NURSES' EXPERIENCES OF FAMILY INTEGRATED CARE IN A NEONATAL INTENSIVE CARE UNIT

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MCur (Clinical)

Submitted in fulfilment of the requirements

MNurs (Clinical) in Neonatal Nursing Science

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uly 2019

DECLARATION

I hereby wish to declare that this dissertation titled “Nurses experience of family integrated care in neonatal intensive care unit” which I hereby submit for the degree Master in Nursing Science at the University of Pretoria is my own work and has not previously been submitted by me for a degree to any other university.

The study was done by me, Em-Esna Swart, under the guidance of my supervisor, Professor C Maree and co-supervisor, Mrs S Rossouw.

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ABSTRACT

NURSES' EXPERIENCES OF FAMILY INTEGRATED CARE IN A NEONATAL INTENSIVE CARE UNIT

Aim: The aim was to explore and describe the experiences of nurses working in a neonatal intensive care unit (NICU) in a South African context regarding family integrated care.

Background: Family integrated care in the NICU has taken family centred care a step further by empowering parents to become the primary caregivers of their infants while their infants are still admitted in the hospital. Advantages demonstrated thus far include: improvement in weight gain of infants, reduction in neonatal infections, improved breastfeeding on discharge, reduction in length of stay in the NICU, reduction in staff utilization, improved bonding and attachment and less parental stress. Despite positive findings from research undertaken by a Canadian healthcare team of the multiple advantages that family integrated care provides for infants and their families, this practise is still new in the South African neonatal context. Family integrated care has been introduced in a particular NICU in a hospital in Northern Cape Province, South Africa. Nurses working in the NICU at this hospital are the facilitators of family integrated care and play a key role in the implementation thereof. However, the researcher observed mixed responses from nurses regarding the implementation of family integrated care, and little is known about the nurses' perceptions of those experiences.

Design and method: A qualitative, interpretivist approach was followed to explore and describe the experiences of the nurses working in a particular NICU regarding family integrated care in that unit. The population of this study was the nurses who worked in the particular NICU. Purposive sampling was used to invite participants to take part in the study. Data was gathered using two focus group interviews, each consisting of four to eight participants. The focus groups were transcribed and analysed by means of qualitative content analysis.

Findings: The findings of the study lead to a better understanding of the experiences of nurses working in an NICU in South Africa regarding the implementation of family integrated care. Knowledge of their experiences might contribute to and influence the maintenance of family integrated care in the study's NICU, as well as support the successful implementation of the phenomenon in other South African NICUs. Furthermore, the study suggests that the implementation of family integrated care in NICUs is

expected to contribute to bonding and attachment, improved long-term relationships, development of psychosocial skills, and to prevent feelings of neglect and abandonment in the infant.

Conclusion: The experiences of the nurses regarding family integrated care included their perceptions of the advantages of family integrated care to mothers, infants and families. Additionally, the challenges they experienced during the implementation process, and suggestions for improving the sustainability of family integrated care in the NICU were discussed.

ACKNOWLEDGEMENTS

I would like to express my sincere gratitude as stated below:

- The Lord my God who gave the opportunity and grace to complete this study to and bless me with this opportunity
- My wonderful family and friends who supported me and encourged me to complete the work I had started.
- My supervisors, Professor C Maree and Mrs SC Rossouw, who helped, guided and supported me during the study to enable me to complete it with grace.
- Mr JN Swart who conducted the focus group interviews.
- The Hospital where the data was collected.
- Ms LM Goosen who was so enthusiastic and supported the implementation of family integrated care in the neonatal intensive care unit.
- Northern Cape Department of Health for allowing me to collect data.
- All the nurses who participated in the study.
- My dearest friend Dr. J de Kock, who was my greatest supporter when I needed it the most.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF ANNEXURES

LIST OF ABBREVIATIONS

NICU Neonatal intensive care unit

CHAPTER 1: OVERVIEW OF THE STUDY

1.1 INTRODUCTION

The birth of a new infant into a family is usually a very exiting experience. This excitement, however, will come to an end when an infant is born prematurely or sick and is admitted to a neonatal intensive care unit (NICU). The normal bonding and attachment processes between parents and their infants are interrupted when they are separated. O'Brien et al. (2013:1) and Bracht et al. (2013:115-126) indicate that parents need to be involved in the treatment and care of their infants while they are still in hospital. The importance of attachment of infants to a parent and the life-long effect this attachment has on trust, mental health, emotional coping mechanisms and emotional intelligence of infants has been described (Schore 2001:7-66; Carmen et al. 2012:568-577). A lack of attachment is associated with attachment anxiety, depression, lack of emotional intelligence and emotional dysfunctional aspects (Lanciano et al. 2012:755-758).

