations and extend no warranties of any kind, either express or implied for merchantability or fitness for a particular purpose, other than those stated in this Agreement.

12. **General Terms and Conditions.** (a) No party shall be entitled to assign or transfer this Agreement or the rights and obligations hereunder to any third party without the prior written approval of the other parties. (b) This Agreement including the attached Schedules represents the entire understanding between or among the parties related to the Study and supersedes all previously or contemporaneously executed agreements related to the Study. (c) This Agreement shall not be amended, modified, varied or supplemented except in writing signed by each of the parties. (d) No failure or delay on the part of any party hereto to exercise any right or remedy under this Agreement shall be construed or operate as a waiver thereof. (e) The parties hereto are independent contractors. Nothing contained herein shall be deemed or construed to create between or among the parties hereto a partnership or joint venture or employment or principal-agent relationship. No party shall have the authority to act on behalf of any other party or to bind another party in any manner. (f) Each party to this Agreement assumes responsibility for its own obligations under this Agreement. (g) No party shall use, or authorize others to use, the name, symbols, or marks of another party hereto or its staff for any endorsement purposes without prior written approval from the party whose name, symbols or marks are to be used. (h) This Agreement shall be governed by and construed in accordance with the laws of the

Province of Ontario and the federal laws of Canada applicable therein. (i) *Counterparts* This Agreement may be executed in any number of counterparts with the same effect as if all parties had signed the same document. All of these counterparts will for all purposes constitute one agreement, binding on the parties, notwithstanding that all parties are not signatories to the same counterpart. A faxed or emailed PDF copy or photocopy of this Agreement executed by a party in counterpart or otherwise will constitute a properly executed, delivered and binding agreement or counterpart of the executing party.

Acknowledged and agreed by:

Disclosing Institution:
SUNNYBROOK RESEARCH INSTITUTE

Name: Michael Julius
Title: Vice President Research
Date: 2.4.15

Name: Rod England
Title: Director, Research Finance
Date: 2/5/15

Disclosing Investigator:
Marian DeLand, PCM

Date: Feb 17/15

Receiving Institution:
YORK UNIVERSITY

Name: Joan Broussard
Title: Director, Research Grants
Date: 29 January 2015

Receiving Investigator:
Mina Singh, Professor

Date: January 31st /2015

REVIEWED BY:

Appendix V

Mothers' and Fathers' Needs Importance Mean Subscales Scores

Needs Importance Variable	Mean	Mean	t-statistics	*p*-value (2-tailed)	*df*
	Mothers *n* = 14	Fathers *n* = 10			
Assurance	3.89	3.78	.840	.410	22
Proximity	3.82	3.71	1.01	.323	22
Information	3.82	3.67	1.21	.241	22
Comfort	3.38	3.37	.084	.933	22
Support	3.34	3.22	.766	.452	22

Notes: * = $p < .05$ (2-tailed)

Appendix W

Mothers' and Fathers' Needs Met Mean Subscales Scores

Needs Met Variable	Mean	Mean	t-statistics	*p*-value (2-tailed)	*df*
	Mothers *n* = 14	Fathers *n* = 10			
Proximity	3.69	3.73	-.290	.774	22
Assurance	3.62	3.68	-.276	.785	22
Information	3.49	3.49	-.021	.984	22
Comfort	3.52	3.41	.624	.539	22
Support	3.16	3.06	.544	.592	22

Appendix X

Parents' Ranking of the Fifteen Highest Met Needs (*n* = 24)

Item #	Needs Met Statement	Mean	SD	Percentage of Parents Response (%)			
				Never Met (1)	Sometimes Met (2)	Usually Met (3)	Always Met (4)
39	To see my infant frequently. ** (P)	4.00	.000	0	0	0	100
3	To be able to visit my infant at any time. ** (P)	3.92	.282	0	0	8.3	91.7
53	To know how my infant is being treated medically. ** (I)	3.92	.282	0	0	8.3	91.7
56	To see that the NICU staff provide Comfort to my infant, such as giving my infant a pacifier, using blankets to Support my infant's body, and talking softly to my infant. ** (C)	3.92	.282	0	0	8.3	91.7
38	To receive Information about my infant at least once a day. ** (P)	3.88	.448	0	4.2	4.2	91.7
40	To know specific facts concerning my infant's progress. (A)	3.88	.488	4.2	0	0	95.8

Parents' Ranking of the Fifteen Highest Met Needs (*n* = 24) (continued)

