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# The assessment of family needs of infants admitted into the neonatal ward at an academic tertiary hospital in Johannesburg

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# THE ASSESSMENT OF FAMILY NEEDS OF INFANTS ADMITTED INTO THE NEONATAL WARD AT AN ACADEMIC TERTIARY HOSPITAL IN JOHANNESBURG

By

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Submitted in Partial Fulfilment of the Requirements for the Degree of Master of Science in Nursing in the Faculty of Health Sciences, University of the Witwatersrand

Johannesburg, 2016

**DECLARATION**

I, Kebuang Precious Wakwena, declare that this research report is my own work. It is being submitted for the degree of Master of Science (Nursing) at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.



Kebuang Precious Wakwena

1st Day of November, 2016

## DEDICATION

Mr Hupologang Wakwena my loving husband; thank you for your overwhelming support during the study period. To my sons Tsheto, Phazha and Dikano, you are a gift from God and to my dearest mom Mrs Tinawo Gucha for having made me realize my potential.

In loving memory of my dad, Mr Eleck Solomon Gucha who was my source of wisdom and inspiration. May your soul find eternal peace daddy.

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ABSTRACT

Celebrating the birth of a baby is often interrupted when the baby is born prematurely or with medical conditions warranting admission to the neonatal ward. The admission automatically separates the baby from the family, thus disrupting the infant-parent bonding and shaking attainment of parental role after discharge. This separation exerts pressure and stress on the family, disturbing the family systems equilibrium. The stress experienced by families has been associated with the physical environment of the neonatal ward and the ineffective family-nurse interactions. With increasing demand by consumers for family-centred care in the neonatal ward and with family needs being often overlooked by the intensive care nursing staff, it is evident that family needs in the neonatal ward require further exploration.

The purpose of this study was to investigate the needs of families of infants admitted to the neonatal ward. The objectives were to describe needs of families of infants admitted to the neonatal ward as identified by family members and explore and describe similarities and differences in needs of families at point A (0-24 hours of admission) and point B (96- 120 hours of admission). A quantitative, descriptive and cross-sectional design was used to achieve the research objectives; non-probability convenience sampling was used to identify 90 respondents (n=90). A quarter (23) and three quarters (67) were recruited from the Neonatal Intensive Care Unit (NICU) and High Care Unit (HCU) respectively. The Neonatal Intensive Care Unit Family Needs Inventory (NFNI) was used for data collection. Descriptive and inferential statistics were used to analyse the data.

The top three family needs identified by the cohort of family members who responded to the questionnaire were: the need for assurance (91.7%) information (87.5%) and proximity (81.8%). The need for assurance remained the top most priority need throughout the data collection process. Variations existed on how respondents scored the need for information (87.5% vs. 90.9%) and proximity (81.8% vs.75.0%) at point A and point B. There were no statistical significant differences on family needs between the data collection points.

From the research findings it was concluded that family needs change over time. Recommendations were drawn based on the research findings.

**Key Words:** Family needs, critically ill/preterm infant, neonatal ward, infant-parent bonding, family centred care, nurse, stress.

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LIST OF ABBREVIATIONS

ACRWC-African Charter for the Rights and Welfare of the Child

AACN-American Association of Critical Care Nurses

ADHD-Attention-Deficit/Hyperactivity Disorder

BFHI-Baby-Friendly Hospitals Initiative

CEO-Chief Executive Officer

CFHI-Child-Friendly Healthcare Initiative

CCFNI-Critical Care Family Needs Inventory

FCC- Family-centred care

HCU- High Care Unit

ICU- Intensive Care Unit

I-CVI- Item - Content Validity Index

KMC-Kangaroo Mother Care

PICU-Pediatric Intensive Care Unit

NFNI-Neonatal Intensive Care Unit Family Needs Inventory

NICU- Neonatal Intensive Care Unit

SANC- South African Nursing Council

SPSS- Statistical Package for Social Sciences

UNCRC-United Nations Convention on the Rights of the Children

UNICEF- United Nations Children's Fund

UNAIDS- United Nations Programme on HIV and AIDS

WHO-World Health Organization

# CHAPTER ONE: OVERVIEW OF THE STUDY

## 1.0 INTRODUCTION

In intensive care nursing the standard expected from care providers is the extension of care to the family of the critically ill patient. Patient-centred care is guided by the needs of the patient. Family-centred care (FCC) aims to involve and include family in the care of the patient and the needs of the family guide care. In the first chapter of this research report the background to the study, problem statement, purpose of the study, research question, research objectives, and significance of the study and definition of terms are presented. An overview of the research methods used is highlighted.

## 1.1 BACKGROUND TO THE STUDY

The birth of a child often brings joy to the family members as they celebrate the new life brought on earth. And yet the story changes when the child is born with severe health problems which require admission into the neonatal ward. A critical illness threatens life and poses the possibility of a catastrophic outcome for the child and affects the entire family, shaking its identity, structure and performance. The admission of an infant in the neonatal ward, poses a threat to the parental role as nurses attend to the basic needs of the infant and parents experience loss of control. The resultant separation of the infant from the parent and failure to initiate breastfeeding in newborns or interruption of breastfeeding in older infants delays or interrupts the process of attachment (Obeidat, Bond & Callister, 2009). Adjusting to the unusual, threatening, public and medically oriented atmosphere of the neonatal ward has always been a challenge to parents of

infants admitted in this setting (Fregran, Fagermoen & Helseth, 2008). Institutional rules around parental access, for example prescribed visiting times, lack of rooming in facilities, created more barriers to parental involvement in the care of their infants or children. In a study by Shaw, Deblois, Ikuta, Ginzburg, Fleisher and Kopman (2006), admission of the infant to the neonatal ward compromised the mother's ability to protect and care for the infant and they expressed agony associated with that. Additionally, mothers expressed distress related to failure to celebrate their little one with their families.

Altered parental role delayed or failed attachment and challenges of the neonatal ward experience were proven to have enduring effects on the health of family and its performance (Trajkovski, Schmied, Vickers & Jackson, 2012). Scrutiny of the precise causes of anxiety showed that symptoms of acute stress disorder were powerfully allied with intimidation to the parental role (Mvungi-Kitemangu, 2009; Trajkovski et al., 2012). Mothers may feel puzzled, nervous and restless and may struggle to be acquainted with and bond with the baby if they are deprived of opportunities to look after their infants. Healthcare providers' attitude and behaviour impact on parents' experiences of the neonatal ward and their approach to care can support or worsen parents' coping with the situation. Child nursing acknowledges an infant's family as recipients of health care with the child. True holistic care of the child integrates family members, restores family functioning and improves patient outcomes (Sturdivant & Warren, 2009).

Family-centred care (FCC) in neonatal and paediatric care was identified as an approach to delivering health care that is "parent-led with the nurse acting as a consultant or counsellor, fostering open, honest dialogue with the family" (Irlam & Bruce, 2002:28). In order "to render family centred care and support to the family, full partnerships between the family of a child in the critical care unit and the nurse are developed" (Roets, Rowe-Rowe & Nel, 2012: 625). This approach enabled the holistic and continuous care of the child by two experts: parents who contribute psychological, social, spiritual and cultural care and nurses who mainly contribute the physiological aspect of care ensuring sustained quality care. By adopting family-centred care, nurses are able to implement "supportive interventions used in intensive care are those that focus on decreasing feelings of isolation, strengthen coping efforts and enhance adjustments to illness" (Maxwell, Stuenkel & Saylor, 2007:368).

The initial step of the nursing process is the identification of patient needs. This also forms the initiation of family-centred care in NICU; the identification of the family needs. According to Mundy (2010) nurses who supported and met the following needs of families; assurance, closeness or proximity, information, comfort and support throughout a serious sickness, enabled families to stand by the critically sick patients and this had a constructive impact on patients' recuperation.

## 1.2 PROBLEM STATEMENT

Family-centred care is the standard expected of critical care providers in intensive care hence the development and provision of family support programs forming an integral part of care. For the successful and effective development and implementation of such programs, identification of family needs is the starting point. A preliminary literature review revealed that the majority of studies conducted on the family needs of patients admitted into the intensive care units in South Africa have focused on adult patients (Gundo, 2010; Schmollgruber, 2002). There is no research that has been conducted to establish the family needs when an infant is admitted to the neonatal ward in the same context. Paediatric nursing has at its foundation family-centred care and studies have established that the needs of families of infants or children admitted to intensive care vary from those of families of adult patients. The research question for this study was therefore: What are the needs of families of infants hospitalized into the neonatal ward?

## 1.3 PURPOSE OF THE STUDY

The purpose of the study was to investigate the needs of families of infants admitted to the neonatal ward at an academic tertiary hospital in Johannesburg.

## 1.4 OBJECTIVES OF THE STUDY

The objectives of the study were to:

- Describe needs of families of infants admitted to the neonatal ward as identified by family members.
- Explore and describe similarities and differences in needs of families at first contact, point A (0-24 hours) and second contact, point B (96-120 hours).

### 1.4.1 JUSTIFICATION FOR THE TWO DATA COLLECTION POINTS

In this research the researcher assessed family needs at two different points, A (0- 24 hours) and B (96- 120 hours). "Initially, the stressful experience of neonatal ward admission is global in nature, as parents recover from the shock and assimilate the issues facing them, thus there is a shift of concerns from the mother (e.g. birth trauma, separation and alteration to the parental role) to the infant (e.g. long-term concerns about chronic illness)" (Reid & Bramwell, 2003:288). The second data collection point was a point at which most infants' condition was stable and families anticipated discharge hence knowing the pertinent needs at this specific point could help healthcare providers produce appropriate discharge plans, follow up and identify how well the family was ready and confident to take the baby home. This was important as needs vary along the neonatal ward journey. "One need may take precedence over another and priorities may change as the patient's status changes" (Punthmatharith, Buddharat & Kamlangdee, 2007: 499).

## 1.5 SIGNIFICANCE OF THE STUDY

Central to advancement of FCC is assessing the needs of the family and nurses in the neonatal ward need to be receptive and appreciate these needs. It has been established from the literature surveyed that no studies of family needs of infants hospitalized in the neonatal ward has been conducted in South Africa. As such, this study seeks to describe the needs of families when an infant is admitted to the neonatal ward.

Additionally, the study will create a platform for the implementation of strategies aimed at enhancing family-centred nursing care which in turn will bring better clinical outcomes, a shorter hospitalisation period in the intensive care unit, reduce incidences of litigation, better coping mechanisms for the family and cost savings.

## 1.6 PARADIGMATIC PERSPECTIVES

### Synergy Model for Patient Care

According to the American Association of Critical Care Nurses (AACN) "synergy model" for Patient Care (Curley, 1998) , the core concept of the re-conceptualized model of certified practice is that the capabilities of the nurse are determined by the necessities of the patients and families. When the necessities and features of a patient, clinical unit or system are harmonised with a nurse's capabilities then synergy is the outcome.

In this study family needs were identified, from the identified needs the nurse was then able to derive his/her competencies and expertise, the neonatal ward is expected to provide resources and nurses with skills and competencies that match the family needs. This study was aligned with the re-conceptualized synergy model for patient care and hence this model was found to be appropriate to be adopted in this study and the researcher based the study on the following assumption.

- Patients are biological, social and spiritual entities who are present at a particular developmental stage. The whole patient (body, mind and spirit) must be considered.
- The patient, family and community all contribute to providing a context for the nurse-patient relationship
- Patients can be described by a number of characteristics. Characteristics are connected to each other. Characteristics cannot be looked at in isolation.
- Nurses can be described based on a number of dimensions. The interrelated dimensions paint a profile of the nurse
- A goal of nursing is to restore a patient to an optimal level of wellness as defined by the patient. Death can be an acceptable outcome in which the goal of nursing care is to move a patient toward a peaceful death (Reed et al., 2007)

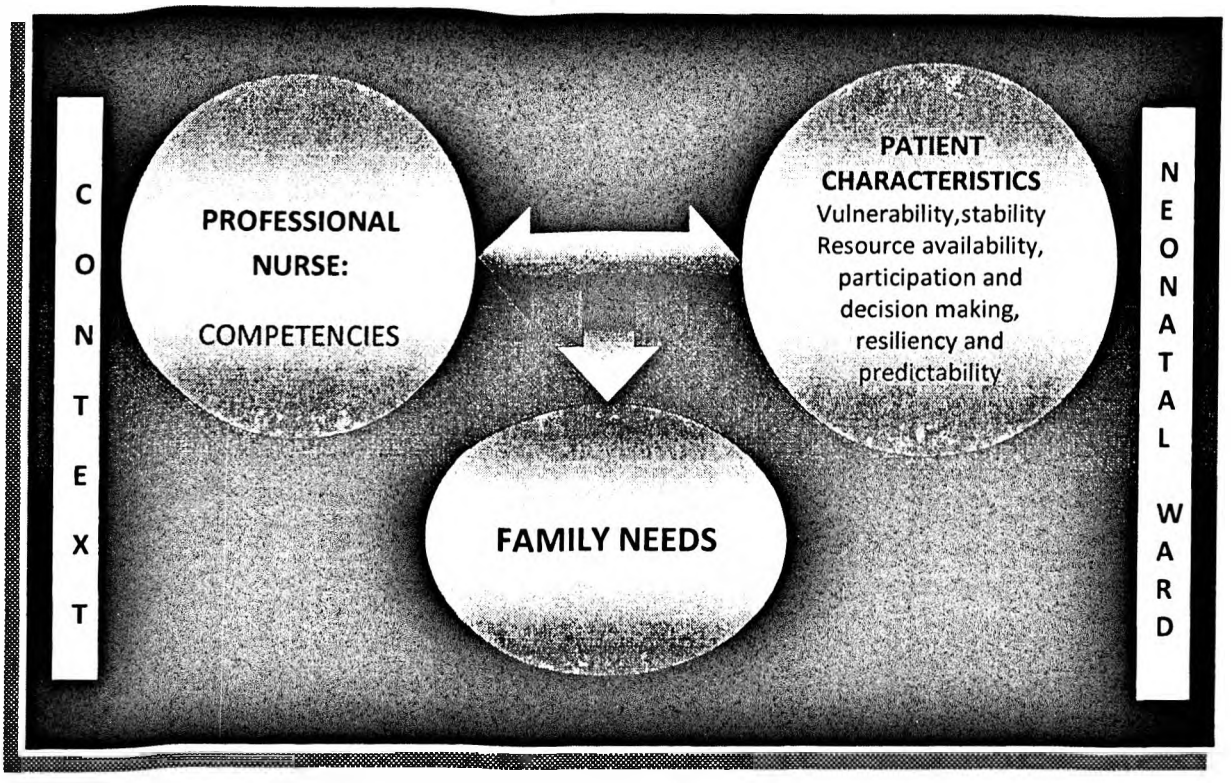



**Figure 1.6.1** Synergy model for patient care

In the figure above the family needs are drawn from the patient characteristics. The nurse uses his/ her competencies/skills to identify the patient characteristics by engaging with the patient as a unique individual. It then follows that family needs are recognized and caring practices are tailored to the individuality of the patient and the family.

## 1.7 DEFINITION OF TERMS

The following are contextually derived terms utilised consistently in the study:

**Nurse-** "A nurse is a licensed person who is registered with the South African Nursing Council (SANC) based on completion of a recognized education and training programme to nurture, assist and treat the client, who can be an individual, family or group, sick or well, in the performance of those activities that contribute to the attainment or maintenance of health, to optimal recovery and rehabilitation or to peaceful, dignified death. In working with the clients according to prescribed professional codes, they are acknowledged as equal partners by helping them gain independence as rapidly as possible" (SANC, 2005:25).

**Staff Nurse**- "A person educated to practice basic nursing in the manner and to the level prescribed" (SANC, 2005:25).

**Professional Nurse**- "A person who is qualified and competent to independently practice comprehensive nursing in the manner and to the level prescribed and who is capable of assuming responsibility and accountability for such practice" (SANC, 2005:25).

**Neonatal ward** – A unit of a hospital that provides care and treatment of newborns through the age of 28 days. The unit is designed with special equipment to care for babies born early with low birth weight or who have a medical condition that requires specialised treatment within the unit, there are four different levels of care; the Neonatal Intensive Care Unit (NICU), the High Care Unit (HCU), the Low Care Unit (LCU) and

the Transitional Unit (TU) (Online: www.liverpoolwomens.nhs.UK). For the purpose of this study the neonatal ward refers to the NICU and HCU.

**High care unit**- This is a unit where intensive care is provided to infants post extubation and requiring highly skilled staff. Provided for babies with less serious problems but who still need a great deal of observation and support and for those who are recovering from critical illness (Online: www.liverpoolwomens.nhs.UK).

**Neonatal intensive care unit (NICU) -** A unit providing quaternary, intensive care to infants with life threatening problems intubated and on mechanical ventilation. This unit combines advanced technology and trained healthcare professionals to provide specialised care for babies who need intensive medical attention. The specialised trained healthcare professionals involved in care of the babies includes neonatologist, respiratory therapists, occupational therapists, dieticians, lactation consultants, nurse practitioners, pharmacists, social workers, medical doctors and hospital chaplains (Online: www.stanfordchildrens.org). This unit admits infants from birth to the age of 12 months.

**Infant**- For the purpose of this study infant is defined as a baby aged 0 – 12 months admitted to the neonatal ward 0- 24 hours. An infant is a child who is in the earliest stage of extra uterine life, a time extending from the first month after birth to approximately 12 months of age, when the baby is able to assume an erect posture (Online: www.thefreedictionary.com/infant.

**Need-** According to Kosco and Warren (2000:61) a need is defined as "a requirement which if supplied, relieves or diminishes their distress or improves their sense of adequacy or well-being".

## 1.8 RESEARCH METHODOLOGY

### 1.8.1 Research Design

A quantitative, descriptive and cross-sectional design was used to meet the objectives of the study. "Descriptive studies are used when little is known about a particular phenomenon and the researcher observes, describes and documents various aspects of a phenomenon" (Soussa, Driessnack & Mendes, 2007: 504). According to Soussa et al. (2007: 503) "one reason for undertaking non- experimental designs is that some variables cannot be manipulated for ethical reasons and in some instances independent variables have already occurred so no control over them is possible". Because of the nature of the research setting and the psychological distress associated with the neonatal ward admission, in order to avoid causing further suffering to these families it was relevant that the researcher studied this phenomenon as it occurred naturally without any manipulation.

The research setting was the neonatal ward (NICU and HCU) in a tertiary academic hospital in Johannesburg. The respondents in the study were the family members with critically sick infants admitted to the neonatal ward for not longer than 24 hours. Non-

probability convenience sampling method was used to identify the respondents. The sample size was calculated to be 90 respondents (n= 90), interviewed at two intervals, point A (within 0- 24 hours of admission) and (within 96- 120 hours of admission). A quarter (23) and three quarters (67) of respondents were recruited from NICU and HCU respectively.