To address the need for bonding and attachment, approaches such as developmental care, kangaroo mother care and family centred care have been implemented. Despite these approaches, parents still express feelings of loss and helplessness and of being excluded from the care process. To overcome these feelings, a family integrated care approach has been developed to empower the parents and allow the family to play an active role in the multi-disciplinary team during the care and treatment of their infant, and to optimise opportunities for bonding and attachment of the infant to a parent (O'Brien et al. 2013:1; Sizun and Westrup 2004:F385). This practice, however, is not common in South African NICUs where typically nurses are the primary caregivers of infants and parental involvement is limited.

Family integrated care has been implemented in a particular NICU in a public hospital in the Northern Cape Province of South Africa. As facilitators of family integrated care, the nurses are key role players. Previous observations by the researcher of nurses' attitudes towards family integrated care indicated a mixed response (some positive and some negative). On further investigation, it became apparent that little is known about the experiences of South African NICU nurses in this regard. Consequently, the motivation for this study was to explore nurses' experiences of family integrated care in order to understand the challenges and opportunities that local NICU nurses face, as well as the perceptions held by those nurses regarding family integrated care. The information gained from this research could be used to feed into a larger study focusing on the improvement of family integrated care in NICUs.

1.2 BACKROUND AND RATIONAL

This study was conducted in an NICU which is a specialised facility to care for premature and sick newborn infants, from birth to the age of 28 days, or until transfer or discharge from the unit (Coovadia and Wittenberg 2009:113). To care for the special needs of these infants, an NICU usually comprises of highly technical equipment and specialised medical and nursing teams. Premature infants who are born before the age of 37 weeks of gestational age, and infants in need of intensive care, are admitted to the NICU. Reasons for admission might include the need for mechanical ventilation, long term intravenous therapy, arterial lines, as well as specialised care for feeding disturbances, underweight conditions, congenital abnormalities and any other high risk condition related to infants. Healthcare teams perform emergency procedures such as resuscitation, intubation, surgical procedures, administering of medication and other complex procedures. The care tends to be not well-structured and allows for a variety of interpretations, and often the healthcare team remains the primary caregivers.

Developmental care is an approach to lower stress levels in the preterm infant by focussing on the individual's developmental needs and readiness to interact with external stimuli (O'Brien et al. 2013:2). Developmental care includes involvement of families with their infants to manipulate external stimuli and to use appropriate handling and touch. Family centred care is one of the principles of developmental care whereby the family members (especially the mother and father) are involved in some care activities, but they are not part of the multi-disciplinary team (O'Brien et al. 2013:1). Developmental care has presented positive results for infants and families such as shorter length of stay in hospital, decreased stress levels in infants, less nosocomial infections, improved weight gain, less invasive procedures, improved bonding, improved breastfeeding and digestion and in the long-term, improved reaching of developmental milestones (Sizun and Westrup 2004:F385). The process followed to involve family in care activities is usually not well structured.

Kangaroo mother care is an approach that focuses on the physical involvement between family and infants, where the infant, clothed with only a diaper, is placed on the bare chest of the caregiver for as much skin-to-skin contact as possible, and breastfeeding is promoted if the caregiver is the mother (Callister 2015:198). The researcher's experience is that Kangaroo mother care is usually not implemented in South African NICUs, but is seen as a follow-up approach of care for stable premature infants.

Developmental care and Kangaroo mother care lower the stress levels of the family members and newborns, and for the newborns, better weight gain, less nosocomial infections and improvement in breastfeeding result (Gillian et al. 2011:541). Despite these known positive effects, families may still feel side-lined and there may be a lack of bonding and attachment (Woodhead et al. 2014:6). In 1979, Estonian mothers were involved in the care of their own premature infants due to a shortage of nurses and it was then observed that bonding and attachment occurred between the mothers and their infants. This involvement was referred to as parental integrated care or family integrated care.