Item #	Needs Met Statement	Mean	SD	Percentage of Parents Response (%)			
				Never Met (1)	Sometimes Met (2)	Usually Met (3)	Always Met (4)
55	To hold my infant in my arms and against my skin as soon as I can. (P)	3.88	.488	4.2	0	0	95.8
48	To know why my infant is undergoing certain procedures. ** (I)	3.83	.482	0	4.2	8.3	87.5
52	To know that my infant is being handled gently by healthcare providers. ** (A)	3.83	.482	0	4.2	8.3	87.5
14	To be assured that the best care possible is being given to my infant. ** (A)	3.83	.482	0	4.2	8.3	87.5
17	To have a private place to breastfeed or use a breast pump. ** (S)	3.83	.403	0	4.2	8.3	87.5
20	To know exactly what is being done for my infant. (I)	3.75	.532	0	4.2	16.7	79.2

Parents' Ranking of the Fifteen Highest Met Needs (*n* = 24) (continued)

Item #	Needs Met Statement	Mean	SD	Percentage of Parents Response (%)			
				Never Met (1)	Sometimes Met (2)	Usually Met (3)	Always Met (4)
35	To feel that the hospital personnel care about my infant. (A)	3.75	.442	0	0	25	75
8	To have the waiting room near the NICU. (C)	3.75	.442	0	4.2	8.3	87.5
42	To be recognized as important to my infant's recovery. (A)	3.75	.442	0	0	25	75

Note: * = Needs statements identified by nurses; ** = Needs statements ranked the same by parents and nurses; (A) = Assurance; (C) = Comfort; (I) = Information; (P) = Proximity; (S) = Support

Appendix Y

Nurses' Ranking of the Fifteen Highest Met Needs (*n* = 16)

Item #	Needs Met Statement	Mean	SD	Percentage of Nurses Response (%)			
				Never Met (1)	Sometimes Met (2)	Usually Met (3)	Always Met (4)
3	To be able to visit my infant at any time. *, ** (P)	3.94	.250	0	0	6.3	93.8
17	To have a private place to breastfeed or use a breast pump. *, ** (S)	3.81	.403	0	0	18.8	81.3
38	To receive Information about my infant at least once a day. *, ** (P)	3.56	.629	0	6.3	31.3	62.5
14	To be assured that the best care possible is being given to my infant. *, ** (A)	3.56	.512	0	0	43.8	56.3
39	To see my infant frequently. *, ** (P)	3.50	.632	0	6.3	37.5	56.3
50	To know that my infant is being treated for pain. (A)	3.50	.632	0	6.3	37.5	56.3
48	To know why my infant is undergoing certain procedures. *, ** (I)	3.50	.632	0	6.3	37.5	56.3

Nurses' Ranking of the Fifteen Highest Met Needs (*n* = 16) (continued)

Item #	Needs Met Statement	Mean	SD	Percentage of Nurses Response (%)			
				Never Met (1)	Sometimes Met (2)	Usually Met (3)	Always Met (4)
56	To see that the NICU staff provide Comfort to my infant, such as giving my infant a pacifier, using blankets to Support my infant's body, and talking softly to my infant. *, ** (C)	3.44	.814	0	18.8	18.8	62.5
30	To have a bathroom near the waiting room. (C)	3.38	.619	0	6.3	50	43.8
34	To receive understandable explanations. (A)	3.38	.719	0	12.5	37.5	50
52	To know that my infant is being handled gently by healthcare providers. *, ** (A)	3.38	.619	0	6.3	50	43.8
53	To know how my infant is being treated medically. *, ** (I)	3.38	.619	0	6.3	50	43.8
36	To be allowed to help with my infant's physical care. (I)	3.31	.602	0	6.3	56.3	37.5

Nurses' Ranking of the Fifteen Highest Met Needs (*n* = 16) (continued)

Item #	Needs Met Statement	Mean	SD	Percentage of Nurses Response (%)			
				Never Met (1)	Sometimes Met (2)	Usually Met (3)	Always Met (4)
37	To be told about transfer plans while they are being made. (P)	3.31	.704	0	12.5	43.8	43.8
54	To have the neonatal unit quiet and lights dimmed at regular times to let my infant rest. (S)	3.31	.704	0	12.5	43.8	43.8

Note: * = Needs statements identified by parents; ** = Needs statements ranked the same by parents and nurses; (A)= Assurance; (C)= Comfort, (I)= Information; (P)= Proximity; (S)= Support

Appendix Z

Correlation between the Infants' Illness Severity and Needs Met Variables for Parents' (n = 24)

	Illness Severity	Assurance	Proximity	Information	Comfort	Support
Illness Severity	1	-.406	-.143	-.310	-.040	-.019
Assurance		1	.641**	.819**	.642**	.616**
Proximity			1	.693**	.488*	.431*
Information				1	.556**	.699**
Comfort					1	.499*
Support						1

Note: * = p < .05 (2-tailed); ** = p < .01 (2-tailed)