### 1.8.2 Research Methods

The protocol was submitted for peer review to the department of Nursing Education to determine the achievability of the study. The protocol was also submitted to the School of Therapeutic Sciences Assessor Group and the study was approved by the University Postgraduate Committee. The Human Research Ethics Committee (Medical) of University of Witwatersrand (Protocol No. M150452) granted ethical clearance to carry out the study. Authorization was requested from the Hospital Management, Head of Paediatric and Operational Managers of NICU and HCU to carry out research in the neonatal wards of the academic hospital. The researcher developed a data collection package for families comprising: an envelope, cover letter, consent form, the NICU Family Needs Inventory (NFNI) questionnaire, and information sheet about the study. The envelope was labelled with the study code for example 01 for the first participant and the questionnaires were labelled; 01A for data collection point A (0-24 hours) and 01B for data collection point B (96-120 hours). The data collector administered the same questionnaire to the same respondents at each data collection point. Respondents meeting the study criteria were invited to participate in the study. Prior to consenting to be part of

the study respondents were allowed time to read and comprehend the information sheet. Respondents agreeing to be part of the study were requested to complete a consent form and the cover letter which contained information about participant's profile; names, contact details, physical address and assigned study code to ensure all participants complete the data collection cycle. At any given point respondents were allowed to pull out from the study without attracting any penalty. Respondents were allocated code numbers, no personal names were used and all questionnaires were stored in a locked facility accessible to the researcher and the supervisor. Electronic data (spreadsheets, data analysis, results) were encrypted and the password kept by the researcher. During data collection the researcher observed for any signs of distress such as crying or any discomfort and if the respondent experienced this the researcher postponed data collection and counselled the parent. Additional counselling and social support was provided by the social worker for the Paediatric Department. The researcher facilitated communication with the medical team to address any concerns about the care of participants' infants in addition to referral to social worker for emotional/social support.

A pilot study was carried out to establish the achievability of the study and identify problems that may be encountered during the data collection process. The findings of the pilot study were reported together with the findings of the main study. Data was analysed utilising descriptive and inferential statistics. Demographic and dependent variables were analysed using descriptive statistics. Chi-Square analysis was applied to calculate the level of association between demographic data and the constructs. To compare the

findings of family needs identified at the two intervals McNemar's test was utilised. The statistical significance was set at the level of 0.05 (p=0.05). Prior to statistical analysis data was screened in order to inspect for any coding errors, outliers, and data skewness to help establish the need for extensive data clean up measures.

### 1.8.3 Validity and Reliability of the instrument

To establish content validity of the NFNI, Ward (2001:282) requested six registered NICU nurses to evaluate content of the CCFNI modified for paediatrics which resulted in the addition of 10 needs statements as suggested by the neonatal nurses. The 62 need statements questionnaire was then sent to five expert family-centred care nurses for validation and 56 needs statements were retained. The investigator further administered the 56 needs statements questionnaire to five neonatal family members for review and the majority agreed that all 56 statements represented the important requirements of families of infants admitted to NICU. The reliability of the 56 item NFNI was calculated to be 0.91 using Cronbach Alpha (Ward, 2001:283).

## 1.9 SUMMARY

Chapter 1 (one) of the research report provided an outline of the study. The background to the study, problem statement, research question and objectives, purpose and significance of the study was presented. A brief overview of the research methodology and ethical considerations has been outlined. The rest of the research report will be presented in the following format:

Chapter 2: Literature review

Chapter 3: Research Methods

Chapter 4: Data analysis

Chapter 5: Discussion of findings, limitations, recommendations and conclusion.

## CHAPTER 2: LITERATURE REVIEW

### 2.0 INTRODUCTION

This review of literature explored the care of an infant in the NICU, family centred care, the impact of admission on family and the role of family were also discussed. Family needs in the NICU were identified, followed by a discussion on the role of the nurse in the NICU and finally the summary.

### 2.1 CARE OF AN INFANT IN NICU

Advances in medical technology and changes in disease profiles have resulted in the increased admission of infants into the NICU coupled with provision of specialist nursing care. In child nursing, the infant and family are cared for as one unit, which applies in the intensive care setting.

Historically children and infants have long been considered a special and fragile set of population which requires security and firm rights. Inherent to nursing, "is respect for human rights, including cultural rights, the right to life and choice, to dignity and to be treated with respect" (McSherry, Pearce, Grimwood & McSherry, 2012:9). Law and legal reform have a key role in protecting and ensuring the fulfilment of the rights of vulnerable children. Children's rights in South Africa are protected by the United Nations Convention on the Rights of the Children (UNCRC), the African Charter for the Rights and Welfare of the Child (ACRWC) (Hendricks, 2014). The family is viewed by the UNCRC as the core system which has a principal obligation to protect and care for the child and the states are obliged to shield, maintain and uphold the child- family

relationship. The obligation of the state to offer distinctive fortification for a child who is underprivileged of his/ her family atmosphere is also stipulated in the convention. The overarching guiding principle with this convention is the "best interest of the child". The UNCRC is grounded in the acknowledgement of the right to child existence, welfare and growth. "States are thus obliged to adopt approaches to ensure these rights are realized" (UNICEF & UNAIDS, 2004:13). All levels of child development being spiritual, ethical, emotional and social are underlined thus warranting complete and harmonious growth of the child. In the South African setting, child nursing recognises that "every child has the right to family care" (South Africa, 1996:13, section 28 (1)); (a) throughout hospitalization and their family members play a crucial part in the consent process to medical procedures. In order to provide holistic care in the NICU, Ward (2001) proposes the family-centred care model as an approach to care where families are incorporated in all aspects of the infant's management and facilitates the protection of infant and family wellbeing.

### 2.1.1 Family centred care

FCC as a concept describes a tradition which identifies the family as the central foundation of support and consciously acknowledges family engagement indispensable to uphold the wellbeing of all family members (Shields, Pratt & Hunter, 2006). FCC is defined by the following principles; "people are treated with dignity and respect, healthcare providers communicate and share complete and unbiased information with patients and families in ways that are affirming and useful, patients and families build on strengths by participating in experiences that enhance control and independence and

finally collaboration among patients, family members and providers occurs in policy and program development, professional education and the delivery of care" (Dunn, Reilly, Johnston, Hoopes & Abraham, 2006: S95). In the context of children's healthcare setting "FCC is defined as the professional support of the child and the family through a process of involvement and participation, underpinned by empowerment and negotiation and it is characterized by a relationship between healthcare professionals and the family, in which both parts engage in sharing the responsibility for the child's health" (Frederiksen & Mikkelsen, 2011:1159). Even though embedded in the Western culture, cognizance of the basic features of FCC in developed and developing states has been highlighted, thus enhancing global relevance of the concept in healthcare delivery.

Classically, neonatal care have been persistently technology driven, provider centred where family roles in caring for their own babies is sternly restricted. The psychosocial needs of the family remain unattended. FCC for sick newborns seeks to develop and nurture the family's role in partnership with the clinical care delivery team. "FCC creates an environment that is responsive to the family-identified needs, culturally sensitive and provides a setting in which family is empowered and encouraged to support care for their baby as the constant caretaker from admission onward until discharge" (Maria & Dasgupta, 2016:11). FCC marks a paradigmatic swing in neonatal care in which family members are granted an active participatory role through their contribution in the care of their babies and families being viewed as partners in care rather than guests. FCC has been widely accepted and has demonstrated favourable outcomes pertaining to the baby and the family. The impact is evident on better weight gain, shorter length of hospital

stay and increased breast feeding rates amongst neonates and infants (Maria & Dasgupta, 2016). Furthermore, outcomes on family have shown better conversant and self-assured parents who are able to cope better with stress, fear and altered parental role and enhanced parental-infant bonding including improved family's readiness in caring for the baby post discharge (Maria & Dasgupta, 2016). "FCC provides the strong supportive foundation families in neonatal units need to optimize the lifelong relationship between themselves and their babies as well as to optimize the baby's physical, cognitive and psychosocial development" (Craig, Glick, Phillips, Hall, Smith & Browne, 2015:S5).

"The separation of parents from their baby in the neonatal unit combined with parental mental health problems such as depression, post-traumatic stress disorder and anxiety can adversely affect the parent-baby relationship resulting in adverse outcomes for the baby's social and emotional development and behavioural and cognitive functioning" (Craig et al., 2015:S5).Furthermore, "high rates of psychological distress among neonatal ward parents and lifelong medical and neurodevelopment problems among many preterm and low birth weight infants further demonstrate the need to continue to incorporate FCC into neonatal ward policies, procedures and culture" (Craig et al., 2015:S5).

FCC in the neonatal unit cannot be discussed in isolation without integrating the parent-infant bonding and the attachment process. According to Cox and Bialoskurski (2001:670) "bonding is defined in the literature as the formation of attachment between the mother and her new born infant which is usually assumed to be an automatic process that occurs at birth". "The newborn has a natural instinct to attach to its closest caregiver, most often the mother and this attachment is important for the child's survival during the

first period of life" (Wigert, Johansson, Berg & Hellstrom, 2006: 36). If this attachment is interrupted the child's emotional development is negatively challenged (Wigert et al., 2006). Seminal work by Klaus and Kennell found that the critical period for establishment of a positive bond between mother and child is the first hours and few days after birth. However, taking other factors into consideration this is not always the case, for instance bonding may not always be observable in the neonatal ward specifically in the NICU. Most frequently families do not always have unlimited access to the infant because of the scary, overwhelming environment and unwelcoming behaviours displayed by caregivers. Prematurity and related mother- infant detachment at birth can generate specific challenges not likely to be experienced by families with healthy infants (Wigert et al., 2006). Attachment and bonding is troubled when the infant is admitted to a neonatal ward, where mothers can occasionally visit but rarely connect with the infant for prolonged time periods. The parents find themselves in an acute crisis when a child is born with a health problem warranting neonatal ward admission, with most mothers feeling guilty, insufficient and ashamed in relation to their husband, own parents and the community because of the inability to give birth to a fit, strong baby (Wigert et al., 2006).

Care in the neonatal ward is mainly focused on high technology and sophisticated machines, consequently, nurses and other healthcare providers find it difficult to integrate care and relationship building in such a setting. Instead of opportunities for parent-infant attachment being emphasized, literature demonstrated power struggles between the mothers and the nurses with each trying to position herself as the "expert" on the infant, (Wigert et al., 2006).

In this view, it is of utmost importance that the caregivers actively work for the parents' participation in the care of the infant. "Separation from the baby was found to be most difficult aspect for the mother when their newborn child was hospitalised in the neonatal ward, it involves a great deal of emotional strain for the mother" (Wigert et al., 2006: 36).When the mother is supported by an individualised approach to care and appropriate communication is used, attachment can be facilitated, Wigert et al. (2006) and active parent participation in the care of the infant promotes parent-child bonding. Furthermore, when mothers are given responsibility for the daily care of their infant, they feel more secure in their maternal identity. "Family stress, strengths and needs and their impact on the parent-infant attachment process as well as the physical and social aspects of the neonatal ward atmosphere must be kept in mind when planning interventions" (Smith, Sira, Desai & Engelke, 2014: 346). According to Wigert et al. (2006) parental participation in the care of the infant can include social activities such as talking to the baby, holding, stroking, washing and feeding the baby. "Not acknowledging the mother, including her needs is understood to be uncaring, leading to suffering where the mother's dignity is insulted and the mother's participation is very crucial, where they are seen as a natural part of care, with unique needs, supported to celebrate her motherhood in neonatal unit hence influencing maternal feelings in a positive direction" (Wigert et al., 2006:39). Nurses are in a central position to ensure that participation by mothers directs care in the NICU.

"Organisations are promoting meaningful integration of family-centred care into their standard practices and guidelines" (Dunn, Reily, Johnston, Hoopes & Abraham, 2006:95)

and the healthcare system in South Africa is not an exception. The health care system in South Africa has adopted various child care strategies and standards to guide care in an effort to cultivate and implement the culture of family-centred care in service delivery.

The Child-Friendly Healthcare Initiative (CFHI) is a system of care, derived from the UNCRC, and focuses on entire well-being of children at different age groups admitted to health care institutions. The identified 12 (twelve) care standards are linked to measurable outcome criteria aimed at improving the quality child care (Coetzee, 2010:78). Care of infants in NICU is drawn from the Baby-Friendly Hospitals Initiative (BFHI) which was launched by the World Health Organization (WHO) and the United Nations Children's Fund (UNICEF) in 1991 (Wieczorek, Schmied, Dorner & Dur, 2015) and Kangaroo Mother Care (KMC) which is a model of care which eases low-birthweight infants' shift from intra to extra uterine life and support parents' role at the neonatal ward (Blomqvist, Frolund, Christine & Nyqvist, 2013). These two programs support exclusive breastfeeding for 6 months and skin to skin care of infants. The initiative provides nurses with an intervention framework enabling them to manage and treat the infant by giving best possible care; implement effective resuscitation, emergency and continuing care for critically ill children; pain management; support family-centred care and provide family with information to help them in making health care decisions and ensure best possible nutrition (Coetzee, 2010). According to Berkat and Sutan (2014) breastfeeding is associated with improved patient outcomes; namely low infant mortality and enhances infant-maternal attachment. The academic institution where the study was conducted is an internationally credited facility and nurses receive continued training in

all the aspects of care in the initiative. Since NICU delays parent-infant bonding and disturbs breastfeeding a KMC ward was opened in 2010 where physiologically stable infants from the NICU are nursed on continuous skin to skin care under the supervision of nurses. "KMC has proven effective in initiating and promoting longer breast feeding periods, enhancing bonding and providing comfort during painful procedures, supports motor development and helps promote rest" (Hunt, 2007:14). Literature supports the consensus that "parents are virtually the suitable resolution makers for infants and children who have not yet attained decision- making capability" (Gilmour, Harrison, Cohen & Vohra, 2011:151). The BFHI encourages nurses to empower parents by implementing an educational program preparing them for discharge and to equip them with skills necessary to transition care from hospital to the home environment. Preparing parents for discharge enhances their confidence and readiness to fully assume their parental role which they missed while the infant was in neonatal ward. Empowered parents are able to continue appropriate care of the infant at home, reducing the need for readmission and ensuring good health, growth and development.

In order for children's rights and the FCC model of care to be realized, nurses' skills, competencies, education must be linked to the patients' needs and the standards in the healthcare institution. Therefore applying some models may assist nurses in offering safe and standard nursing care appropriate to patients' needs thus enhancing patients' satisfaction. It is imperative to utilise conceptual models because they brighten what is crucial or pertinent to a discipline (Curley, 2004). According to Khalifehzadeh, Jahromi and Yazdannik (2012:18) "nursing models consider the specific patients' needs and result

in providing skilled nurses and appropriate facilities to obtain the desirable results". The American Association of Critical Care Nurses' (AACN's) synergy model for patient care was applied in this research study. The model identifies the patient as the central focus and defines the bond that links the nurses with their competencies and the patient's needs (Reed, Cline & Kerfoot, 2007). The model also provides an outline for result assessment for the patient, the nurse and the system. The characteristics present in the healthcare system directly affect the nurses' ability to address patients' needs and ultimately the success of the patient outcomes. According to Reed et al. (2007), the synergy model is composed of three components namely; eight patient characteristics (resiliency, vulnerability, stability, complexity, resource availability, participation in care, participation in decision making and predictability), eight nurses' dimension in practice (clinical judgment, advocacy/moral agency, caring practices, collaboration, systems thinking, response to diversity, facilitator of learning and clinical inquiry) and finally the systems characteristics (patient-centred care philosophy, shared leadership, learning environment, nurse-physician collaborative practices and resources to support evidence-based practice, outcome evaluation and patient safety). The healthcare system performs as an enabler to support patients' needs and has the capacity to cherish the professional practice atmosphere of the nurse.

By embracing the features of patients implanted in the synergy model for patient care, nurses will be able to identify patients' needs along the continuum of illness. Curley (1998:66) found that "at any point, patients may fluctuate in their positions along these eight continuums, which can change within minutes". In this view, nurses need to

develop effective communication strategies via nurse to nurse reports which are inherent to proper communication standards and guidelines set by the healthcare environment within which care is being rendered. For effective and sufficient information amid caregivers and throughout practice surroundings, nurses must initially have a detailed understanding of their patients and families (Reed et al., 2007). Additionally, the synergy model framework offers a way of consolidating personal and objective information in relation to patients and their families, thus leads to consistent identification of needs and continuous care is sustained across the period of ailment. Within the synergy model and similar to patient/family-centred care, patients and families are supported to become vigorous participants in the patient/ family–nurse interface where the nurse facilitates the family's ability to engage in decision making regarding the sick patient. The model uplifts and acknowledges appropriate features of the nurse's interactions with the patient, the system and the nurse colleagues in the healthcare forum.

## 2.2 IMPACT OF ADMISSION ON FAMILY

Mendonca and Warren (1998:59) defined family as "a spouse, parent, and child or identified significant other who waits in the intensive care unit waiting room". Cypress (2011:274) found that "the admission of an infant to NICU may result in an emotional turmoil, role conflict, and a high level of stress, interruption of normal home routines, sleep disturbances and potential changes in relationships among family members". According to Halm (1990) the admission crisis disrupts the family system's state of

equilibrium, hence, the mobilization of family coping mechanisms and recognition of resources available is what is required for the restoration of the equilibrium within the family system. This crisis necessitates the identification of family needs and identified needs being addressed appropriately.

### 2.2.1 The critically ill infant

"Hundreds of thousands of medically fragile infants spend their first few weeks or months of life in the neonatal intensive care unit because of problems such as hypoxia, respiratory disorders, cardiovascular disorders, congenital infection, intrauterine drug exposure, brain injury and prematurity, with pre- mature and low birth weight infants comprising the majority of NICU patients" (Kessenich, 2003: 1).

Parental closeness in the neonatal ward has been linked with enhanced infant outcomes namely, better sleep associated with skin to skin contact in pre term infants, parents' participation in pain management reduces pain in preterm infants and reduces the administration of pain medications, infant massage with moderate pressure may increase levels of hormones such as brain growth-promoting factor (IGF-1) and oxytocin, potentially having progressive effects on brain functioning and development (Flacking, Lehtonen, Thomson, Axelin, Ahlqvist, Moran, Ewald, Dykes & SCENE group, 2012). Furthermore, "exposure to human speech during the neonatal period, especially mother's voice adds linguistic value that can be crucial for the initial wiring of the brain for language acquisition" (Rand & Lahav, 2014: 243). According to Rand and Lahav (2014), prematurity frequently causes compromised neurodevelopment, the principal challenge is

atypical language development. "Approximately 25- 30% of preterm infants experience difficulties in language acquisition, which at school age frequently surface as general behavioural emotional problems, poor verbal comprehension, attention deficits and lower intelligence quotient" (Rand & Lahav, 2014: 243). "Premature exposure to the extra uterine environment may negatively affect the proliferation, organization and selective pairing of neurons in the preterm infants' maturing brain as well as regional brain volumes" (Kessenich, 2003: 2). Deficits in visual- motor and visual-spatial skills have also been reported in premature and low birth weight (Kessenich, 2003) and it is suggested that it could be a result of "cortex or basal ganglia caused by medical conditions such as hypoxia, asphyxia, chronic lung disease, intraventricular haemorrhage and seizures as well as physiological stress in the extra uterine environment" (Kessenich 2003: 3). The outcomes associated with early life separation of the infant from the mother underlines the need for health care providers to address family needs in the neonatal ward.