Gallo et al. (2016:333) describe the origin of family integrated care in 1979 in Estonia as a humane care model, which provided mothers with the necessary support and education to help take care of their own infants in hospital and become primary caregivers, even if their infants were still admitted in the NICU.

After the implementation of the concept of family integrated care in Estonia, results indicated better bonding and attachment between infants and mothers, and many advantages for infants such as: increased weight gain, shorter hospital stays, less nosocomial infections in infants, better breastfeeding and less medication errors. Based on these observations, studies were undertaken in an NICU at Mount Sinai (Toronto, Canada) in 2004, which revealed the following results: 30% improvement in weight gain of infants, 30% reduction in infections, 20% reduction in length of stay in NICUs, and 50% reduction in utilization of nurses (Sizun and Westrup 2004:F385).

During the initial studies done at Mount Sinai, O'Brien et al. (2013:1) reported that many concerns were raised by the medical team members about infection risks, liability and the capability of family members. The results though were positive, with reduced parental stress and the staff involved confirmed that family integrated care was safe and feasible to use (O'Brien et al. 2013:1).

Family integrated care encourages family members to be active members of the health team and provide most of the care for their infant, while the healthcare providers teach and support the family members during the process (O'Brien et al. 2013:1). Family integrated care is also a gradual, structured process which evolves from uncomplicated to advance activities as the family members become competent and comfortable in taking care of, touching and communicating with their infant.

During family integrated care, the family members are present and actively involved during doctors' rounds, which differs from other more traditional approaches in NICUs. The family is involved in nappy care, routine care, monitoring of vital signs such as: temperature, breathing and heart rate, feeding of their infant and record keeping of observations and actions. These interventions allow the family members to play an active part in the infant's life and allow them to bond and care for their infant, and they get to know and understand their new infant's needs. Understanding and adhering to the needs of the infant results in bonding and attachment between the infant and family member(s) and benefits the infant for the rest of its life (Galarza-Winton et al. 2013:335). Following the success of the Mount Sinai study, family integrated care has since been expanded to several NICUs in Canada and has had consistently similar results (O'Brien et al. 2013:1).

Studies on the implementation of family integrated care in NICUs in South Africa have not yet been conducted. The practice of family integrated care in the South African context is very similar to practices in other countries which experience limited resources and staff shortages. Under these circumstances, nurses are the key play role players in the implementation of family integrated care. The primary focus of this study, therefore, was to explore and describe the experiences of nurses in an NICU in Northern Cape Province, South Africa, who had been exposed to, or involved in, the implementation of family integrated care.

1.3 PROBLEM STATEMENT

When infants are born prematurely or are critically ill they are admitted to an NICU. In this highly sophisticated environment, the infants receive intensive care with highly technical equipment and specialised medical teams, whose priority is to preserve life (O'Brien et al. 2013:1). The care in NICUs includes performance of emergency procedures, resuscitation, intubation, surgical procedures, giving of medication and other activities, which often resulted in families being separated and excluded from the care of their infants (O'Brien et al. 2013:1).

Separation from the parents can cause stress in the infant and can lead to abnormalities in motoric and neurological development as well as lack of bonding and attachment (Gillian et al. 2011:541). Lack of bonding and attachment in turn can have lifelong negative effects on the infant such as: poor relationships with other people, poor development of psychosocial skills, and feelings of neglect and abandonment. Bonding and attachment are involved in the development of emotional intelligence and psychological and neurological development. It is therefore crucial to reduce stress levels,

facilitate bonding and create attachment between family and infant (Seyada, Shelton and Venere 2008: 61), all of which may be improved by family integrated care.

Family integrated care emerged as a gradual, structured process of empowerment of families as caregivers in NICUs and takes place under the supervision of the neonatal staff (O'Brien et al. 2013:1; Bracht et al. 2013:115). Following this process, families are educated, supported and involved in non-invasive activities such as: basic care, feeding, administration of medication to their infants and recording of care given from simplest to complex activities. The family becomes an active part of the health team by participating in physical care, ward rounds and informed decision making (O'Brien et al. 2013:1; Galarza-Winton et al. 2013:335).

The NICU of relevance in this study implemented family integrated care but had challenges with regards to a lack of resources and staff shortages. Nurses in this particular NICU are the facilitators and key role players in the implementation of family integrated care, but the researcher observed mixed responses and at times resistance and lack of enthusiasm from the nurses, which may have been a consequence of their experiences with the family integrated process. Therefore, it was assumed that the nurses' experiences might have influenced the manner in which family integrated care was implemented in the NICU. This observation formed the basis of this study which was to explore the experiences of nurses in the NICU.

1.4 SIGNIFICANCE OF THE STUDY

Family integrated care has many advantages, such as: improved weight gain, improved breastfeeding on discharge, less parental stress and it is safe and feasible to use in an NICU (O'Brien et al. 2013:1). Furthermore, family integrated care contributes to bonding and attachment, which is crucial for positive long-term outcomes of the infants and their families. However, the implementation of the process has implications for neonatal staff. By identifying the staff's experiences of the implementation of family integrated care in an NICU (including their challenges, opportunities and perceptions), new strategies can be developed to optimise and evaluate implementation.

The study further contributes to knowledge and provides a better understanding of the implementation of family integrated care in NICUs in the South African context.

1.5 RESEARCH QUESTION

The research question of this study was therefore: What are the experiences of nurses regarding family integrated care in an NICU in South Africa?

1.6 AIM

The aim of the study was to explore and describe the experiences of nurses regarding family integrated care in an NICU in South Africa.

1.7 CONCEPT CLARIFICATION

Neonatal Intensive Care Unit (NICU): Neonates, from birth to 28 days of life, who need specialised care from a multi-disciplinary team are admitted into a special area of the hospital called the Neonatal Intensive Care Unit (NICU). The NICU is equipped with the latest technology and experienced health care professionals take care of these tiny patients (Stanford Children Health 2019).

For the purpose of this study, the NICU is the ward in a public hospital where infants who are preterm or sick are admitted after birth and treated and cared for by specialised healthcare teams until they are discharged.

Family integrated care: Family integrated care is an approach that actively involves the family as a member of the NICU team by providing them with structured guidance to understand the unique needs of their own infant and where they are taught how best to care for their infant's needs (O'Brien et al. 2013:1).

For the purpose of this study, family integrated care refers to a concept that involves family members (commonly the parents) of a neonatal infant to gradually, consciously and through a structured process, become more involved in the physical and emotional care of their own infant, under supervision and support of the health care providers (nurses, doctors and an occupational therapist). Though most of the time it is the mothers who are involved, and as far as possible the fathers, it can also be a grandmother or other family member, especially if the mother is very ill or has passed away. The term: family integrated care, was retained to be consistent with the approach described in the literature.

Experiences: Experience refers to "the observing, encountering, or undergoing of things generally as they occur in the course of time; … knowledge, or practical wisdom gained from what one has observed, encountered, or undergone" (Random House Kemerman Webster's College Dictionary 2010:n.p.). As a person gains experience, it changes his / her understanding as well as attitude and actions (Parvez 2014:n.p.). In this study, the term is used to refer to observing and encountering family integrated care in an NICU by the nurses and includes what family integrated care means to the nurses, what is working well, what the perceived challenges and opportunities are, as well as any other aspects of family integrated care within the NICU.

1.8 PHILOSOPHICAL ASSUMPTIONS

Botma et al. (2010:106) refer to assumptions as automatic, spontaneous convictions that belong to the researcher and that meta-theoretical assumptions refer to the more philosophical orientation of the researcher. According to Botma et al. (2010:187) and Polit and Beck (2017:8), qualitative research can make use of social constructivism as a philosophical assumption, and this is the theory which was followed in this study.

1.8.1 Ontological assumptions

Ontology aims at the science of how we view the world through the nature of reality during the research process (Polit and Beck 2017:8). Botma et al. (2010:106) indicate that interpretivistic research (including social constructivism), assumes that what we believe is constructed through meaning and understanding that is developed through what we experience. In this study the researcher assumed that the nurses constructed their own meaning and understanding during the experience of family integrated care in a South African NICU. The meaning and understanding that they constructed would determine their approach and relationships during the implementation of family integrated care. It was thereof considered important for the researcher to understand the experiences of the nurses working with family integrated care in a particular NICU in South Africa in order to understand their actions and perceptions.