Pre-term infants are particularly vulnerable to deafening erratic sounds from irrelevant sources such as alarms, ventilators, phones and staff chats that often define the neonatal ward environment (Wachman & Lahav, 2010). The physical and the psychological aspects of the neonatal ward environment is the most important factor in neonatal development. A number of activities go on in the neonatal ward; this is so because of the large numbers of healthcare specialists engaged in providing care to the vulnerable infants. Thus the neonatal ward is characterised by repeated processes, tactile stimulation and exposure to brightness and deafening sounds which may cause functional stress on

infants and results in increased hospitalisation period in neonatal ward and eventually reduce intellectual maturity (Hunt, 2007). Moreover, these vulnerable infants are incidentally affected by the family's anxiety and the inability to offer sufficient care. The supportive role of the nurse is of great magnitude during hospitalisation to the neonatal ward as it will improve on the quality and frequency of family participation in the ward.

Early life separation, prolonged or repeated physical separation between parent and newborn alters development and impairs ongoing bonding process (Flacking et al., 2012). Infants in the intensive care unit are at greater risk for long-term medical and developmental problems, it is therefore important to understand the greater risk that infants admitted in the neonatal ward have of developing psychological, emotional and behavioural disturbance (Maroney, 2003). Hunt (2007) highlighted that at age 12 infants previously admitted to the intensive care unit showed a significant greater risk of attention-deficit/hyperactivity disorder (ADHD), generalised anxiety and symptoms of depression. It therefore calls for attention to maintain a state of equilibrium, particularly across this crucial time when rapid formation of the central nervous system is taking place (Wachman & Lahav, 2010).

### 2.2.2 The family/caregiver

The machines that support life in the neonatal ward may cause families astonishment and unease and it is often devastating to see incubators as well as the healthcare staff examining the infant (Hunt, 2007). According to Turan, Basbakkal and Ozbek

(2008:2857) "giving injections to infants, inserting tubes, intravenous lines and taking blood have been the procedures shown to cause the most parental stress". Nevertheless, understanding the purpose of the interventions and the equipment connected to their infant frequently makes parents to perceive the experience not to be stressful (Turan et al., 2008). Increased family involvement when providing care supports effective cultivation of family-centred care in clinical practice. The more families are involved the more they become knowledgeable hence placed in a better position to make informed decisions.

## 2.3 ROLE OF FAMILY

The role of family members is an important component of family-centred care. Earlier on the role of families consisted chiefly of accompanying a child in neonatal ward, however since the continuous evolution of family-centred care the roles have tremendously broadened with opportunities for collaboration with healthcare providers including involvement in systems change in healthcare.

According to Mitchell and Chaboyer (2010), family members enact closeness at a time of critical illness by their presence by the bedside of the critically sick patient thus providing the ICU patient with a feeling of being connected to the real world. Mitchell, Chaboyer, Burmeister and Foster (2009) and Maxwell et al. (2007) stated that family members act as alternative verdict makers and supporters for patients. According to Hupcey (2000),

during their stay in Intensive Care Unit (ICU) patients receive support, comfort and hope from their families. Mitchell and Kean (2013:664) mentioned that "policy drives continue to shift care from the acute into the community care setting with patients being discharged ever quicker and sicker, leaving family members to facilitate and frequently provide post discharge care to the recovering intensive care unit patients". Additionally, families have turned out to be an essential internal resource for caring of patients at community level, given the resource- limited health and public care funds. The multifaceted and extended course of recuperation from a serious illness therefore has to be contextualized within the family systems (Griffiths, 2010). Mitchell and Kean (2013:670) stated that "the integration of families in today's healthcare system is thus mandatory as families will become the caring resource for these patients during an often prolonged recovery trajectory". Furthermore, this collaboration has the potential to tackle the family needs and enrich information sharing better.

Families also bring insight to the critical illness situation as the intensive care unit patient will not know or remember the critical illness trajectory or their period in an intensive care unit whereas families experience the entire critical illness period (Paul & Rattray, 2008).In a study by Riley, White, Graham and Alexandrov (2014:319) "nurses believe the best examination of patients occurred when patients' families were present". Cypress (2011:274) found that "the role that the family may actually play in the intensive care unit depends on the interactions and the types of relationships that develop between the nurse and the family of the critically ill patient".

## 2.4 IDENTIFYING THE FAMILY NEEDS

Mundy (2010:157) argues that "improving well-being is the role of all healthcare providers especially nurses who innately foster health through caring". When an infant is admitted in the neonatal ward the healthcare team concentrate their focus on the sick child, neglecting the emotional and psychological needs of the parents.

Apprehension for the infant's wellbeing and survival and the effect of clinical care and machinery on the neonatal ward are dynamics that may seriously disturb parents (Tran, Medhurst & O'Connell, 2009). Molter in 1979 investigated family needs through an examination of 23 graduates and a review of literature, 45 need statements were established. The statement "to feel there is hope" was ranked mostly important while the statement "to talk about negative feelings such as guilt or anger" was ranked least important. Leske in 1986 conducted a follow up research investigating needs of relatives of critically ill patients. The resultant tool was named the Critical Care Family Needs Inventory (CCFNI). In 1990 Kirschbaum carried out a descriptive research which established the needs of parents of children admitted in a Pediatric Intensive Care Unit (ICU) by modifying the CCFNI to use in a paediatric setting. Eight additional need statements were incorporated in the instrument. Additional statements were identified; "feeling there is hope" and" being assured the best care is being given" as important

needs (Ward, 2001:20). Then Ward (2001) developed the NFNI through the revision of the CCFNI modified by Kirschbaum in 1990 for PICU.

A review of literature revealed that several studies confirmed and categorised needs as; the need for information, comfort, support, proximity and assurance (Bialoskurski, Cox & Wiggins, 2002; Fisher, 1994; Jacono, Hicks, Antonioni, Brien & Rasi, 1990; Kirschbaum, 1990; Leske, 1986 & Molter, 1979).

### 2.4.1 Need for information

For effective execution of family-centred care, information sharing is the cornerstone for its foundation and it does assists parents to be empowered and gain confidence in helping make informed decisions about their infant's plan of care. Excluding families from continuing information sharing and ongoing decisions involving their infants needs escalate their anxiety and stress levels. Cockcroft (2011) noted that information sharing that is insufficient, ambiguous, and incompatible and deficient in negotiation erects an obstacle to successful implementation of FCC. Inconsistencies in the information that staff share with parents may heighten their anxiety levels. A study by Bialoskurski et al. (2002) investigated needs and priorities of mothers of infants in the NICU, in their study the highest rated needs were the need for precise, unswerving and theme exact information and the need for unvarying messages amongst the healthcare team. Unceasing information sharing, healthy relations and effective communication strategies amid the healthcare team and parents have been shown to reduce parental anxiety and

stress (Punthmatharith, Buddharat & Kamlangde, 2007). Consistent with these findings, Ward and Hayes (2001) found that assurance and information needs were rated mostly important amongst parents with infants admitted in the NICU. Jacono et al. (1990) compared alleged family members' needs of patients admitted in the adult ICU and in the NICU, similarly both families highlighted understandable information as a precedence need.

"Physicians view families as the prime caregivers of the patient in an ICU, thus it is imperative that the healthcare team share detailed information concerning the patient's prognosis and that their main responsibility is to provide care to the patient" (Riley et al., 2014:319). Findings in the same study revealed that "families felt 'panic' if their loved one's health status was not reported in a timely manner and felt incompetent making caregiver decisions that were based on infrequent and inadequate medical updates" (Riley et al., 2014:319).

In the catastrophe of admission and strangeness of the intensive care unit surroundings, the restless family unit in search of information and effective coping strategies may be misinterpreted as 'demanding' by the team Alavi and Blanchard (2008:225). Therefore, an understanding must occur between intensive care unit staff and families so that a communal understanding of procedures, language and engagement occurs in the unit. As intensive care unit nurses concentrate their energy towards improving patient care it is vital to remember that family members' needs for information are relevant and important

elements of the care they deliver. Hence they should facilitate and advocate for their inclusion into the neonatal ward environment.

### 2.4.2 Need for Assurance

The admission of an infant to a neonatal ward can cause confusion and shock for the parents, hence they are incompetent to comprehend descriptions and grant care to the infant. The healthcare team need to fulfil their need for assurance. Some research studies demonstrated that family members ranked assurance needs as priority needs (Kasper & Nyamathi, 1988; Kirschbaum, 1990; Ward, 2001). In children's intensive care unit parents are often concerned about their infant's safety, comfort and that their infants are receiving the best care. Similarly, Mundy (2010) assessed the needs of parents in NICU, results revealed that the need for assurance was ranked highest with a mean score of 3.89 and the lowest rated need was the need for support with a mean score of 3.33. A study by Lee and Lau (2003) found that family members of intensive care unit patients ranked the need for assurance highest within 24-72 hours period of a patient's admission.

### 2.4.3 Need for proximity

The physical presentation of the infant in neonatal ward can pose barriers to family proximity to the infant and this causes parents to experience depression, anxiety, anger and fear. This frustration compromises the attainment of parental role. Physical contact is significant during neonatal ward admission. Nurses must teach parents how to hold and

feed the infant and encourage them to touch the baby. This helps to alleviate anxiety and depression experienced by parents as they are enabled to interact more with the infant.

According to Vazquez and Cong (2014), when parents first arrive in the neonatal ward, they are overwhelmed and terrified by the surrounding. They need to know what the machines, wires and alarms do and mean and the rules for their baby. Such information is the foundation in paving the way for parent proximity to the infant. In this study mothers expressed fear of dislodging the IV lines, endotracheal tubes and oxygen tubing. Parents clearly mentioned the need for proximity. For example, one mother described "if I could get hold of them. I think that's the only thing right now that would make me feel closer right now". Another mother expressed that they are there to give their infants closeness and contact and to make a bond with them. The barrier that exists between parents and infants in the neonatal ward is devastating. Healthcare providers must take the advantage of early intervention to ensure better and healthy parent-infant relationship.

### 2.4.4 Need for support

Mundy (2010: 161) revealed that support need was ranked lowest by family members of infants in NICU, specifically the support needs statements "to have support group with other family members available" and "to be able to talk to other parents whose infants are in NICU" had the lowest mean (2.93 and 2. 95) respectively. This is consistent with findings from a survey by Ward (2001) where the least vital subscale need was the need for support.

However, findings from Dobbin, Bohlig and Sutphen (1994) showed that 73.7% of participants in their study indicated a desire to speak to another parent with a similar situation and 54% desired a family support group.

### 2.4.5 Need for comfort

In a study by Lee and Lau (2003), family members ranked the need for comfort lowest. Family members give priority to the needs of the patient as compared to their own needs (Agard & Harder, 2007). Results of a study by Mundy (2010: 161) showed that parents rated need for comfort lower, citing "to have comfortable furniture in the waiting room", the mean was 2.90, which was relatively low as compared to scores for other need statements.

## 2.5 THE EVOLUTION OF FAMILY NEEDS

Historically many infants were delivered in a home environment and care was offered virtually solely by the mother and the extended family (Gooding, Copper, Blaine, Franck, Howse & Berns, 2011). By early 1900s advances in technology led to the advent of incubators and premature infants were placed in these incubators. During this period their mothers were not allowed to provide care to their infants. This epoch marked the commencement of the spilt-up of newborn care from their families (Gooding et al., 2011). The authors highlighted that the care for the newborns and their mothers moved from household, patient and family engrossed to the hospital in 1930. The overarching

issue was concern about infection control; this led to sterner hospital rules concerning family company and partaking in the newborn's care. Gooding et al. (2011) highlighted that by the late 1940s some acknowledgement of the necessity to attend to family needs for closeness in the hospital scenery arose; consequently a movement for patient and FCC trailed in the 1970s and the ideologies of FCC in the NICU were announced in 1993 by Helen Harrison. In her summary of ideologies of family-centred neonatal care she noted that "all of us had a collective credence that parents should be able to engage more abundantly in caring for and actively engage in decision making for their hospitalised infants" (Gooding et al., 2011:21).

## 2.6 ROLE OF THE NURSE

The scope of nursing practice is engrossed within the synergy model, which highlights the role of the nurse in the intensive care unit. Nurses' current clinical practice is evidence based and guided by research and literature. In this view, nurses must persistently question and evaluate clinical practice in order to provide informed practice and create positive change within the healthcare setting through research utilization and consistent literature review. By integrating their clinical experience, knowledge gained from literature and reflecting on the current practice nurses can be able to make sound clinical judgement in the healthcare arena, hence improve on patient/family outcomes and satisfaction. If nurses are vigilant and objective in their caring practices, then they will become receptive to the distinctiveness of the needs of the family and their patient thus generating a considerate and healing atmosphere intended to promote ease and avert

anguish. In this regard, nurses can uphold the patient/family values and beliefs and ultimately offering care that is tailored to the needs of the patient and the family. Nurses need to be sensitive and appreciative of the differences in cultural, spirituality, gender, racial, ethnicity, socioeconomic status and age amongst patients and caregivers and the healthcare personnel. As they try to incorporate these aspects in their care, nurses must also consider the context in which caring occurs, for example, the institution and the society, so that ethical sensitive care is provided. By so doing nurses are respecting patients' and family rights for autonomy, beneficence, non-maleficence and justice.

In their professional role as the coordinators of the multi-disciplinary health care team, nurses are in an exceptional spot to comprehend the preferences of intensive care unit patients and their families. In reference to the role of nurses, Krimshtein, Luhrs, Puntillo, Cortez, Livote, Penrod and Nelson (2011:1326) observe that "by facilitating information sharing they are able to advance communication amongst patients, families and the medical squad".

Clinical and ethical dilemmas do arise in the healthcare setting and nurses must be able to explore and actively engage in negotiation with other members of the multi-disciplinary team. Spence (2011:642) noted that "advocacy has been a universal subject in nursing principles and seen as a valuable means to empower nurses in their trained role and it provides a technique for nurses to maintain and to defend their patients' welfare". There are diverse perceptions of patient support ranging from fortification of the patients'

privileges, ensuring ease and safety for the patients who are unable to speak for themselves. The two distinct foci of caring highlights the receptive view for the inimitable needs of individuals and the universal obligation of care on the basis of contracted and organisational responsibilities and regulations. Nurses must remain alert to the possibilities for abuse that arise with vulnerable neonates and infants. In the context of the neonatal ward or the research setting nurses are expected to be in the forefront regarding protection of the patients' rights and ensuring comfort of the infants and their families. Caring strives to defend patients' solemnity, thereby addressing the needs of the patient.

Most importantly, advocates maintain and uphold the privileges of the patient in the health care forum, assist erect competence to advance society healthiness and augment health strategic initiatives concentrating on existing secure and quality care. Advocates are well-matched to tackle the barriers of patient-centred care in our multi-faceted healthcare structure. Evidence based practice is the driving force which can enable nurses to competently contribute in discussions about patient's needs. The nurse is the solitary individual who knows the setting where care is offered and for this reason she can draw a panel of caregivers collectively towards the paramount significance of the patient and the family. Advocacy ascertain joint venture amongst healthcare providers, patients and families to guarantee that decisions value patients' preferences and ensure that patients are empowered and hence enabled to make decisions and partake in their individualized care. With this global mobilization towards FCC nurses are expected to sustain parents

support by sharing accountability for the infant care and aiding smooth progress of parental engagement in all dimensions of care.

The healthcare delivery system is disjointed and in each setting families and infants come across several care providers with each facing their challenges typical to their situation, discipline and therapeutic goal. This fragmentation puts vulnerable children and families at greater threat for reduction in healthiness and performance, unaddressed psychosocial requirements and redundant healthcare expenditure related to lengthy hospitalizations and increased rate of readmissions. There is a need for improved coordination of care across the complexity of the healthcare system to bridge the gap between consumers and the system. Specifically, nurses are vital in the coordination and collaboration role in the healthcare system.

Collaboration between nurses and parents enables families to be more engaged in resolution making and persuade the course of the infant's recuperation. Moreover parents obtain support from nurses underlining the significance of adopting a family-centred care model in healthcare setting (Gooding et al., 2011). Unsatisfactory interactions between the parent and the nurse may get to further than the traumatic incident in the NICU and breed additional belief of helplessness and further figure parents' relations with professionals in the future (Lam, Spence & Halliday, 2007). By sharing joint venture, parents have a chance to voice out some of their pressures with the team and win their support.

During sickness of a family member, families go through complex stages of adjustment of their day by day schedule and way of life in order to contain the illness. In order to manage the ailment, to know it and the management that it entail and also to have power to sustain the family member affected with the illness, the other family members require psychotherapy, (Merimaa, 2012). The nurse facilitates the process of predicament and adjustment discovery thus helping in the adjustment process. It is fundamental for nurses to search patients' needs so that a suitable manner and kind of support are identified.

## 2.7 SUMMARY

The support from nurses for family members in the NICU promotes family's ability to support and advocate for the fragile infant. Family needs in the NICU must be assessed and appropriately addressed with respect to each family's unique characteristics. Need for assurance is the consistent need of priority among family members in literature. Families in the NICU need to be empowered to actively engage in caring for the infant and in order to facilitate the attachment process. Admission to the NICU undoubtedly creates a potential crisis in the family system and affects the overall neurodevelopment of the infant. The NICU environment is intimidating and scarring for the family members and it worsens the family stress because of the threat to parental role in the setting. Neonatal care is inherent to ethico legal framework, FCC model and the use of standards and guidelines to guide clinical practice. The healthcare system serves as a catalyst to sustain patient needs and to nurture the professional practice setting for the nurse. The achievement of the patient and the nurse is honestly related to the triumph of the

complete healthcare structure. Nurse's competencies and expertise are derived from the needs of the patient.

The following chapter will discuss the research methods.

# CHAPTER THREE: RESEARCH METHODS

## 3.0 INTRODUCTION

In this chapter, the study setting, the design, population and sampling procedures are outlined. The instrument and procedure for data collection as well as the pilot study was described.

## 3.1 RESEARCH DESIGN

A non-experimental, quantitative, descriptive and cross-sectional design was used to meet the study objectives. According to, Burns and Grove (2011:24), "quantitative research is a formal, objective, rigorous, systematic process for generating numerical information to describe new situations, events or concepts and examine relationships among variables". Descriptive studies give information or insight about naturally occurring events and they achieve this through gathering data, organizing, determining frequencies of certain features, tabulating the data collected thus facilitating interpretation of findings and aiding the reader to understand the data distribution.

## 3.2 RESEARCH SETTING

The research setting was the neonatal ward (NICU and HCU) in a tertiary academic hospital in Johannesburg. The neonatal ward specializes in the care of critically ill infants during the neonatal period. This ward admits infants presenting with both surgical and

medical conditions. The unit is staffed by doctors, professional and enrolled nurses, neonatal and paediatric intensivists, respiratory therapists, child care specialists and clerks. Complex technology and equipment are used to deliver intensive healthcare, particularly mechanical ventilators and patient monitoring systems.

The neonatal ward bed capacity was 15 in PICU/NICU and 35 for high care unit, with 30 nurses for the PICU/NICU and 52 nurses for the HCU. The nurse-patient ratio in the PICU/NICU is 1: 2. The PICU/NICU admits infants from paediatric ward, emergency ward, high care unit, and transitional unit and feeder clinics. The average length of stay in the PICU/NICU is 7 days. The HCU is divided into the two levels i.e. high care 1 which has 20 beds, with a nurse- patient ratio of 1: 3 and high care 2 with a bed capacity of 15 beds and nurse-patient ratio of 1: 4. The average length of stay in the HCU is 14 days. The HCU mostly admits premature babies, critically sick infants who do not need invasive respiratory support from the transitional unit and the PICU/NICU. However, the unit may admit infants from outside the academic hospital within 72 hours of delivery. On admission the infants receive care in the high care level 1 and once stabilized are transferred to the high care level 2.

## 3.3 TARGET POPULATION

Brink, van der Walt and van Rensburg (2013:123) define a research population as "a complete set of persons or objects that possess some common characteristic that is of

interest to the researcher". A research population is sometimes referred to as a target population. The respondents in this study were families of critically ill infants admitted to the neonatal ward between 0-24 hours and 96-120 hours. A preliminary record review conducted in February 2015 revealed that approximately 1651 and 362 children were admitted to the HCU and NICU respectively during the period of 01 January, 2014 to 31 December, 2014. The total admission to the neonatal ward was 2013 patients during this period. It can therefore be concluded that on average there were 168 children admitted to the neonatal ward in a month.

## 3.4 SAMPLE AND SAMPLING METHOD

Burns and Grove (2011:40) state that "sampling defines the process of selecting a group of people or events, behaviours or other elements with which to conduct a study". Non-probability convenience sampling was utilised to pick the respondents to take part in the study. This sampling method was chosen because there was no available register for the study population. Gerrish and Lacey (2006:175) mentioned that "non- probability is used when it is necessary to derive a sample in cases where the study population cannot be identified in advance or a complete list is not available from which a sample can be derived". This sampling framework is considered less rigorous because of the bias associated with it resulting in a sample less representative of the total population. Nevertheless, Gerrish and Lacey (2006) argue that the alternative of not undertaking the research because a sampling frame is not available may impoverish knowledge about

important groups of people such as the homeless, family carers, single parents and other groups where a register does not exist. Burns and Grove (2007:338) argue that "convenience samples are inexpensive, accessible and usually less time consuming to obtain and are commonly used in healthcare studies because sampling frames are not available for many populations and it is difficult to find adequate subjects for studies".

To ensure that the sample size for this study was adequate as well as representative of the total population a statistician was consulted to calculate the sample size, power analysis and confidence interval. Thus the results depicted that to obtain a power analysis of 80% at a confidence interval of 95 % the sample size was calculated to be 90 respondents, completing the questionnaire at two intervals. Based on the record of admissions from the previous year, it was estimated that the NICU admits approximately a quarter of the overall admissions. To obtain a sample representative of the population for each unit, fractional sampling was used to recruit a quarter (23) of the respondents from NICU and the remaining three quarters (67) from HCU. The researcher managed to interview 90 respondents for this study which was adequate since it was the anticipated sample size.

According to Burns and Grove (2007:324), "sampling criteria also referred to as eligibility criteria; include a list of characteristics essential for eligibility or membership in the target population". Inclusion criteria define the characteristics that prospective subjects must possess if they are to be included in the study. The target population in this

study constituted family members of infants admitted to neonatal ward. The following inclusion and exclusion criteria were used:

### 3.4.1 Inclusion Criteria

Inclusion criteria are the "characteristics that the subject or elements must possess to be part of the target population" (Burns & Grove, 2007:291). For this research study a family member (mother, father, guardian) with an infant being admitted to the neonatal ward who was; aged above 18 years, able to speak and understand English, Zulu or Tswana, willing to take part in the study and to fill the questionnaire during 0-24 hours of admission of an infant to the neonatal ward and willing to meet with the researcher 96-120 hours post admission for the second stage of data collection was invited to take part in the study.

### 3.4.2 Exclusion Criteria

"Exclusion criteria are those characteristics that can cause an element to be excluded in the target population" (Burns & Grove, 2011:291).Use of exclusion criteria can augment internal validity and make a study more viable for instance eliminating participants who would be difficult to follow up reduces costs and excluding patients who might be harmed by participation serves ethical purposes (Humphreys & Weisner, 2000) In this study, family members whose infants had congenital abnormalities and poor prognosis, parents with multiple births because they could have different needs as compared to parents of a single birth were excluded. Mostly infants with congenital abnormalities are

critically sick and their condition's prognosis is usually poor. In this view family members might be overwhelmed by their infant's condition. Because of the poor prognosis the researcher anticipated that the infants might die before data collection process was completed and this could impact negatively on the research findings. Children more than 12 months were excluded from the study. The researcher anticipated that family needs for children more than twelve months differ from family needs for children below 12 months old.

## 3.5 DATA COLLECTION

Burns and Grove (2011:41) defined "data collection as the precise, systematic way of gathering information relevant to the research purpose or the specific objectives, questions or hypothesis of the study". Data collection for this study was conducted between the months of August and November 2015.

### 3.5.1 Data collection procedure

Once ethical clearance from the Human Research Ethics Committee and approval from the institution's management was received; data collection commenced in the neonatal ward. During the data gathering period the researcher went to the neonatal ward every morning and identified infants admitted within the 0-24 hours period, the researcher reviewed the infants' charts to establish if the infants met the inclusion criteria for the study (See section 3.4). For infants being admitted from within the research institution it

was easy to establish if the respondents met the inclusion criteria as the information pertaining to their demographic data was readily available within the infant's chart. Respondents' information for infants admitted from outside the research institution was not readily available in the infant's chart; hence the researcher had to wait for visiting time and meet the parents to establish whether they met inclusion criteria of the study to recruit them. The researcher introduced herself to the parents who met the study inclusion criteria and briefly introduced her study to them.

Respondents interested in the study were then taken to a private room in the neonatal ward where a sheet containing detailed information about the study was given. Adequate time to read and comprehend the information sheet was offered to the respondents prior to giving consent to take part in the study. The respondents were requested to complete a cover letter which contained information pertaining to respondent's profile: names, contact details, physical address and the assigned code to ensure all respondents completed the data collection cycle. The whole process of recruitment, reading of information sheet, obtaining consent, completing of the respondent contact details and completion of the questionnaire (NFNI) took approximately 45 minutes. To maintain anonymity and confidentiality respondents were requested not to present their names on the questionnaire but rather use code numbers. The questionnaire was self-administered and researcher administered during the data collection process. The researcher elected to be present during completion of the questionnaire to identify and support families in emotional distress as a result of their infants' admission to neonatal ward. Proximity to

the respondents' enhanced accuracy of data collected as respondents could address clarity issues with researcher.

Upon the completion of the first phase A of data collection an appointment was set with the respondents for the second phase B (within 96-120 hours) in the neonatal ward. The appointment was set for 96 hours to allow the follow up of respondents to be within the time frame for second phase B. Respondents who did not present themselves for the appointment were contacted telephonically and reminded to complete the second questionnaire within 120 hours. Phase B of data collection was completed as scheduled because almost all respondents visited their infant daily to provide expressed breast milk.

The data from the questionnaires was captured on a spreadsheet daily and the hard copies stored in a locked cupboard by the researcher.

### 3.5.2 Instrument

The Neonatal Intensive Care Unit Family Needs Inventory (NFNI) (Appendix D) developed by Ward (2001) was used to collect data for this study. Permission was granted by Dr Kelly Ward to use the NFNI (Appendix G). A preliminary literature survey revealed that the NFNI has not been used in the South African context.

### 3.5.3 Development of the NFNI

The NFNI was developed through revision of the CCFNI customized for paediatric use by Kirschbaum in 1990. One of the first researches investigating the needs of the family was carried out by Molter in 1979 in which 45 need statements were established which provided the framework for the Critical Care Family Needs Inventory (CCFNI). Kirschbaum in 1990 modified the CCFNI to identify needs of parents of children hospitalised in a paediatric intensive care unit, 8 additional needs explicit to parental needs in PICU were incorporated in the instrument. In 2001, Kelly Ward revised the CCFNI (which was modified by Kirschbaum for PICU) to develop the NFNI (Ward, 2001).

The investigator requested six registered NICU nurses to evaluate content of the CCFNI modified for paediatrics. The nurses listed additional need statements they regarded important to parents of hospitalized infants which were not in the PICU instrument. The nurses developed 10 additional need statements. The data was analysed and grammatical changes were made, 62 need statements constituted the NFNI (Ward, 2001:282).Five expert family-centred care nurses examined the 62 need statements questionnaire and 56 needs statements were retained. The investigator further administered the 56 needs statements questionnaire to five neonatal family members for review and the majority agreed that all 56 statements represented the indispensable parents' needs of infants admitted to NICU. The reliability of the 56 item NFNI was calculated to be 0.91 using

Cronbach Alpha. The value is similar to those obtained in other previous studies indicating a sufficient measure of internal consistency (Ward, 2001).

The NFNI questionnaire comprises two sections:

**Part one** collected participant's demographic data, which comprised 6 items namely; age, race, gender, educational level, relationship to the patient and marital status.

**Part two** consisted of a 56 need statement items which required the respondents to rate each need statement on a 4 point Likert scale in the format: *not important (1), slightly important (2), important (3) and very important (4).*

3.5.4 Validity and Reliability

To establish whether the language and terms used in the instrument were clear and easy to understand the instrument was distributed to 5 neonatal experts. The experts were requested to appraise individual items on the measure as well as the complete instrument, to value whether individual items were applicable and appropriate in terms of the construct and identify any difficulties in understanding the individual statements of the instrument. A four point Likert scale of clarity was used and each item's content validity index (I-CVI) calculated by summing up the number of experts rating 3 or 4 for each item and dividing by the total number of experts. Polit, Beck and Owen (2007:2) stated that "items with an item content validity of 0.78 or higher for three or more experts could be

considered evidence of good content validity". The item content validity for the NFNI was > 0.78 for all the need statements. The table below elaborates on the findings.

**TABLE 3.1 Summary of expert response towards relevance of need items in the NFNI**

| | ITEM | Expert 1 | Expert 2 | Expert 3 | Expert 4 | Expert 5 | Calculated I-CVI |
|---|---|---|---|---|---|---|---|
| | **NEEDS FOR SUPPORT** | | | | | | |
| 1 | To have explanations of the environment before going into the NICU for the first time | 4 | 4 | 3 | 3 | 4 | 1 |
| 2 | To have directions about how I can provide care to my infant in the NICU | 4 | 4 | 3 | 2 | 3 | 0.8 |
| 3 | To receive help in responding to the reactions of my infant's siblings | 4 | 4 | 3 | 1 | 3 | 0.8 |
| 4 | To have a private place to breastfeed or use a breast pump | 4 | 4 | 3 | 4 | 3 | 1.0 |
| 5 | To be able to talk to other parents whose infant is in the NICU or has had a similar situation | 4 | 4 | 3 | 3 | 3 | 1.0 |
| 6 | To have a support group of other families available | 4 | 4 | 3 | 3 | 3 | 1.0 |
| 7 | To have someone to help with transportation | 2 | 3 | 3 | 3 | 3 | 0.8 |
| 8 | To share my feelings about what has happened | 3 | 3 | 3 | 3 | 4 | 1.0 |
| 9 | To have friends/family nearby for support | 3 | 3 | 3 | 3 | 2 | 0.8 |
| 10 | To have someone be concerned with my health | 4 | 4 | 3 | 2 | 4 | 0.8 |
| 11 | To have a place to be alone while in the hospital | 2 | 2 | 3 | 3 | 3 | 0.8 |
| 12 | To have pastor, clergy or other person from my church visit | 2 | 3 | 3 | 3 | 3 | 0.8 |
| 13 | To have another person with you when visiting the NICU | 2 | 4 | 3 | 3 | 3 | 0.8 |
| 14 | To talk about the possibility of my infant's death | 4 | 3 | 2 | 3 | 4 | 0.8 |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| 15 | To be given information about individuals that could help with problems concerning my situation | 4 | 4 | 4 | 2 | 4 | 0.8 |
| 16 | To have the neonatal unit quiet and lights dimmed at regular times to let my infant rest | 3 | 3 | 4 | 4 | 4 | 1.0 |
| 17 | To have a place to sleep near the NICU | 3 | 4 | 2 | 3 | 4 | 0.8 |
| 18 | To be allowed to have my infant's siblings visit | 4 | 3 | 3 | 2 | 4 | 0.8 |
| | **NEED FOR INFORMATION** | | | | | | |
| 17 | To have classes about premature infants and their special care needs | 4 | 4 | 3 | 4 | 4 | 1.0 |
| 18 | To be given reading material concerning my infant's medical needs | 4 | 4 | 3 | 4 | 4 | 1.0 |
| 19 | To know which staff members could give information about my infant's health and general wellbeing | 4 | 4 | 3 | 2 | 3 | 0.8 |
| 20 | To talk to the doctor caring for my infant everyday | 4 | 4 | 3 | 3 | 2 | 0.8 |
| 21 | To have a specific staff person to call at the hospital when unable to visit. | 4 | 3 | 3 | 3 | 2 | 0.8 |
| 22 | To know why things were done for my infant | 4 | 4 | 3 | 4 | 4 | 1.0 |
| 23 | To know how my infant is being treated medically | 4 | 4 | 3 | 4 | 4 | 1.0 |
| 24 | To know exactly what is being done for my infant | 4 | 4 | 3 | 4 | 4 | 1.0 |
| 25 | To help make decisions about my infant's plan of care | 3 | 3 | 3 | 2 | 3 | 0.8 |
| 26 | To feel it is alright to cry | 4 | 4 | 3 | 3 | 4 | 1.0 |
| 27 | To be allowed to help with my infant's physical care | 4 | 4 | 3 | 3 | 3 | 1.0 |
| | **NEED FOR PROXIMITY** | | | | | | |
| 28 | To hold my infant in my arms and against my skin as soon as I can | 4 | 4 | 3 | 1 | 3 | 0.8 |
| 29 | To be called at home about important changes in my infant's condition | 4 | 4 | 3 | 4 | 1 | 0.8 |
| 30 | To be able to visit my infant at any time | 4 | 4 | 3 | 4 | 1 | 0.8 |
| 32 | To be told about transfer plans while they are being made | 4 | 4 | 3 | 2 | 4 | 0.8 |
| 33 | To receive information about my infant at least once a day | 4 | 4 | 3 | 2 | 4 | 0.8 |
| 34 | To have the waiting room near the neonatal unit | 4 | 4 | 3 | 3 | 1 | 0.8 |
| 35 | To talk to the same nurse every day | 4 | 3 | 2 | 3 | 4 | 0.8 |
| 36 | To see my infant frequently | 4 | 4 | 3 | 4 | 4 | 1.0 |
| | **NEED FOR ASSURANCE** | | | | | | |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| 37 | To have questions about my infant answered honestly | 4 | 4 | 3 | 4 | 4 | 1.0 |
| 38 | To feel there is hope | 3 | 3 | 2 | 3 | 4 | 0.8 |
| 39 | To be assured that the best care possible is being given to my infant | 4 | 4 | 3 | 4 | 4 | 1.0 |
| 40 | To have explanations given that are understandable | 4 | 4 | 3 | 4 | 4 | 1.0 |
| 41 | To know the expected outcome for my infant | 4 | 4 | 3 | 3 | 4 | 1.0 |
| 42 | To know specific facts concerning my infant's progress | 4 | 4 | 3 | 4 | 4 | 1.0 |
| 43 | To know that my infant is being handled gently by the healthcare providers | 4 | 4 | 3 | 3 | 4 | 1.0 |
| 44 | To know that my infant is being treated for pain | 4 | 4 | 3 | 4 | 4 | 1.0 |
| 45 | To feel that the hospital personnel care about my infant | 4 | 4 | 3 | 3 | 4 | 1.0 |
| 46 | To be recognized as important in my infant's recovery | 4 | 4 | 3 | 3 | 4 | 1.0 |
| 47 | To feel free to choose to stay or leave when my infant is experiencing painful procedures | 2 | 3 | 4 | 3 | 3 | 0.8 |
| 48 | To be assured it is alright to leave the hospital for a while | 3 | 3 | 3 | 3 | 4 | 1.0 |
| | **NEED FOR COMFORT** | | | | | | |
| 49 | To have a waiting room for the neonatal unit | 4 | 4 | 3 | 3 | 4 | 1.0 |
| 50 | To have comfortable furniture in the waiting room | 4 | 4 | 3 | 1 | 3 | 0.8 |
| 51 | To have comfortable chairs at my infant's bedside | 4 | 4 | 3 | 1 | 4 | 0.8 |
| 53 | To feel accepted by the hospital staff | 4 | 4 | 3 | 3 | 4 | 1.0 |
| 54 | To have a telephone near the waiting room | 3 | 3 | 3 | 1 | 3 | 0.8 |
| 55 | To see that the NICU staff provide comfort to my infant, such as giving my infant a pacifier, using a blanket to support my infant's body and talking softly to my infant | 3 | 3 | 3 | 1 | 3 | 0.8 |
| 56 | To have a bathroom near the waiting room | 4 | 4 | 3 | 4 | 4 | 1.0 |

According to Zamanzadeh, Rassouli, Abbaszadeh, Alavi- Majd, Nikanfar and Ghahramanian (2014:164), "content validity addresses the degree to which items of an instrument sufficiently represent the content domain, provides preliminary evidence on

construct validity of an instrument and it can provide information on the representativeness and clarity of items and help improve an instrument through achieving recommendations from an expert panel". As per table 3.1, 4 or 5 experts agreed on the relevance of the need items per construct and the I-CVI for the NFNI needs statements ranged between 0.8 and 1.0 indicating that the instrument was adequate to measure the constructs and the items were clear.

### 3.5.5 Pilot Study

The questionnaire was piloted at the research site from 17–21 August 2015. Nine (7 HCU and 2 NICU) family members of infants being admitted to neonatal ward who met the study criteria were invited to complete the questionnaire. The pilot study was carried out to establish the achievability of the study and identify problems that may be encountered during the data collection process. The questionnaire was easily readable and understandable and no changes were made. Completion of the questionnaire took 45 minutes and did not interfere with parents' visiting time with their infants. As a result parents availed themselves for the second phase of data collection which occurred at 96 – 120 hours post admission to neonatal wards. All the aims of the pilot study were adequately achieved. The findings of data from the pilot study were presented together with the findings of the main study.

## 3.6 ETHICAL CONSIDERATION

Ethics help to determine the difference between acceptable and unacceptable behaviours. Historically, deliberation of ethical issues has been a trait of medical research and continues even to date. University of Nottingham (2013:13) states that "protocols should be submitted for consideration, comment, guidance and approval to a specially appointed ethical review committee, which must be independent of the investigator, the sponsor or any other kind of undue influence". Ethical review and clearance is necessary to ensure that the research is carried out in harmony with prevailing moral values, with smallest hazard to participants.

In light of this, the researcher applied the following ethical considerations in the study:

- The protocol was submitted for peer review to the Department of Nursing Education to evaluate the relevance of the study in Paediatric Nursing.
- The protocol was submitted to the School of Therapeutic Sciences Assessor group to obtain permission to conduct the study in accordance with the university's postgraduate committee (Refer to appendix H).
- Human Research Ethics Committee (Medical) of University of Witwatersrand granted ethical clearance for the research to be conducted (Refer to Appendix I) Protocol No. M150452).
- Permission was requested to gain entry to the research setting and collect data from the management of the hospital of the participating institution (refer to

Appendix B). Appendix J is the letter received from the hospital management granting permission for data collection.