1.8.2 Epistemological assumptions

Epistemology focuses on the methods, theories and concepts of how we know and understand something rather than the knowledge itself. It looks at the structure of information, how we can

explain experiences, how a social phenomenon can be known, or the "how we can know" (Botma et al. 2010:40). In this study, an understanding of the experiences of nurses involved in the implementation of family integrated care in an NICU in South Africa was gained by means of interaction with the nurses in order to construct an understanding of their experiences.

1.8.3 Methodological assumptions

Methodology refers to the guiding structures in practicing research, to obtain the knowledge that the researcher wishes to study (Botma et al. 2010:41). This study was based on the assumption that nurses would construct meaning and understanding based on their experiences of family integrated care in the NICU, and that they would be willing to share it with the researcher during interaction. By conducting a qualitative descriptive study, it was considered possible to obtain meaningful data regarding the nurses' experiences through observation and focus group interviews.

1.9 DELINEATION

The participants were only from one specific NICU in a public hospital in the Northern Cape Province, which implies that only their voices were heard. The voices of those who chose not to participate, and those from other settings were not heard. The focus was on the experiences of the nurses regarding family integrated care in the NICU, and not of all stakeholders, the latter of which is planned in a follow-up study.

1.10 RESEARCH DESIGN

The research design followed in this study was a qualitative, descriptive, contextual design, as described by Botma et al. (2010:289). It is qualitative in nature because the study aimed to obtain in-depth understanding of the phenomenon (experiences of nurses of family integrated care in an NICU in South Africa). The findings were described to give meaning and understanding of the challenges, opportunities and perceptions of the nurses regarding family integrated care in the NICU. It was contextual, as the purpose was not generalisation, but only to provide a description of a particular context, which was the NICU of a public hospital in the Northern Cape Province, South Africa. The design is discussed in more depth in Chapter 3.

1.10.1 Methodology

Methodology refers to the methods followed based on the chosen design, which is directed by the research problem to increase trustworthiness of the results to the fullest (Botma et al. 2010:289). Qualitative researchers are of the opinion that people build their own reality by experiences in life and that knowledge is obtained by the interaction between people (Botma et al. 2010:288).

1.10.2 Context

The study was conducted in a 10-bed NICU of a public hospital in the Northern Cape Province, situated next to the maternity ward. The NICU also has a 12-bed kangaroo mother care unit next to it that serves as a step-down from the NICU. Parents have 24 hours access to their infants. The average occupancy of the NICU was approximately 150% of preterm or sick neonatal infants in need of intensive care or high care. The average length of stay in the NICU was 60 days. The kangaroo mother care unit was fully occupied at all times (The Hospital Statistics 2016).

There were usually three permanent registered nurses or two registered nurses, one enrolled nurse and a nurse auxiliary on every 12-hour shift to care for approximately 15 neonatal infants (average staff: patient ratio of 1:4 to 1:5) (The Hospital Statistics 2016).

Parents were supported and kept informed on the expectations and condition of their infants by the nursing staff. Developmental care was practised in the unit and kangaroo mother care was encouraged for the stable preterm infants. Family integrated care was then added and practised with all infants admitted to the NICU. All the mothers who had infants in the NICU were required to make use of the accommodation provided by the hospital close to the NICU. Mothers were educated on family integrated care responsibilities in a structured manner according to their readiness and abilities and based on each individual infant's needs.

1.10.3 Selection of participants

The population included the persons with the characteristics that the researcher was interested in. Participants were defined as the people who were well informed and willingly agreed to take part on invitation to the research study (Botma et al. 2010:52). In this study, the population was the nurses (3 registered nurses, 1 enrolled nurse and 5 nursing auxiliaries) working in an NICU in a selected public hospital in the Northern Cape Province of South Africa.

Sampling criteria should guide the choice of the population, based on including and excluding criteria (Botma et al. 2010:200). In this study the total population who met the inclusion criteria was invited. The inclusion criteria were as follows:

- Nurses (registered nurses, enrolled nurses and nursing auxiliaries) working in the particular NICU, as they would had experienced family integrated care in the NICU.
- They had to participate voluntarily.