- Permission to recruit respondents and collect data from the NICU and HCU was requested from the Head of Paediatric Department and the Operational Manager. (Refer to Appendix C). Appendix K is the letter granting permission.
- Dr Kelly Ward granted permission for the utilization of the NFNI as referenced in Appendix G.
- An information letter (Appendix A) served as an invitation to potential respondents. Respondents were allowed to withdraw at any time without any penalty.
- A consent form was signed by each respondent indicating their willingness to be part of the study (Appendix E). In addition they completed a cover letter (refer to Appendix F) with their contact details to ensure a complete data collection procedure at 2 phases. This information is excluded from data analysis to maintain confidentiality (Appendix F)
- To uphold confidentiality and anonymity of the respondents, code numbers instead of personal names were used during the phase of data collection and reporting writing. All questionnaires were kept in a lockable facility accessible to the researcher and supervisor. Electronic data was encrypted and the password kept by the researcher.
- All data was retained for the period stipulated by the University of Witwatersrand's research policy.

- Data analysis was conducted in consultation with a statistician from the School of Public Health (Wits University).

## 3.7 SUMMARY

The research methodology applied to conduct this study was discussed in this chapter. The NFNI was validated for use in the research setting and pilot study established the feasibility of data collection. Data collection was completed on the sample size (N=90) calculated over a 4 month period. The following chapter will outline the presentation of results and data analysis.

# CHAPTER FOUR: DATA ANALYSIS

## 4.0 INTRODUCTION

This chapter describes the approach used to analyse data and presentation of the study's findings. Data was collected from ninety family members n= 90, at two points, point A (0-24 hours of admission) and point B ( 96-120 hours of admission) to the neonatal ward. Raw data was entered into Microsoft excel spreadsheet. Errors were verified and corrected. A statistician then imported data into the Statistical Package for Social Sciences (SPSS) software for analysis. Data was analysed using descriptive and inferential statistics. Statistical test used in this study included Chi-square and McNemar's test.

## 4.1 APPROACH TO DATA ANALYSIS

The sample size was determined after consulting a statistician. The level of statistical significance was set at the level of 0.05 (p=0.05). To obtain a power analysis of 80% at a confidence interval of 95% the sample size was calculated to be 90 participants (n= 90), interviewed at two intervals.

### 4.1.1 Response rate

The response rate for this study was a hundred percent (100%). The total sample of ninety (n=90) respondents completed and returned the questionnaire at each data

collection point yielding one hundred and eighty (180) completed questionnaires at the end of the data collection process.

4.1.2 Organization of data for analysis

Data from the one hundred and eighty (180) questionnaires was captured on an Excel spreadsheet, cleaned for errors and entered into the SPSS program for analysis. Demographic data for the respondents was described by use of descriptive statistics (percentages, means, range and standard deviation). All numbers with decimals in these findings were rounded off to one decimal place for easy presentation. The full Likert scale on the NFNI questionnaire was captured and analysed for each need statement.

4.1.3 Data Analysis Tools

Frequencies (f), percentages (%), ranges, means and standard deviations were used to describe demographic data and to summarize responses to each item on the NFNI questionnaire at data collection point A and point B. A table was used to present the results for easy interpretation.

The Chi-Square test was applied to calculate the level of association between demographic variables and the constructs (support, information, proximity, assurance and comfort) in the NFNI questionnaire.

To describe similarities and differences of family needs identified at point A and point B, frequencies (f), percentages (%) and cross tables were used to present top important needs and least important needs.

The McNemar's Test for symmetry was used to determine if there was change in the item responses between point A and point B of the total sample (n=90). The full Likert scale on the NFNI was used. To determine the level of significance, p-values were calculated for each need statement. Values between 0.0 and 0.35 were considered to indicate a small change over time in needs identified by respondents at Point A and Point B, meaning respondents identified similar needs at both data collection points. Increases in the p-value from 0.36 to 1 imply a greater change in responses between the two points.

Cronbach reliability alpha was applied to this study to examine reliability of the Likert scale on the measuring instrument with respect to the five need constructs (support, information, proximity, assurance and comfort). Items of the instrument should be assessed for content validity to determine how well they measure the attribute under investigation (Burns & Grove, 2007). The closer the Cronbach reliability alpha is to 1.0 the better the internal reliability of the items in the scale (Polit & Beck, 2008). The Cronbach alpha for this study was calculated to be 0.94 which indicated that there was a greater level of internal reliability of the data that was collected.

4.1.4 Reporting of results

The data that was collected yielded a large amount of data. For ease of presentation and organisation of findings the researcher had to report findings that will address the research objectives clearly. A weighted average score for each need statement was used to decide on which items to report. The total weighted average score for each item was out of 4.0. Hence all items with a weighted average score of 3.5 and above and 2.0 and below were reported. The items with a weighted average score of 3.5 and above and 2.0 and below were considered most important and least important respectively.

## 4.2 RESULTS AND ANALYSIS OF FINDINGS

### 4.2.1 Questionnaire Part 1: Respondents Demographic Data

Six items included in part one of the questionnaires related to family members demographic data. These items were age, race, gender, educational level, relationship to the patient and marital status. A total of ninety (n=90) family members were included in the sample.

**Table 4.1** Socio-demographic data of respondents (n=90)

| **Socio-demographic Variable** | | **Number of respondents (n)** | **Percentage (%)** |
|---|---|---|---|
| **AGE** | | | |
| | 18-22 | 22 | 24.4 |
| | 23-27 | 18 | 20.0 |

| | | | |
|---|---|---|---|
| | 28-32 | 27 | 30.0 |
| | 33- 37 | 18 | 20.0 |
| | More than 37 | 5 | 5.6 |
| **RACE** | Black | 85 | 94.4 |
| | White | 1 | 1.1 |
| | Coloured | 1 | 1.1 |
| | Indian | 3 | 3.3 |
| **GENDER** | | | |
| | Female | 86 | 95.6 |
| | Male | 4 | 4.4 |
| **EDUCATIONAL LEVEL** | | | |
| | None | 2 | 2.2 |
| | Sub A- B | 0 | 0.0 |
| | Grade 1-7 | 4 | 4.4 |
| | Grade 8-12 | 55 | 61.1 |
| | Tertiary | 29 | 32.2 |
| **RELATIONSHIP TO PATIENT** | | | |
| | Mother | 86 | 95.6 |
| | Father | 4 | 4.4 |
| | Guardian | 0 | 0.0 |
| **MARITAL STATUS** | Single | 59 | 65.6 |
| | Married | 30 | 33.3 |
| | Divorced | 1 | 1.1 |

| | | | |
|---|---|---|---|
| | Widowed | 0 | 0.0 |

4.2.1.1 Age

The mean age of the family members was 28.06 [SD 5.9]. The age ranged between eighteen (18) years to older than 37 years. Most (n=27; 30.0%) were in the age group 28-30 years followed by (n=22; 24.4%) in the 18-22 years age group, the 23-27 years and 33-37 years groups were represented by eighteen (18) (20.0%) and the least number of respondents was the greater than thirty seven (37) years group with five (5) (5.6%) respondents. It was relevant to put an enquiry about age because the NICU experience disturbs the ability to assume the parenting role in the future, young parents will have difficulties assuming this role. Nurses need this information to help them identify the kind of need each respondent will need and thus be in a position to prepare and assist them transition to full parental role successfully. According to Dudek-Shriber (2004), young parents are not sure of what to do and are less responsible in relation to assuming the parental role. A study by Reid and Bramwell (2003:286) revealed that "older mothers reported less stress with younger mothers with less education and poor socioeconomic status reporting more stress". It was also noted that increasing maternal age was significantly associated with greater parenting satisfaction, greater time commitment to the parental role and more optimal mothering behaviours (Reid & Bramwell, 2003).

4.2.1.2 Race

The findings revealed that majority of respondents, eighty five (n=85) 94.4% were Black, followed by Indian three (n=3) 3.3% and both White and Coloured had one (n=1) 1.1% each. In South Africa the population is predominately Black. Given the racial, cultural, ethnic and linguistic differences generated by South African history, it was assumed that the differences in race would influence findings with regard to family needs in neonatal ward. The classification of race contributes to inequalities in health and health access (Caprio, Daniels, Drewnowski, Kaufman, Palinka, Rosenbloom & Schwimmer, 2008). Perceived discrimination and racial bias remains a major concern in the healthcare sector (Egede, 2006).

4.2.1.3 Gender

The findings on the genders of the respondents, a majority eighty six (n=86) 95.6%) were females and minority four (n=4) 4.4% males. Female parents are the primary caregiver and they may feel a greater responsibility for their infant due to extreme physical maternal attachment they have had during pregnancy (Franck & Spencer, 2003). "Research reveals patients may be treated differently by healthcare providers according to whether they are male or female and prospective patients may also behave in gendered ways that impact on their health needs" (Taylor & Green, 2008:3227). An awareness of needs in relation to gender is therefore relevant in the neonatal ward.

4.2.1.4 Educational level

The distribution for educational level indicated that majority, fifty five (n=55) 61.1% had done grade 8-12, followed by tertiary qualification, twenty nine (n=29) 32.2%, four (n=4) 4.4% had done grade 1-7, two (n= 2) 2.2% had no educational level. Family needs vary between educational statuses of respondents. Educated parents are eager to learn and familiarize themselves with their infant's condition and prognosis therefore expects nurses to share information with them to empower them to actively participate in the care of the infant. Parents with lower educational level, although they predominantly rely on nurses' explanations of infant's condition may not interrogate information given therefore participate minimally in infant care. According to Miquel-Verges, Donohue and Boss (2011) parents who are educated are more comfortable and confident in asking questions, more able to participate in their infant's care and are more able to collaborate in decision-making as compared to illiterate parents.

4.2.1.5 Relationship to the patient

Findings pertaining to family members' relationship to the patient revealed that majority, eighty six (n=86) 95.6% were mothers and fathers, four (n=4) 4.4%. It was anticipated that family needs might be influenced by the relationship to patient. The physical and emotional attachment with the baby is determined by the relationship of the respondent to the patient, hence needs of biological parents might differ from needs of guardians. The process of connecting to the baby post giving birth to a premature baby is different across mothers and fathers (Hagen, Iversen & Svindseth, 2016). Fathers reported that their time

in NICU was the start of a relationship with their baby and they also reported strong feeling of guilt as they were unable to spend more time in the NICU as they had to take care of their work and other family members (Hagen et al., 2016). In contrast, mothers experienced more helplessness and were more reluctant to prepare for the future because of fear of their baby passing away (Hagen et al., 2016). In this view, needs are unique to individuals depending on the relationship to the patient.

#### 4.2.1.6 Marital status

The distribution showed that majority, fifty nine (n=59) 65.6% were single, followed by married, thirty (n=30) 33.3%, divorced were one (n=1) 1.1%.Marital status was included to assess if there was any relationship with the family needs in the NICU. "Between 26% and 36% of children living in an unmarried family household are below the poverty level compared with only 10% of children living with married parent" (Higginbothan & Skogrand, 2010:133). Consequently, with many ICUs having restricted visitation policies (Al-Mutair, Plummer, Clerehan & O'Brien, 2013) single parents might struggle to visit their infant daily hence putting a strain on attempts directed towards facilitating parental role acquisition and attachment.

### 4.2.2 Questionnaire Part 2: Family needs

#### 4.2.2.1 Identification of family needs

This section comprised of fifty-six (56) need statements on the NFNI to which responses were obtained from the respondents through researcher and self-administered

questionnaires on two separate occasions, point A (0-24 hours of admission) and point B (96-120 hours of admission) to the neonatal ward. The number of respondents was ninety (n=90), however, in some cases responses to the need statements were less than expected because there were instances where the respondents chose two options for a need statement or left it blank and in that case the response was disqualified.

Data was analysed to identify the most and least important need statements per need category on scale, item levels and construct between point A and point B. Note that for purposes of easy presentation of findings and to be able to report findings that were essential in addressing the objectives of the study the researcher reported need statements with a weighted average score of 3.5 and above and 2.0 and below. However, in some instances need statements with scores less than 3.5 appeared because of the difference in scores between point A and point B. Descriptive statistics in the form of frequencies (f) and percentages (%) were used to describe family needs. Results of this process showed that majority of need statements recorded a weighted average score of 3.5 and above at both point A (31; 55.36%) and point B (30; 53.57%). At point A only one need statement "to have a place to be alone while in the hospital" recorded a weighted average score of 2.0. In this study, most of the needs statements scored above 2.0 hence it can be concluded that overall all need statements were either important or very important to the respondents. The results were presented in **Table 4.2 (page 72- 75).**

Data was then summarized to determine the order of importance of the five constructs (support, information, proximity, assurance and comfort) at point A and point B. The total need statements that scored 3.5 and more under each construct were summed up and a percentage (%) calculated based on the total number of the need statements that composed that particular construct. This was appropriate because of the difference in the number of need statements in each need construct. From this process it was concluded that the order of the constructs was different at point A and B, specifically in the order; assurance (91.7%), proximity (87.5%), information (81.8%), comfort (28.6%) and support (11.1%)) at point A and at point B in the order; assurance (91.7%), information (90.9%), proximity (75.0%), comfort (28.6%) and support (5.6%). These findings showed that the top priority need constructs to the respondents were; need for assurance, information and proximity. Hence from now on the discussion of the findings in this research study will be focused on these three constructs. The results of this process were presented in **Figure 4.1 (page 71).**

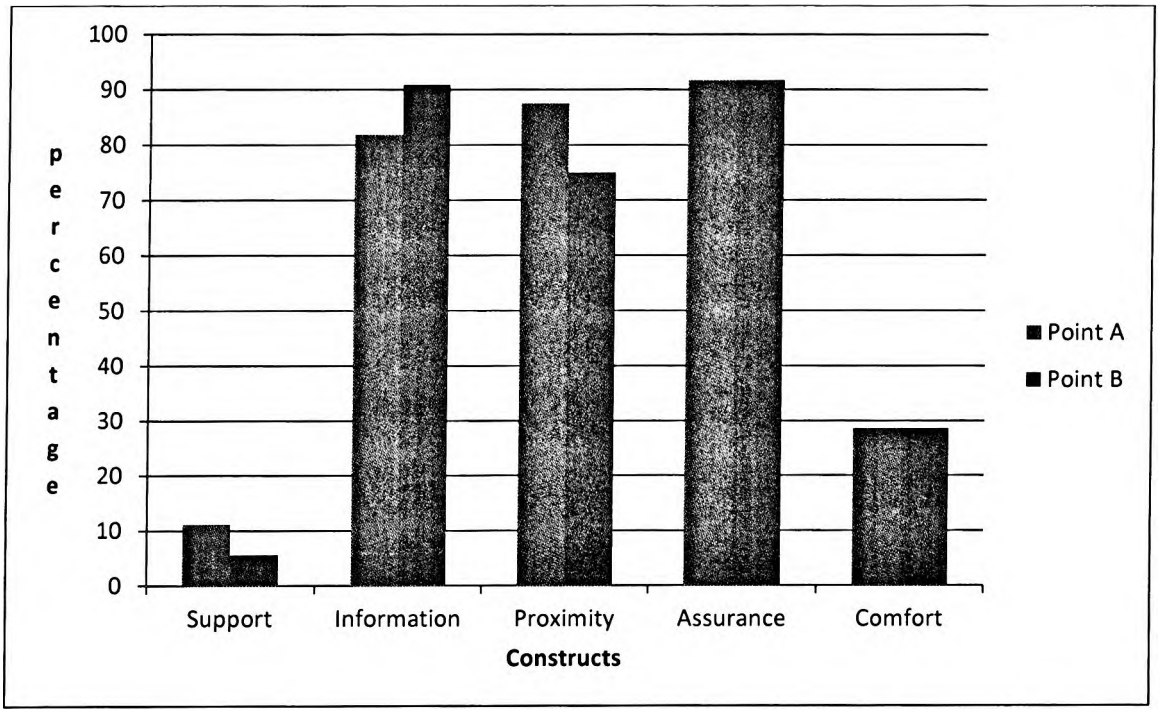



**Figure 4.1** Respondents scores on the constructs at point A and point B

**Table 4.2 Summary of the most and least important need statements identified by family members at point A and point B**

| | Need statement | Not important | | Slightly important | | Important | | Very important | | Weighted average score | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | | A | B | A | B | A | B | A | B | A | B |
| Support | To have explanations of the environment before going into the NICU for the first time. | 3 (3.3%) | 2 (2.4%) | 2 (2.2%) | 7 (8.2%) | 27 (30%) | 30 (35.3%) | 58 (64.4%) | 46 (54.1%) | 3.6 | 3.4 |
| | To have directions about how I can provide care to my infant in the NICU. | 0 (0%) | 3 (3.5%) | 0 (0%) | 4 (4.7%) | 23 (25.6%) | 32 (37.6%) | 67 (74.4%) | 46 (54.1%) | 3.7 | 3.4 |
| | To have someone to help with transportation. | 7 (7.8%) | 1 (1.2%) | 9 (10%) | 7 (8.1%) | 29 (32.6%) | 30 (34.9%) | 45 (50%) | 48 (55.8%) | 3.2 | 3.5 |
| | To have a place to be alone while in the hospital. | 43 (48.9%) | 40 (47.1%) | 15 (17%) | 13 (15.3%) | 18 (20.5%) | 13 (15.3%) | 12 (13.6%) | 19 (22.4%) | 2.0 | 2.1 |
| Information | To have classes about premature infants and their special care needs. | 4 (4.4%) | 1 (1.2%) | 2 (2.22%) | 5 (5.9%) | 20 (22.2%) | 12 (14.1%) | 64 (71.1%) | 67 (78.8%) | 3.6 | 3.7 |
| | To be given reading material concerning my infant's medical needs. | 0 (0%) | 1 (1.2%) | 4 (4.4%) | 4 (4.7%) | 24 (26.7%) | 14 (16.3%) | 62 (68.9%) | 67 (77.9%) | 3.6 | 3.7 |
| | To know which staff members could give | 1 (1.1%) | 0 (0%) | 2 (2.2%) | 2 (2.3%) | 25 (27.8%) | 21 (24.4%) | 62 (68.7%) | 63 (73.3%) | 3.6 | 3.7 |

| | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | information about my infant's health and general wellbeing. | | | | | | | | | | |
| | To talk to the doctor caring for my infant every day. | 2 (2.2%) | 1 (1.2%) | 3 (3.3%) | 3 (3.5%) | 21 (23.3%) | 21 (24.4%) | 64 (71.1%) | 61 (70.9%) | 3.6 | 3.7 |
| | To have a specific staff person to call at the hospital when unable to visit. | 4 (4.4%) | 2 (2.4%) | 5 (5.6%) | 4 (4.7%) | 27 (30%) | 25 (29.4%) | 54 (60%) | 54 (63.5%) | 3.5 | 3.5 |
| | To know why things were done for my infant. | 3 (3.3%) | 2 (2.4%) | 0 (0%) | 1 (1.2%) | 29 (32.2%) | 22 (25.9%) | 58 (64.4%) | 60 (70.6%) | 3.6 | 3.6 |
| | To know how my infant is being treated medically. | 2 (2.2%) | 2 (2.3%) | 4 (4.4%) | 3 (3.5%) | 22 (24.4%) | 22 (25.6%) | 62 (68.9%) | 59 (68.6%) | 3.6 | 3.6 |
| | To know exactly what is being done for my infant. | 1 (1.1%) | 0 (0%) | 2 (2.2%) | 3 (3.6%) | 24 (26.7%) | 21 (25%) | 63 (70%) | 60 (71.4%) | 3.7 | 3.7 |
| | To help make decisions about my infant's plan of care. | 2 (2.2%) | 2 (2.3%) | 6 (6.7%) | 4 (4.7%) | 23 (25.6%) | 17 (19.8%) | 59 (65.6%) | 63 (73.3%) | 3.5 | 3.6 |
| | To be allowed to help with my infant's physical care. | 2 (2.2%) | 4 (4.7%) | 6 (6.7%) | 4 (4.7%) | 23 (25.6%) | 23 (26.7%) | 59 (65.6%) | 55 (64%) | 3.4 | 3.5 |
| | To hold my infant in my arms and against my skin as soon as i can. | 3 (3.3%) | 0 (0.0%) | 7 (7.8%) | 8 (9.3%) | 15 (16.7%) | 11 (12.8%) | 65 (72.2%) | 67 (77.9%) | 3.6 | 3.7 |
| **Proximity** | To be called at home about important changes in my infant's | 3 (3.3%) | 0 (0.0%) | 3 (3.3%) | 5 (5.9%) | 13 (14.4%) | 9 (10.6%) | 71 (78.9%) | 71 (83.5%) | 3.7 | 3.8 |

| | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | condition. | | | | | | | | | | |
| | To be able to visit my infant at any time. | 2 (2.2%) | 0 (0.0%) | 1 (1.1%) | 1 (1.2%) | 19 (21.1%) | 22 (25.6%) | 68 (75.6%) | 63 (73.3%) | 3.7 | 3.7 |
| | To be told about transfer plans while they are being made. | 4 (4.4%) | 2 (2.3%) | 3 (3.3%) | 5 (5.8%) | 19 (21.1%) | 15 (17.4%) | 19 (21.1%) | 64 (74.4%) | 3.6 | 3.6 |
| | To receive information about my infant at least once a day. | 2 (2.2%) | 2 (2.3%) | 3 (3.3%) | 1 (1.2%) | 24 (26.7%) | 25 (29.1%) | 61 (67.8%) | 58 (67.4%) | 3.6 | 3.6 |
| | To have the waiting room near the neonatal unit. | 2 (2.2%) | 3 (3.5%) | 6 (6.7%) | 9 (10.5%) | 31 (34.4%) | 37 (43%) | 51 (56.7%) | 37 (43,0%) | 3.5 | 3.3 |
| | To see my infant frequently. | 3 (3.4%) | 2 (2.4%) | 5 (5.6%) | 3 (3.5%) | 19 (21.3%) | 26 (30.6%) | 62 (69.7%) | 54 (63.5%) | 3.6 | 3.6 |
| **Assurance** | To have questions about my infant answered honestly. | 2 (2.2%) | 0 (0.0%) | 1 (1.1%) | 2 (2.4%) | 11 (12.4%) | 9 (10.6%) | 75 (84.3%) | 74 (87.1%) | 3.8 | 3.8 |
| | To feel there is hope. | 0 (0.0%) | 0 (0.0%) | 1 (1.1%) | 3 (3.5%) | 17 (19.1%) | 14 (16.3%) | 71 (79.8%) | 69 (80.2%) | 3.8 | 3.8 |
| | To be assured that the best care possible is being given to my infant. | 1 (1.1%) | 0 (0.0%) | 2 (2.2%) | 2 (2.4%) | 14 (15.7%) | 18 (21.2%) | 72 (80.9%) | 65 (76.5%) | 3.8 | 3.7 |
| | To have explanations given that are understandable. | 1 (1.1%) | 1 (1.2%) | 1 (1.1%) | 2 (2.3%) | 18 (20.2%) | 14 (16.3%) | 69 (77.5%) | 69 (80.2%) | 3.7 | 3.8 |
| | To know the expected outcome for my infant. | 1 (1.1%) | 0 (0.0%) | 3 (3.4%) | 3 (3.5%) | 20 (22.5%) | 18 (20.9%) | 65 (73.0%) | 65 (75.6%) | 3.7 | 3.7 |
| | To know specific facts concerning my infant's progress. | 0 (0%) | 0 (0%) | 0 (0%) | 2 (2.3%) | 16 (18%) | 21 (24.4%) | 73 (82%) | 63 (73.3%) | 3.8 | 3.7 |
| | To know that my | 1 | 1 | 1 | 1 | 18 (20.2%) | 16 | 69 (77.5%) | 68 | 3.7 | 3.8 |

| | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | infant is being handled gently by the healthcare providers. | (1.1%) | (1.2%) | (1.1%) | (1.2%) | | (18.6%) | | (79.1%) | | |
| | To know that my infant is being treated for pain. | 1 (1.1%) | 0 (0.0%) | 3 (3.4%) | 3 (3.5%) | 17 (19.3%) | 12 (14.0%) | 67 (76.1%) | 71 (82.6%) | 3.7 | 3.8 |
| | To feel that the hospital personnel care about my infant. | 1 (1.1%) | 0 (0.0%) | 2 (2.3%) | 1 (1.2%) | 24 (27.3%) | 14 (16.3%) | 61 (69.3%) | 71 (82.6%) | 3.6 | 3.8 |
| | To be recognized as important in my infant's recovery. | 0 (0%) | 0 (0%) | 3 (3.4%) | 3 (3.5%) | 22 (24.7%) | 11 (12.8%) | 64 (71.9%) | 72 (83.7%) | 3.7 | 3.8 |
| | To feel free to choose to stay or leave when my infant is experiencing painful procedures. | 4 (4.5%) | 5 (5.8%) | 6 (6.7%) | 9 (10.5%) | 6 (6.7%) | 13 (15.1%) | 59 (66.3%) | 59 (68.6%) | 3.5 | 3.5 |
| **Comfort** | To feel accepted by the hospital staff. | 3 (3.4) | 0 (0.0%) | 1 (1.1%) | 4 (4.7%) | 26 (29.2%) | 20 (23.3%) | 59 (66.3%) | 62 (72.1%) | 3.5 | 3.7 |
| | To see that the NICU staff provide comfort to my infant, such as giving my infant a pacifier, using a blanket to support my infant's body and talking softly to my infant. | 2 (2.2%) | 0 (0%) | 4 (4.4%) | 4 (4.7%) | 29 (32.6%) | 31 (36%) | 54 (60.7%) | 51 (59.3%) | 3.5 | 3.5 |

4.2.2.2 Comparison of family needs between point A and point B

Data were analysed to rank top need statements between point A and point B on the top three constructs (assurance, information and proximity). This was done by comparing the weighted average scores of each need statement at point A and at point B.

**Table 4.3 Summary of family needs between point A and point B**

| Construct | Item No. | Need statement | Weighted average score | | Sig-value (McNemar's test) |
|---|---|---|---|---|---|
| | | | Point A | Point B | |
| INFORMATION | 17 | To have classes about premature infants and their special care needs. | 3.6 | 3.7 | 0.3 |
| | 18 | To be given reading material concerning my infant's medical needs. | 3.6 | 3.7 | — |
| | 19 | To know which staff members could give information about my infant's health and general wellbeing. | 3.6 | 3.7 | — |
| | 20 | To talk to the doctor caring for my infant every day. | 3.6 | 3.7 | 1.0 |
| | 21 | To have a specific staff person to call at the hospital when unable to visit. | 3.5 | 3.5 | 0.6 |
| | 22 | To know why things were done for my infant. | 3.6 | 3.6 | — |
| | 23 | To know how my infant is being treated medically. | 3.6 | 3.6 | 0.9 |
| | 24 | To know exactly what is being done for my infant. | 3.7 | 3.7 | 1.0 |
| | 25 | To help make decisions about my infant's plan of care. | 3.5 | 3.6 | 0.7 |
| | 27 | To be allowed to help with my infant's physical care. | 3.4 | 3.5 | 0.6 |
| PROXIMITY | 28 | To hold my infant in my arms and against my skin as soon as I can. | 3.6 | 3.7 | — |
| | 29 | To be called at home about important changes in my infant's condition. | 3.7 | 3.8 | — |
| | 30 | To be able to visit my infant at any time. | 3.7 | 3.7 | — |
| | 32 | To be told about transfer plans while they are being made. | 3.6 | 3.6 | 0.8 |
| | 33 | To receive information about my infant at least once a day. | 3.6 | 3.6 | 0.8 |
| | 34 | To have the waiting room near the neonatal unit. | 3.6 | 3.3 | 0.1 |
| | 36 | To see my infant frequently. | 3.6 | 3.6 | 0.5 |
| | 37 | To have questions about my infant answered honestly. | 3.8 | 3.8 | — |

| | | | | | |
|---|---|---|---|---|---|
| **ASSURANCE** | 38 | To feel there is hope | 3.8 | 3.8 | 0.2 |
| | 39 | To be assured that the best care possible is being given to my infant. | 3.8 | 3.7 | — |
| | 40 | To have explanations given that are understandable. | 3.7 | 3.8 | 0.6 |
| | 41 | To know the expected outcome for my infant. | 3.7 | 3.7 | — |
| | 42 | To know specific facts concerning my infant's progress. | 3.8 | 3.7 | — |
| | 43 | To know that my infant is being handled gently by the healthcare providers. | 3.7 | 3.8 | 0.5 |
| | 44 | To know that my infant is being treated for pain. | 3.7 | 3.8 | 0.4 |
| | 45 | To feel that the hospital personnel care about my infant. | 3.6 | 3.8 | 0.1 |
| | 46 | To be recognized as important in my infant's recovery. | 3.7 | 3.8 | 0.2 |
| | 47 | To feel free to choose to stay or leave when my infant is experiencing painful procedures. | 3.5 | 3.5 | — |

Eleven (11) need items under the need for assurance had a weighted average score of 3.5 and more, from these items, seven (7) items (37, 38, 40, 43, 44, 45 and 46) recorded a weighted average score of 3.8 each at point B and four (4) need items (37, 38, 39 and 42) scored 3.8 at point A. Under the need for information the highest weighted average score recorded was 3.7 at both point A (item 24) and point B (items 17-20 and 24). Findings showed that with regard to the need for proximity, at point A the highest weighted average score was 3.7 for items 29-30 whereas at point B the highest weighted average score was 3.8 for item 29 and 3.7 for items 28 and 30. At point A the needs were still in the order assurance, proximity and information and at point B in the order assurance, information and proximity. However, from these findings regarding weighted average scores per need item, it can be deduced that respondents' need for assurance, information and proximity increased from point A to point B. A possible explanation for these findings was that families were more willing and ready to participate in their infant's care after 4 days of admission to the neonatal ward and that was not feasible because of the physical barriers in the intensive care unit in relation to baby being connected to a ventilator. **Table 4.3 (page 77-78)** represents a summary of the findings.

Data were also analysed in order to determine if time spent in the neonatal ward influenced how family members perceived needs between point A and point B. P-values were calculated using McNemar's test for symmetry. Testing was done at 0.05 level of significance (p=0.05). Findings indicated that there was no statistical significance between point A and point B. The need items scored more than 0.05 and in some cases the test could not run because the number of respondents between point

A and point B was not symmetrical. However, bigger values for McNemar's test indicated that family members scored differently for a particular need statement at point A and point B. The lower values of McNemar's test for a particular need statement showed that respondents scored almost similar for that statement at both point A and point B. **Table 4.2** summarized the findings.

4.2.3 Relationship between demographic variables and the constructs

Data were analysed to establish whether there was any association between the demographic variables (age, race, gender, educational status, relationship to patient and marital status). A Chi-Square test was run between demographic variables of the respondents and all the need constructs (support, information, proximity, assurance and comfort).

**Table 4.4 Summarized the association between the demographic variables and the constructs at point A and point B**

| | | Significance Values (Sig value) | | | | | |
|---|---|---|---|---|---|---|---|
| **Construct** | | Age | Race | Gender | Educational Level | Relationship to patient | Marital Status |
| **Support** | | 0.751 | 0.002* | 0.644 | 0.036* | 0.733 | 0.162 |
| **Information** | | 0.42 | 0.072 | 0.538 | 0.298 | 0.009* | 0.412 |
| **Proximity** | | 0.547 | 0.664 | 0.968 | 0.006* | 0.658 | 0.081 |
| **Assurance** | | 0.629 | 0.855 | 0.495 | 0.026* | 0.75 | 0.938 |
| **Comfort** | | 0.89 | 0.776 | 0.991 | 0.219 | 0.904 | 0.071 |

Key: * = statistically significant (p<0,05)

The results indicated there was no significant association between the age of the respondents and all the constructs. All the significance values (p-values) were greater than the level of significance at 0.05. Findings from a Chi-Square test between race of

respondent and all other needs revealed different results. The results indicated that the significant values (p-values) for need for support against race was less than the level of significance at 0.05 hence there was sufficient evidence that there was an association between race of a respondent and the need for support. All other constructs were not associated to a respondent's race. The results also indicated that all the significance values (p-values) for all the need constructs against gender were greater than the level of significance at 0.05 hence there was no sufficient evidence that there was an association between gender of respondents and all the associated constructs. The results for need for support, need for proximity as well as need for assurance against education level were statistically significant implying that there was a relationship between these constructs and educational level. The other significance values (p-values) were greater than the level of significance at 0.05, there was no sufficient evidence that respondent's educational level was related to both need for information and need for comfort. The results for need for information against relationship to patient showed significance value (p-value) of 0.009 which was less than the level of significance at 0.05. Hence there was sufficient evidence that respondent's relationship to patient was related to need for information. The other constructs (support, assurance, proximity and comfort) were not statistically sufficient to be associated to relationship to patient. The results indicated that all the significance. values (p-values) for all the constructs against marital status were greater than the level of significance at 0.05 implying that there was no sufficient evidence that there was an association between marital status and all the related constructs.

## 4.3 SUMMARY

This chapter presented data analysis and results. Descriptive and inferential statistics were used to describe, synthesize and analyse the data. Findings showed that educational level of the respondents and the constructs (support, proximity and assurance) were statistically significant with p-values less than 0.05. There was sufficient evidence that there was an association between race of the respondent and the need for support (p-value, 0.002). Relationship to patient was shown to influence the need for information.

Top three priorities needs have been identified as the need for assurance, information and proximity. The need statements at point A and point B demonstrated no statistical significance at the set p-value of 0.05. There were variations on how respondents scored each need item statement at point A and point B. Family needs increased from point A to point B hence it can be concluded that needs change over time.

The results also showed that needs change over time, assessing family needs at different time points in the neonatal ward is pertinent. These findings will be discussed in the next chapter in relation to the study objectives. Conclusion of the study and recommendations will be discussed.

# CHAPTER FIVE: SUMMARY, DISCUSSION OF RESULTS, RECOMMENDATIONS AND CONCULSION

## 5.0 INTRODUCTION

In the final chapter of the research report, a summary of the study is presented; followed by a discussion of the main findings with literary support. To conclude the study the limitations, recommendations from the study are outlined.

## 5.1 SUMMARY OF THE STUDY

The purpose of the study was to investigate the needs of families of infants admitted to the neonatal ward at an Academic Tertiary Hospital in Johannesburg.

The objectives of the study were to:

- Describe needs of families of infants admitted to the neonatal ward as identified by family members.
- Explore and describe similarities and differences in needs of families at first contact, point A (0-24hours) and second contact, point B (96-120 hours).

### 5.1.1 Methodology

The study was conducted in a neonatal ward at an Academic Tertiary Hospital. A quantitative, descriptive and cross-sectional design was used to describe family needs and to explore and describe similarities and differences in needs of families at point A and point B. Permissions to conduct the study were obtained from the relevant authorities (see appendix H- K). A pilot study was carried out prior to commencing of the study to test for the achievability of the study. A statistician was consulted to

calculate sample size, power analysis and confidence interval of the study. The NFNI (refer to appendix D) was the instrument used for data collection. The data collection phase ran over a four months period resulting in one hundred and eighty (180) questionnaires completed over the entire data collection phase. Descriptive and inferential statistics were used to analyse data with the assistance from a statistician.

## 5.2 MAIN FINDINGS AND DISCUSSION

The demographic variables in this study indicated that respondents' race was significantly associated with the need for support (p=0.02), educational level was significantly associated with the need for support (p=0.036), proximity (p=0.06) and assurance (p=0.026) and relationship to patient was statistically significant in relation to needs for information (p=0.009). In this study majority of respondents were infants' mothers (95.6%) and fathers (4.6%), findings from this study relating to gender should be taken with caution considering the fact that only four males were respondents.

Superior understanding of infant development has been established to be powerfully allied with parental educational level (Hess, Teti & Hussey- Gardner, 2004). Parents with higher educational level may vigorously seek more information and clarification concerning their infants' prognosis of care in the neonatal ward, leading to enhanced understanding of their infants' ultimate results (Sargent, 2008). In this view, gaining knowledge and understanding about the infant's condition would influence how they could perceive needs for support, proximity and assurance. Majority of respondents (61.1%) in the current study had done grade 8-12 and 32.2% had a tertiary

qualification, consequently, these findings perhaps explains the statistical significance of needs for support, proximity and assurance against educational level, educated individuals are more aware of their rights and privileges in the health arena. Educational status is directly linked to employment and income, educated respondents are able to support themselves financially, in light of this, at point B most of the respondents were travelling between home and the hospital to visit the infant and some might have struggled with travelling funds hence explaining the statistical significance between needs for support, proximity and assurance against educational level.

The statistical significant value between relation to patient and needs for information indicated that there was an association for needs for information between fathers and mothers. However, these findings were not explored further to establish how the two ranked informational needs in this study. On the other hand, Ward (2001:63) found "considerable disparity between gender with mothers placing more weight on acquiring emotional support, assurance and informational needs than fathers did". Mundy (2010:162) showed that "mothers rated support and information needs faintly higher than fathers; however this difference was not statistically significant".

Mundy (2010:161) further found that "African-American parents rated the overall need statements as more important than Whites and Hispanics specifically needs for support, assurance and comfort". Respondents in the study were predominately Black hence in South Africa Blacks are the major population categorised under poverty thus this could explain the significant association between race and needs for support in this study.

5.2.1 First objective: Describe needs of families of infants admitted to the neonatal ward as identified by family members.

Findings from this study showed that generally family members ranked most of the need items as either important or very important during data collection. Overall the top three needs identified by family members in this study were assurance, information and proximity. The need for support was ranked lowest in this population group. Similarly, Lam and Beaulieu (2004) reported that families' needs for information, assurance and proximity headed the list in order of importance, higher than support and comfort. Mundy (2010) supported these findings by ranking family needs from the highest to the lowest as assurance, proximity, information, comfort and support.