The following criteria applied to all nurses employed in the NICU and thus form part of the inclusion criteria:

- Participants were able to communicate in English and/or Afrikaans.
- Participants were above 18 years of age.
- Participants had been exposed to the implementation of family integrated care.

The exclusion criterion was any participant who did not meet the above criteria. Once permission had been obtained from the Ethics Committee of the University of Pretoria, the hospital management and the unit manager of the NICU, the full complement of neonatal staff were informed about the study during a staff meeting and they were invited to participate voluntarily.

1.10.4 Data collection

As described by Botma et al. (2010:204), data were collected by means of focus group interviews using open-ended questions. An interview refers to interaction between two or more people (Botma et al. 2010:201). In this study, two focus group interviews were held with the nurses (registered nurses, enrolled nurses and nursing auxiliaries) working in the particular NICU, which gave all nursing staff an opportunity to attend without disruption of any services. Should it have happened that some of the nursing staff were willing to participate, but they could not attend one of the scheduled interviews, a third opportunity would have been scheduled to accommodate them. The interviews were held in a private room in the hospital. An experienced facilitator conducted the interviews with four and five nurses respectively in the two focus groups, while the researcher was in the room to observe and take field notes. Data collection is discussed in more depth in Chapter 3.

1.10.5 Data organisation, analysis and interpretation

The interviews with nurses working in this NICU were transcribed verbatim. Content analysis then was used to analyse the written data, using the following steps as described by Botma et al. (2010: 223):
Step 1: Organise and prepare the data by transcribing interviews, capturing field notes and audio

material in organised writing, sorting the data to be in order.

Step 2: Develop a general sense by reading through the information and developing a general meaning of the data that is transferred on to notes.

Step 3: Code the data by sorting it into parts or topics to get meaning.

Step 4: Describe and identify themes that refer to important findings.

Step 5: Present findings by discussion of the main themes in a narrative way.

Step 6: Interpret data by finding meaning in the study from the researcher's personal interpretation and existing findings.

The application of these steps is addressed in Chapter 3.

1.11 TRUSTWORTHINESS

Trustworthiness refers to the confidence of accuracy the researcher has in the research (Polit and Beck 2017:559). In this study, the principles of credibility, confirmability, dependability, transferability and authenticity were adhered to. The strategies employed are discussed in more detail in Chapter 3.

1.12 ETHICAL CONSIDERATIONS

When research involves interaction with human beings, ethical principles are important, and the researcher has a responsibility to ensure that the study will not be harmful or disrespectful to the participants (Botma et al. 2010:56). Permission was requested from the Research Ethics Committee, Faculty of Health Science (University of Pretoria); the institution (Hospital Manager of the Hospital) where the study was conducted and the organisation (The Northern Cape Department of Health). The principles of autonomy, justice, beneficence and confidentiality were adhered to and will be discussed in more depth in Chapter 3.

1.13 CONCLUSION

This chapter provided an overview of the study. Chapter 2 consists of a literature review on the practice and implementation of family integrated care. Chapter 3 discusses the research methodology of the study and in Chapter 4, the findings and discussions on the findings of the study are presented. Chapter 5 is the final chapter and discusses the conclusions, challenges and recommendations that were discovered during the study.

CHAPTER 2: LITERATURE REVIEW

2.1 INTRODUCTION

The previous chapter provided an overview of this study, while this chapter focuses on a review of relevant literature. Although family integrated care was implemented in an NICU in the Northern Cape Province of South Africa, it received mixed support from the nursing staff, and therefore the need was identified to explore and describe the nurses' experiences of being exposed to, or involved with, the implementation of family integrated care. The literature that serves as background to this study is related to prematurity and illnesses of the newborn and admission in the NICU; the physiological effect of stress on newborns; infant mental health, bonding and attachment; being a parent of a premature or ill infant in the NICU; stress in new mothers; approaches to reduce stress of infants and parents (including family centred care in the NICU, developmental care, kangaroo mother care and family integrated care); and implementation of family integrated care.

2.2 PREMATURITY, ILLNESS OF THE NEWBORN AND ADMISSION IN THE NICU

In this section the meaning of prematurity and admission in the NICU is discussed. Following that, the physiological effect of stress on newborns; infant mental health, and bonding and attachment are presented. The section ends with a discussion on what it means to be a parent of a premature or ill infant in the NICU.