The need for assurance was identified as the highest ranked need with most need statements scoring a weighted average score of 3.8 specifically items 37-40 and 42-46 in the current study. The high scores for the need for assurance in this study may be attributed to the fact that respondents were confronted with the intimidating and unfamiliar NICU environment with their baby attached to life support machines with tubing all over and hence they got overwhelmed, anxious and were uncertain about the infant's health outcome and they needed assurance about their infant's condition (Fregran et al., 2008). Additionally, when nurses do recognise these needs they may not always address them appropriately because the reality of the neonatal ward situation is that the healthcare team is foremost obligated to devote their attention to meet the needs of the infant and not the family (Khalaila, 2013: 1173). Furthermore, the exclusion of family during invasive procedures and resuscitation increases feelings

of anxiety, frustration and concern for the infant's wellbeing. Cameron, Schleien and Morris (2009) and Pasquale, Pasquale, Baga, Eid and Leske (2010) reported that family preferred to be present during invasive procedures and resuscitation. Respondents in this study reinforced the findings from these two studies by recording a weighted average score of 3.5 for "to feel free to choose to stay or leave when my infant is experiencing painful procedures". Another possible explanation for this was that family members are often always worried about the well-being of their infant during hospitalisation in the neonatal ward hence they need assurance that their infant is well taken care of. Assurance helps them anticipate the kind of outcome to expect and they tend to prepare themselves psychologically in relation to the infant's progress. When nurses provide sufficient, honest and consistent communication and involve parents in the infant's care, parents become assured about their baby and experience less anxiety. The amount of information parents receive and the way nurses share that information with them determines how they will perceive the needs for assurance. Assurance about the patient's condition helps to reduce anxiety and concerns of family members (Chien, Ip & Lee, 2005). According to Sweet and Mannix (2012) communication and information in the form of assurance has been recognised as important needs. Gooding et al. (2011:24) state that "throughout the neonatal ward trajectory, parents should be offered frequent and consistent information about their infant's condition, including realistic prognosis based on the infant's condition and the capabilities of the neonatal unit".

The results in this study also showed that the need for information was amongst the top three priority needs in the population group in this study. A weighted average score of 3.5 or more was recorded for ten (10) need statements out of total of eleven

(11) need statements which comprised the need for information, particularly items (17-25 and 27). Davidson, Powers, Kamyar, Hedayat, Tieszen, Kon, Shepard, Spuhler, Todres, Levy, Barr, Ghandi, Hirsch and Armstrong (2007) reported that understandable information sharing with the family was fundamental for precise evaluation of their needs and was an imperative basic constituent in addressing the family members' needs of intensive care unit patients and is the foundation for establishment of a trustworthy and therapeutic relationship with nurses. Obtaining information has been considered an active and adaptive strategy that has been used by parents in the neonatal ward (Matricardi, Agostino, Fedeli & Montrosso, 2013). Bialoskurski et al. (2002) investigated needs and priorities of mothers in the neonatal ward and findings revealed that "the need for accurate, reliable and topic specific information and the need for regular communication were rated the highest". Similarly, information related needs have been ranked high by parents in neonatal ward, (Mundy, 2010; Ward, 2001). In the current study the high scoring for informational needs was attributed to the fact that most respondents had a higher educational level, therefore the researcher anticipated that they were able to research and gather information from external sources about the infant's condition and hence scored more on needs relating to information. Additionally, because of their higher educational level, respondents in the current study were more aware of their rights for information and they understand the importance of them participating in the decision making process for their infants. As a result the information they receive from the nurses enabled them to actively and successfully contribute in the decision making process. Redshaw and Hamilton (2010:367) noted that "parents describe their experience in the neonatal ward as a progression from being 'watchers', to 'learners'

then 'doers' as they are encouraged and empowered to care for their baby". Based on the scenario described by Redshaw et al. (2010) it can be argued that alongside this path information desires fluctuate. On the other hand, in a true family-centred care culture, the role of the nurse is altered from 'doing' and supervising to becoming a resource and a facilitator (Flacking et al., 2012:1035). People differ in the quantity of information they can incorporate underneath pressure, therefore identifying parents' views through paying attention and scrutinizing will assist nursing staff to identify parents' cues and react properly (Cockcroft, 2012). Consequently, Redshaw et al. (2010:367) note that "well-timed and suitable communication procedures lessen pressure, boost understanding of care and advancement and facilitate contribution in decision making". Giving information is crucial as it alleviates anxiety and stress related to the hospitalised infant and hence enables family members to develop effective coping strategies and actively engage in the process of decision making.

The need for proximity comprised of eight (8) need statements, seven (7) need statements (28-30, 32-34 and 36) scored weighted average scores of 3.5 and above. The advanced technology atmosphere, scheduled clinical practice and the characteristics of sick infants often impede with hard work to ascertain and preserve close proximity (Skene, Franck, Curtis & Gerrish, 2012). On admission of the infant to the neonatal ward the medical team focused on stabilising the child's condition with a lot of procedures being performed and hence meeting the needs for proximity was compromised with family members having to wait outside the neonatal ward most of the time and were only asked to come in once the infant's condition was stabilised. According to Cockcroft (2012:108), "parents can feel guilt for not being able to take care of their baby and the delay in being able to see or touch the baby can

affect bonding". The research setting had an open visitation policy, interestingly respondents in this study scored the need "to be able to visit my infant any time" and "to see my infant frequently" high, perhaps because the nurses determined when they can come to the infant's bedside depending on whether there were procedures or discussions about their infant going on. Gooding et al. (2011:24) observed that "most neonatal wards continue to close during nursing shift changes and reports; new admissions, emergencies and neonatal deaths and parents are often asked to step out during medical procedures despite evidence that parental presence reduce parental anxiety". Shaw et al. (2006) reported that the incapacity to be of assistance, hold, care for the infant, shield the infant from soreness and share the infant with the other family members was the chief source of stress. Shin and White-Traut (2006) established that frequent contact with their mothers gave a sense of psychological stability and initiated maternal attachment, which leads to calming down the psycho-emotional turmoil. Nurses should possess a good understanding of family needs so that they strive to embrace institutional policies and guidelines in addressing needs of parents in the neonatal ward and they should remain active in setting and protecting the rights of vulnerable populations (Cleveland, 2008).

The ability of the respondents to seek source of information in relation to infant's condition because of their high educational level perhaps made them aware of the disease pathology, consequently that influenced their need for proximity because of the anticipated disease outcome. One other thing that the researcher observed was that if parents were allowed to come in then most of the time they were not allowed to hold their infant, they would just roam around and watch over the baby perhaps that was another possible explanation for the high scores for proximity. However, during

the hospitalisation of the infant in the neonatal ward there were periods where the infant was off the ventilator and on room air, these were vital periods that nurses should have maximised in addressing family needs for proximity by allowing them to breast feed, perform skin to skin and change nappies. For parents to be able to participate in infant care-giving; nurses need to encourage and empower them to perform such activities. Furthermore, traditionally families have been viewed as a disturbance and intruder instead of being a partner in care in the intensive care unit (Khalaila, 2013:1178). Changing this attitude could perhaps influence how the healthcare team would meet family's needs for proximity.

An interesting finding in this study was the lowest ranking of need for support in this population group. A possible explanation for this was that the need statements under support were more related to the respondent's personal needs which were scored lower (Ward, 2001). This implies that respondents were not concerned about their personal well-being during the neonatal ward trajectory and the fact that the neonatal ward where the study was conducted had no support group programs in place for family members to learn about them and hence gain insight about the importance of such programs. In this view respondents may have scored support need differently if such programs were in place. Nevertheless, when conducting an analysis of the grouped data, out of eighteen (18) need statements under the need for support only one need statement "to have a place to be alone while in the hospital" scored a weighted average score of 2.0, underlying that support needs were still regarded important in this group. Similarly, Obringer, Hilgenberg and Booker (2012:1655) found that "family members identified 'to be alone at any time' least important".

Consistent with these findings, Ward (2001) and Mundy (2010) found that parents of neonatal ward infants ranked assurance related need statements high and support needs were rated the least important. Some studies in the adult intensive care unit showed findings consistent with the current study findings, Obringer et al. (2012:1655) "reported needs highest to lowest as follows; assurance, information, proximity, comfort and support" . Gundo (2010) investigated nurses' and families' perceptions of family needs in adult intensive care unit and family members scored the need for assurance highest in the same research institution. Khalaila (2013) ranked the importance of family members needs and findings revealed that the top priority needs were information, assurance and proximity and need for support was ranked lowest.

In contrast, a study by Chien et al. (2005) found support need as the most important need category among family members of intensive care unit patients in China. Interestingly, Schmollgruber (2002) investigated professional support needs of culturally diverse families of adult patients in the intensive care unit in the same research institution and found that assurance type of support was ranked lowest whereas comfort type of support was ranked highest.

5.2.2 Second objective: To explore and describe similarities and differences in needs of families at point A (0-24 hours) and point B (96-120).

The order of priority for rating of the needs changed over time. Most (91.7%) of the respondents identified the need for assurance as a priority need at both points. The difference came in the order of the need for proximity and information where at point

A the needs followed the order assurance, proximity and information and at point B the needs were in the order assurance, information and proximity.

Respondents in this study scored the same for the need for assurance at both points of data collection. The higher educational level of respondents enabled them to seek external information with regard to their infant's condition, the knowledge they gained perhaps made their needs for assurance to remain the same as they were aware that in an intensive care unit infant's condition may change instantly. According to Pridham (2006:134), "changes in infant's condition matters to parents as criteria for gauging progress or setbacks".

At point A respondents scored 87.5% for the need for proximity and scored 75.0% on the same construct at point B. The questionnaire at point A was completed on admission of the infant to the neonatal ward and this was a period where parents were in shock and experienced feelings of loss (Cockcroft, 2011). The barrier that exists because of the infant's condition and the neonatal ward environment makes them concerned because of the inability to provide care for the infant such as touching, holding, changing nappy and feeding and be by the infant's bedside, which was reflected in the higher score for proximity at point A. At point B the infant was more stable and now parents were able to provide care to the infant such as changing a nappy, hold and touch their infant. Relatively speaking the need for proximity was still high at point B; a possible explanation for this was that perhaps parents were still not skilful and confident enough to provide care for the infant independently. Furthermore, 96-120 hours later some infants were still connected to a life support machine hence that was still a barrier to parents' ability to be close to and take part in

the care of their infant. Flacking et al. (2012:1033) found that "care practices supporting physical and emotional closeness between the parent and the infant decrease anxiety related to infant's well-being". The absence of a Kangaroo Mother Care guideline in the neonatal ward once the infant was disconnected from a life support machine was also an identified barrier in terms of facilitating breast feeding and performing skin to skin contact. Perhaps if the KMC guideline was available parents' needs for proximity would have been better met and a lower score for the need for proximity at point B would have been recorded.

It was recorded in this study that the need for information was higher at point B (90.9%) as compared to point A (81.9%). The researcher anticipated that a possible explanation for this was that because of the confusion and shock experienced by parents on admission they may not be able to understand and synthesize information shared by nurses at point A and they may not perceive needs for information vital because of the sense of loss and inadequacy experienced as the medical team absolutely take over as they strive to save the infant's life (Cockcroft, 2011). Tran et al. (2009:12) observed that "concern for the infant's health and survival are the parents' priorities on admission to the neonatal ward". Similarly, respondents in this study scored less on needs for information during the 0-24 hours period of admission as they anticipated that the central focus of care was the infant's stability. Moreover, the anxiety experienced by parents on admission of the infant to the neonatal ward may compromise their ability to absorb the information provided by the nursing staff. According to Tran et al. (2009), consequently at point B the needs for information increased underlying the parents' readiness for information after the infant's condition was more stable with the parents' emotional turmoil more calm. Phillips and Tooley

(2005:432) noted that "amidst trying to cognitively and emotionally assess competing treatment options for their infants' care and the various stressors associated with the neonatal ward environment, parents have reported an impaired ability to understand and retain important information". Cockcroft (2011:107) states that "if communication is not effective, parents will miss vital information during admission". It therefore follows that while under pressure and stress associated with the admission of infant, relatives will not remember most discussions. In this view a higher score for information was anticipated at point B as most of the information shared at point A will not be remembered. The 96-120 hours of admission in the neonatal ward is a point where most of the infant's condition was more stable and parents started anticipating discharge home hence their needs for information increased so that they gain confidence and adequate skills to enable them to assume their parental role fully and successfully once discharged. Redshaw and Hamilton (2010:367) observed that "parents may continue to exhibit difficulties relating to their baby, lack confidence and have poorer care-giving skills after discharge". Preparation for discharge is an indicator for family-centred care. Nursing staff should assist and allow parents to assume this parental role. Zimmerman (2012:52) "reported that parents are often scared to even touch their infant and frequently need encouragement and acceptance to participate in care". "Parents' participation from admission onwards has been demonstrated to decrease feelings of loss of control as well as ease the transition from hospital to home" (Cooper, Gooding, Gallagher, Sternesky, Ledsky & Berns, 2007: 36).

McNemar's test demonstrated variations in values between point A and point B, with p-values ranging from 0.1 to 1.0. These values indicated that respondents scored

differently at point A and point B. Specifically the need statements under; information (20-21, 23-25 and 27), proximity (32-33 and 36) and assurance (40, 43 and 44) recorded higher values for McNemar's test ranging from 0.4 to 1.0, thus it can be concluded that respondents scored differently at point A and point B in relation to the listed need statements under the top three need constructs. McNemar's values ranged between 0.1 and 0.3 for the following need statements; information (17), proximity (34) and assurance (38 and 45- 46), these findings suggest respondents scored almost the same for the need statements at point A and point B. Findings from this group also showed that McNemar's test could not run for a number of need statements because of the variations on the respondents' response at point A and point B for a particular need statement, specifically; information (18-19 and 22), proximity (28-30) and assurance (37, 39, 41-42 and 47). More rigorous investigations may give in-depth information on the variations shown by the test.

## 5.3 CONCLUSION OF THE FINDINGS

There was a statistical significance ($p<0.05$) between some demographic variables (race, educational level and relationship to patient) and the need constructs. There was no statistical significance between point A and point B; however, there were variations on how respondents scored need statements at point A and point B on the top three constructs (assurance, information and proximity). Respondents at both points of data collection ranked the need for assurance highest. Significant differences were recorded on two constructs; information and proximity with respondents ranking the need for information higher at point B compared to point A, and ranking needs for

proximity higher at point A than at point B. However, at point B, informational needs scored higher than at point A. Support needs were the least in importance.

## 5.4 LIMITATIONS OF THE STUDY

The study was conducted in an urban setting, the research setting admits a certain profile of the population group, and the researcher suspects that there may be considerable differences between the findings in Gauteng and across other regions in South Africa.

The research was quantitative in nature; therefore did not give in-depth description of the family needs in the neonatal ward. Replication of the study using a qualitative approach could be important to obtain more comprehensive information about the family needs in the neonatal ward.

The researcher did not run any rigorous tests to gain insight and in-depth information in relation to the variations shown by McNemar's test. There is a need to run more tests to be able to understand these variations. For future research, the independent-sample t-test can be used to determine whether there is a statistically significant difference between point A and point B. Furthermore, since the independent- samples t-test assumes that the variable of the two groups A and B being measured are equal in the population it can be applied to test the hypothesis.

The research institution had only one neonatal ward. The study was limited to this one setting with a small sample size. For this reason it would not be possible to generalize findings from this study to wider populations in other neonatal ward.

## 5.5 RECOMMENDATIONS OF THE STUDY

In the interest of improving nursing care and nursing education the following recommendations have been drawn from findings in this study:

### 5.5.1 Clinical practice

Findings in this study showed that support needs were rated least important by family members. The introduction of family support programs could make families view needs for support important after having exposure to such a program. Re-evaluation of the existing resources in the neonatal ward and the staff's capacity to give support to the infant's family is a foundation for structuring an intervention programme to improve family support in the neonatal ward.

Respondents in this study rated needs for assurance, proximity and information as top three priority needs. Family conferences would give family members comprehensive information about infant's condition and also provide them with the opportunity to ask questions about their infant care, clear misconceptions and gain insight into the care that is provided to their infant, thus enabling them to effectively contribute to infant care. Conferences increase interaction between nurses and families and this enables nurses to be attuned to parents' psychosocial needs.

Respondents in this study showed that nurses and doctors do not share information this suggests that sharing information with families should be on a daily basis by the nurse at their level of understanding. Nurses should facilitate and advocate for comprehensive and consistent information sharing between the medical team and the families.

Facilitating the implementation of the open visitation policy adopted by the neonatal ward where the study took place is an important consideration in order to meet family members' needs for proximity. Respondents in this study scored high for "to see my infant frequently" and "to be able to visit my infant at any time" at both points of data collection. This is considerable evidence that family members in this study experienced some form of restriction when visiting their infant in the neonatal ward.

The use of guidelines, standards and protocols should be emphasized in clinical practice. There is a need for the neonatal ward to develop a guideline for KMC once the infant is disconnected from the lifesaving machines. This would also improve on the inconsistencies in clinical practice with regard to addressing the need for proximity.

### 5.5.2 Nursing education

The nursing education in the area of neonatal nursing should emphasize integration of family in the care of the infant in order to aid execution of family-centred care in the neonatal ward based on dignity and respect for the infant and the family.

Nurse educators and nurse managers in the neonatal ward should work collaboratively to address needs of families in the neonatal ward by developing curricula to equip nurses with skills and competencies that will enable them to adequately identify and address family needs. Furthermore, nurse managers in the neonatal ward should create an environment that will nurture the nurses' competencies in addressing family needs.

The education offered to nurses in this area should be tailored to the medico-legal frameworks protecting vulnerable populations in South Africa together with standards, guidelines and policies guiding care in the neonatal ward.

### 5.5.3 Further research

Nurses' perception of family needs in the neonatal ward was not established in this study. The study did not give in-depth knowledge about family needs in the neonatal ward because of the quantitative approach used by the researcher. Recommendations for further research would be to explore the nurses' perceptions of FCC in the same context, working towards building standards of practice. A qualitative study to further explore family needs of infants admitted to the neonatal ward is recommended to get in depth information about family needs.

## 5.6 CONCLUSION

In conclusion, the priority needs in the neonatal ward has been highlighted in this research report. There is a need for nursing education to work collaboratively with neonatal ward nurse managers in developing educational curriculum that would provide nurses with skills and competencies necessary to appropriately attend to family needs in the neonatal ward. The healthcare system should nurture nurses' competencies and tailor them to the patient and family needs. Family needs should guide the care that nurses provide and nurses should always strive to embrace the medico-legal frameworks protecting children when providing care.

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Appendix A Family members information letter

**INFORMATION LETTER**

**THE ASSESSMENT OF FAMILY NEEDS OF INFANTS ADMITTED INTO THE NEONATAL WARD AT AN ACADEMIC TERTIARY HOSPITAL IN JOHANNESBURG**

Dear Participant

Good day,

My name is Kebuang P Wakwena. I am currently reading towards a Master's Degree in Science (Nursing) at the University of the Witwatersrand. Please may I invite you to take part in a research study I am conducting as part of my degree.

I am investigating needs of families of infants admitted to neonatal wards at an academic tertiary hospital in Johannesburg. It has been noticed that often when a baby is admitted into neonatal wards the family experiences anxiety and stress and because doctors and nurses usually focus on caring for the baby, family members may be neglected. This is often because the needs of the family are not known.

You have been selected as a potential participant for this research as your infant is admitted into the neonatal ward. The information you will provide when you answer the questions will help me to describe the needs of families of infants in the neonatal wards immediately and couple of days later during admission. This information will be used to make the doctors and nurses aware of the family needs and help them develop nursing care appropriate to meet the needs of the families.

If you choose to participate you will be requested to complete a questionnaire which will be administered by the reseacher within 0- 24 hours of admission and 96- 120 hours of admission of the infant into the neonatal ward. I will sit with you in a private room and ask you to answer questions related to your needs in the neonatal wards. The questionnaire you will complete is composed of two parts; part one is to give demographic information about yourself and, part two is the Neonatal Intensive Care Unit Family Needs Inventory (NFNI) which comprises 56 questions about needs of families in the neonatal ward. This whole process will take 30 – 40 minutes and will be done once you have visited your baby. I will ask you to sign a consent form to show your willingness to participate in the study. To ensure that you are able to complete the study, please could you also complete a cover letter giving me your contact details? None of this information will be included in the report of the results, so your identity will be known only by me

and supervisor. Further the questionnaires will be assigned a number, the cover letters and consent forms will be stored safely.

There are no immediate benefits from participating in the study. However, it is hoped that the outcome of the study will help establish the family needs of infants admitted to neonatal ward and improve our service delivery on addressing family needs. There is no risk associated with participating in this study; however you may feel uncomfortable as you complete the questionnaire. If such happens the researcher will refer you to the social worker for the paediatric department for counselling. Additionally, the researcher will facilitate communication with the healthcare team for emotional/ social support.

The choice to participate is entirely yours and voluntary. There will be no negative consequence to you or your child if you refuse to participate. If you agree to be part of this study you may withdraw at any given time. When the study is finished (December 2015), you may ask for a copy of the final research report from myself and there will be a copy at the Wits University library.

Thank you for your interest and for considering participation in this valuable study. Please contact me on the below listed address should you have any questions about the study.

Yours Truly,

Kebuang Precious Wakwena
Cell # 073 067 6844
Email address: 878950@students.wits.ac.za

Sizakele Khoza
Child Nursing Lecturer (Wits)

Appendix B Letter to the institution Chief Executive Officer

University of the Witwatersrand
Faculty of Health Sciences
Department of Nursing Education
7 York Road
Parktown
2193

The Chief Executive Officer
Charlotte Maxeke Johannesburg Academic Hospital
5 Jubilee Road
Parktown
2193

Dear Sir/ Madam

**REQUEST FOR PERMISSION TO CONDUCT A RESEARCH AT CHARLOTTE MAXEKE ACADEMIC HOSPITAL**

I am a registered postgraduate student at University of the Witwatersrand, pursuing a Master's Degree in Science- Child Nursing. I wish to conduct a research study at Charlotte Maxeke Academic Hospital in Johannesburg, South Africa as a requirement for the programme. The title of the study is *"The Assessment of Family Needs of Infants Admitted into the Neonatal Ward at An Academic Tertiary Hospital in Johannesburg"*.

Despite strong global interest in family centered care, there is still evidence that some crucial issues are still unresolved and some gaps still remain in our healthcare settings in Africa. We still see resistant clinicians and staff who are unwilling to change and the use of outdated policies that hinder family centered practice. The responsibilities of neonatal staff extend beyond the patients in the intensive care units to include the family members of those patients. For the nurses to initiate family centered care they must become aware of family needs then develop a nursing care plan to appropriately address these needs. With increasing demand by consumers for family centered care in the neonatal wards and with needs of family members being often overlooked by neonatal staff, it is evident that family needs in the neonatal wards require exploration.

The purpose of the study is to investigate the needs of families of infants admitted to the neonatal wards. It has been established from the literature survey that no studies of family needs of infants admitted to a neonatal ward has been conducted in South Africa. The study will create a platform for the implementation of strategies aimed at enhancing family centered nursing care which in turn will bring better clinical outcomes, a shorter length of stay in the neonatal ward, reduces incidences of litigation, better coping mechanisms for the family and cost savings.

All information gathered from the families will be treated with confidentiality. To ensure anonymity code numbers will be used during data collection and data analysis. The data will be safeguarded and accessed by myself and supervisor. In order to obtain ethical clearance from the Committee of Research on Human Subjects of the University of the Witwatersrand I am required to submit a letter from you permitting me to access the research setting and collect data. Data collection will only commence once the study is cleared by the Ethics committee.

I am available to address queries concerning this request and the study on the following modes of communication: cellular number 073 067 6844 or email: 878950@students.wits.ac.za

Yours Truly,

| | |
|---|---|
| Kebuang Precious Wakwena | Sizakele Khoza (Ms) |
| MSc Nursing Student | Child Nursing Lecturer (Wits) |

Appendix C Letter to the Head of Department and Operational Manager of neonatal ward

University of the Witwatersrand
Faculty of Health Sciences
Department of Nursing Education
7 York Road
Parktown
2193

The Head of Department and Operational Managers of NICU and High Care Unit
Charlotte Maxeke Johannesburg Academic Hospital
5 Jubilee Road
Parktown
2193

Dear Sir/ Madam

**REQUEST FOR PERMISSION TO CONDUCT A RESEARCH AT NICU AND HIGH CARE UNIT**

I am a registered postgraduate student at University of the Witwatersrand, pursuing a Master's Degree in Science- Child Nursing. I wish to conduct a research study at Charlotte Maxeke Academic Hospital in Johannesburg, South Africa as a requirement for the programme. The title of my study is *"The Assessment of Family Needs of Infants Admitted into the Neonatal Ward at An Academic Tertiary Hospital in Johannesburg"*.

Despite strong global interest in family centred care, there is still evidence that some crucial issues are still unresolved and some gaps still remain in our healthcare settings in Africa. We still see resistant clinicians and staff who are unwilling to change and the use of outdated policies that hinder family centred practice. For the nurses to initiate family centred care they must become aware of family needs then develop a nursing care plan to appropriately address these needs. With increasing demand by consumers for family centred care in the neonatal wards and with needs of family members being often overlooked by neonatal staff, it is evident that family needs in the neonatal wards require exploration.

The purpose of the study is to investigate the needs of families of infants admitted to the neonatal wards. It has been established from the literature survey that no studies of family needs of infants admitted to a neonatal ward has been conducted in South Africa. The study will create a platform for the implementation of strategies aimed at enhancing family centred nursing care which in turn will bring better clinical outcomes, a shorter length of stay in the neonatal ward, reduces incidences of litigation, better coping mechanisms for the family and cost savings.

All information gathered from the families will be treated with confidentiality. To ensure anonymity code numbers will be used during data collection and data analysis. The data will be safeguarded and accessed by myself and supervisor. In order to obtain ethical clearance from the Committee of Research on Human Subjects of the University of the Witwatersrand I am required to submit a letter from you permitting me to access the research setting and collect data. Data collection will only commence once the study is cleared by the Ethics committee.

I am available to address queries concerning this request and the study on the following modes of communication: cellular number 073 067 6844 or email: 878950@students.wits.ac.za

Yours Truly,

Kebuang Precious Wakwena
MSc Nursing Student

Sizakele Khoza (Ms)
Child Nursing Lecturer (Wits)

Appendix D Data collection instrument (NFNI)

**PART ONE**

RESPONDENT DEMOGRAPHIC DATA

Participants will be asked to place a cross (X) next to the applicable option

CODE NUMBER

| |
|---|
| |

AGE

| | |
|---|---|
| 18- 22 | |
| 23- 27 | |
| 28- 32 | |
| 33- 37 | |
| >37 | |

RACE

| | |
|---|---|
| Black | |
| White | |
| Coloured | |
| Indian | |

GENDER

| | |
|---|---|
| Female | |
| Male | |

EDUCATIONAL LEVEL

| | |
|---|---|
| None | |
| Sub A- B | |
| Grade 1- 7 | |
| Grade 8- 12 | |
| Tertiary | |

RELATIONSHIP TO PATIENT

| | |
|---|---|
| Mother | |
| Father | |
| Guardian | |

MARITAL STATUS

| | |
|---|---|
| Single | |
| Married | |
| Divorced | |
| Widowed | |

**PART TWO**

THE NEONATAL INTENSIVE CARE UNIT FAMILY NEEDS INVENTORY (NFNI) QUESTIONNAIRE

Please indicate with marking (X) how IMPORTANT each of the following need is to you

| | ITEM | Not important (1) | Slightly important (2) | Important (3) | Very Important (4) |
|---|---|---|---|---|---|
| | **NEEDS FOR SUPPORT** | | | | |
| 1 | To have explanations of the environment before going into the NICU for the first time | | | | |
| 2 | To have directions about how I can provide care to my infant in the NICU | | | | |
| 3 | To receive help in responding to the reactions of my infant's siblings | | | | |
| 4 | To have a private place to breastfeed or use a breast pump | | | | |
| 5 | To be able to talk to other parents whose infant is in the NICU or has had a similar situation | | | | |
| 6 | To have a support group of other families available | | | | |
| 7 | To have someone to help with transportation | | | | |
| 8 | To share my feelings about what has happened | | | | |
| 9 | To have friends/family nearby for support | | | | |
| 10 | To have someone be concerned with my health | | | | |
| 11 | To have a place to be alone while in the hospital | | | | |
| 12 | To have pastor, clergy or other person from my church visit | | | | |
| 13 | To have another person with you when visiting the NICU | | | | |
| 14 | To talk about the possibility of my infant's death | | | | |
| 15 | To be given information about individuals that could help with problems concerning my situation | | | | |

| | | | | | |
|---|---|---|---|---|---|
| 16 | To have the neonatal unit quiet and lights dimmed at regular times to let my infant rest | | | | |
| 17 | To have a place to sleep near the NICU | | | | |
| 18 | To be allowed to have my infant's siblings visit | | | | |
| | **NEED FOR INFORMATION** | | | | |
| 17 | To have classes about premature infants and their special care needs | | | | |
| 18 | To be given reading material concerning my infant's medical needs | | | | |
| 19 | To know which staff members could give information about my infant's health and general wellbeing | | | | |
| 20 | To talk to the doctor caring for my infant everyday | | | | |
| 21 | To have a specific staff person to call at the hospital when unable to visit. | | | | |
| 22 | To know why things were done for my infant | | | | |
| 23 | To know how my infant is being treated medically | | | | |
| 24 | To know exactly what is being done for my infant | | | | |
| 25 | To help make decisions about my infant's plan of care | | | | |
| 26 | To feel it is alright to cry | | | | |
| 27 | To be allowed to help with my infant's physical care | | | | |
| | **NEED FOR PROXIMITY** | | | | |
| 28 | To hold my infant in my arms and against my skin as soon as I can | | | | |
| 29 | To be called at home about important changes in my infant's condition | | | | |
| 30 | To be able to visit my infant at any time | | | | |
| 32 | To be told about transfer plans while they are being made | | | | |
| 33 | To receive information about my infant at least once a day | | | | |
| 34 | To have the waiting room near the neonatal unit | | | | |
| 35 | To talk to the same nurse every day | | | | |
| 36 | To see my infant frequently | | | | |

| | | | | | |
|---|---|---|---|---|---|
| | **NEED FOR ASSURANCE** | | | | |
| 37 | To have questions about my infant answered honestly | | | | |
| 38 | To feel there is hope | | | | |
| 39 | To be assured that the best care possible is being given to my infant | | | | |
| 40 | To have explanations given that are understandable | | | | |
| 41 | To know the expected outcome for my infant | | | | |
| 42 | To know specific facts concerning my infant's progress | | | | |
| 43 | To know that my infant is being handled gently by the healthcare providers | | | | |
| 44 | To know that my infant is being treated for pain | | | | |
| 45 | To feel that the hospital personnel care about my infant | | | | |
| 46 | To be recognized as important in my infant's recovery | | | | |
| 47 | To feel free to choose to stay or leave when my infant is experiencing painful procedures | | | | |
| 48 | To be assured it is alright to leave the hospital for a while | | | | |
| | **NEED FOR COMFORT** | | | | |
| 49 | To have a waiting room for the neonatal unit | | | | |
| 50 | To have comfortable furniture in the waiting room | | | | |
| 51 | To have comfortable chairs at my infant's bedside | | | | |
| 53 | To feel accepted by the hospital staff | | | | |
| 54 | To have a telephone near the waiting room | | | | |
| 55 | To see that the NICU staff provide comfort to my infant, such as giving my infant a pacifier, using a blanket to support my infant's body and talking softly to my infant | | | | |
| 56 | To have a bathroom near the waiting room | | | | |

Appendix E Family member consent form

**CONSENT FORM**

THE ASSESSMENT OF FAMILY NEEDS OF INFANTS ADMITTED INTO THE NEONATAL WARD AT AN ACADEMIC TERTIARY HOSPITAL IN JOHANNESBURG

MSc Nursing- University of the Witwatersrand
Student Name: Kebuang P Wakwena
Student #: 878950

I,_____ agree to participate in the research study assessing needs of families of infants admitted to neonatal wards at an academic tertiary hospital in Johannesburg.

I have read and understood the information sheet. I also understand that my participation is voluntary and I can withdraw at any given time without any consequences.

I agree to answer the questions honestly. All the information will remain confidential and my name will not appear anywhere on the questionnaire or the research report.

Code Assigned:

Signature:

Date:

Appendix F Family member cover letter

**COVER LETTER**

THE ASSESSMENT OF FAMILY NEEDS OF INFANTS ADMITTED INTO THE NEONATAL WARD AT AN ACADEMIC TERTIARY HOSPITAL IN JOHANNESBURG

MSc Nursing- University of the Witwatersrand
Student Name: Kebuang P Wakwena
Student #: 878950

I _____ have read and understood the content of the information letter and I have been given the opportunity to ask questions about the study and its procedures. I have consented to participate in the study. For follow up purposes and appropriate data collection procedure, I disclose the following information to the data collector;

NAME:

CODE ASSIGNED:

CONTACT DETAILS:

PHYSICAL ADDRESS:

Signature:

Date:

Appendix G Permission to use the Neonatal Intensive Care Unit Family Needs Inventory (NFNI)

PERMISSION TO USE THE NFNI

Date: Mon, 22 Sep 2014 13:54:57 +0200
Subject: Permission to use the NICU-FAMILY Needs INVENTORY
From: kebuangw@gmail.com
To: kelleyward@hotmail.com

Hello. My name is Kebuang Precious Wakwena. I am currently reading for my Masters degree in Nursing Science at WITS University in Johannesburg South Africa. My research topic is " The Assessment of Family Needs of Infants Admitted into the Neonatal Ward at An Academic Tertiary Hospital In Johannesburg ". I am requesting for permission to use the NICU-family needs inventory instrument for data collection.

Thank you

Kebuang Precious Wakwena
Registered Professional Nurse
Bachelor of Nursing Science- University of Botswana
Masters of Science -Wits University (Student)
Contact Numbers:
+27 730 676 844/ 828 616 876 (RSA)
+267 72 913 631/ 73 913 631 (Botswana)
Email: kebuangw@gmail.com

---

On 23 Sep 2014 16:05, "kelley ward" <kelleyward@hotmail.com> wrote:

You have my permission to use the NICU Family Needs Inventory for your research. Here is the tool.

NICU Family Needs Inventory All Items.d

Sincerely,

Kelley Ward, PhD, RN, C

Appendix H Approval of research title from Postgraduate Committee

UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

Private Bag 3 Wits, 2050
Fax: 027117172119
Tel: 02711 7172076

Reference: Ms Thokozile Nhlapo
E-mail: thokozile.nhlapo@wits.ac.za

11 June 2015
Person No: 878950
PAG

Mrs KP Wakwena
PO Box 4250
African Mall
Gaborone
0000
Botswana

Dear Mrs Wakwena

**Master of Science in Nursing: Approval of Title**

We have pleasure in advising that your proposal entitled *The assessment of family needs of infants admitted into the neonatal ward at an academic tertiary hospital in Johannesburg* has been approved. Please note that any amendments to this title have to be endorsed by the Faculty's higher degrees committee and formally approved.

Yours sincerely

Mrs Sandra Benn
Faculty Registrar
Faculty of Health Sciences

Appendix I Ethics clearance certificate

R14/49 Ms Kebuang Precious Wakwena

# HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

## CLEARANCE CERTIFICATE NO. M150452

| | |
|---|---|
| **NAME: (Principal Investigator)** | Ms Kebuang Precious Wakwena |
| **DEPARTMENT:** | Nursing Education<br>Charlotte Maxeke Johannesburg Academic Hospital |
| **PROJECT TITLE:** | The Assessment of Family Needs of Infants Admitted to Neonatal Wards at an Academic Tertiary Hospital in Johannesburg |
| **DATE CONSIDERED:** | 24/04/2015 |
| **DECISION:** | Approved unconditionally |
| **CONDITIONS:** | |
| **SUPERVISOR:** | Sizakele Khoza |

**APPROVED BY:** Professor P Cleaton-Jones,Chairperson, HREC (Medical)

**DATE OF APPROVAL:** 10/06/2015

**This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.**

**DECLARATION OF INVESTIGATORS**

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary in Room 10004, 10th floor, Senate House/2nd Floor, Phillip Tobias Building, Parktown, University of the Witwatersrand. I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report.**

Principal Investigator Signature Date 04/03/2016

**PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES**

Appendix J Letter of permission from the Chief Executive Officer of the institution

Appendix K Permission letter from the Head of Paediatrics Department and Child Health

TPH 49

**DEPARTMENT OF HEALTH**

C M Johannesburg Academic Hospital
Department of Paediatrics and Child Health
Private Bag X39
JOHANNESBURG
2000
Tel: 011 488-4246

28 May 2015

**TO WHOM IT MAY CONCERN**

This serves to confirm that permission has been granted to Ms. Kebuang P. Wakwena (MSc nursing student) to conduct the study "The assessment of family needs of infants admitted into the neonatal ward at an Academic Tertiary Hospital in Johannesburg" in the Department of Paediatrics and Child Health.

Please contact me should you need any further information.

Yours sincerely

**Prof. P.A Cooper**
**Academic Head: Department of Paediatrics and Child Health**

Appendix L Letter of editorial work from the language editor

UNIVERSITY of BOTSWANA

**Department of Distance Education**

Corner of Notwane and Mobuto Road,
Pvt Bag UB 00707 Gaborone,
Botswana

Tel: [267] 355 2423
Fax: [267] 355 5247
chanda.butale-nyoni@mopipi.ub.bw

**To:** **Sizakele Khoza**

**Address:** **WITS Department of Nursing Education**

**Date:** **28 April 2016**

**Subject:** **The Assessment of Family Needs of Infants Admitted into the Neonatal Ward at an Academic Tertiary Hospital in Johannesburg**

**RE: EDITORIAL WORK ON KEBUANG WAKWENA'S THESIS**

This serves as confirmation that editorial work was done by the Dr. Chandapiwa Butale on the thesis entitled The Assessment of Family Needs of Infants Admitted into the Neonatal Ward at an Academic Tertiary Hospital in Johannesburg. All grammatical, semantic, formatting and typographical issues were addressed. The document was edited according to the prescriptions of the APA Manual 5th Edition as per the requirement of the WITS Department of Nursing Education.

Sincerely,

Butale, Chandapiwa PhD
Credentials: *BA English & French (University of Botswana); MS Instructional Technology (California State University, USA); PhD (Ohio State University, USA).*