2.2.1 Meaning of prematurity and admission in the NICU

Prematurity refers to infants who are born before 37 weeks of gestation (duration of pregnancy). When an infant is born prematurely the infant has not developed to a mature enough state to allow the infant to adapt to extra-uterine life. The infant needs to adapt after birth in several manners. Firstly, the infant needs to breathe on his/her own by making use of the physiological lung functions that the infant has at that time. All the systems in the body need oxygen to function which can only be obtained and provided by proper lung functioning and gaseous-exchange in the lungs. Secondly, nutrition needs to be absorbed and digested as the mother no longer provides nutrition via the placenta and umbilical cord to the unborn infant (Winston and Chicot 2016:14).

Infants are often nursed on life-depending respiratory support systems, fully dependent on intensive care which often results in the healthcare team becoming the primary caregivers and subsequently, family members are excluded from the care of their infant (Woodhead et al. 2014:18). When healthcare teams perform routine or highly skilled procedures, it is referred to as conventional care, during which families are often left out. Even if they are encouraged to play a more supportive role, parents are not allowed to assist in the initial clinical procedures and care of the infant. Families may be informed about the condition and progress of their infant, but are not given the opportunity to be an active part of the physical care rendered which would empower them as primary caregivers and facilitate bonding and attachment (Woodhead et al. 2014:18). This results in the infant being physically, psychologically and emotionally separated from its parents (O'Brien et al. 2013:1), causing stress in newborns.

2.2.2 Physiological effect of stress on newborns

Stress is defined by the American Institute of Stress as any factor that threatens the health of the body or has an adverse effect on functioning, for example, stress includes: injury, worry or disease (Bernal 2017 n. p.). Stress results in changes in the balance of hormones in the body. As discussed in an article by the American Institute of Stress, stress can have a broad range of effects on emotions, behaviour and moods. As discussed in the following paragraphs, stress has an effect on the: nervous, endocrine, respiratory, renal, gastrointestinal, cardiac, and musculoskeletal systems. These effects are applicable to prematurely born infants who are not mature enough to adapt to extra-uterine life and who often present with symptoms of stress (Bernal 2017 n. p.). Stress in neonates can be caused by a number of factors not present during intra-uterine life, during which the infant was protected against sound, touch, light, micro-organisms, movement, positioning and many more elements (Urden, Stacy and Lough 2014: 800-810). Stress in an infant, especially a prematurely born infant, is a danger to the health of that infant because of the physiological response to stress.

The body of the infant will respond to emotional stress and physical stress, including pain, by stimulation of the endocrine system. The nervous system could be affected triggering the "fight-or-flight" response, whereby the sympathetic-nervous system will signal the adrenal glands to secrete adrenaline (Bernal 2017 n. p.). Several glands are affected by stress and the body responds by secreting specific hormones (Urden, Stacy and Lough 2014: 800-810). In this study, only two will be discussed as they play an important role in stress responses in the infant body.

The adrenal cortex gland secretes cortisol and adrenaline when the body experience stress. Cortisol has the effect of lowering histamine release, increasing glucose levels, lowering immune system response, and reducing gastric acid secretion (resulting in poor absorption and digestion of milk). Adrenalin, on the other hand, will affect the body by increasing heart rate, insulin level, metabolic rate, blood pressure, sodium retention and peripheral vasoconstriction (Urden et al. 2014:800-810).

A second gland that is affected by stress, is the posterior pituitary gland which increases vasoconstriction and water retention and reduces urine output. When vasoconstriction in the body occurs, blood vessels constricts. Vessels that are constricted become narrow and this reduces the ability of blood and oxygen to be transported and delivered to the cells in the body (Urden et al. 2014: 800-810). The respiratory system is affected since the lungs have to work harder to obtain more oxygen in response to the body's increased demand (Bernal 2017 n. p.)

The renal system can also be affected by the stress response, as kidney functioning is dependent on pressure levels in the vessels. Vasoconstriction will result in an inability of the kidneys to regulate urine and waste products excretion. Reduced urine output can lead to the accumulation of unwanted acids and harmful waste products in the body (Urden et al. 2014: 800-810). The cardiac system may be affected by an increase in heart rate and effort with which the heart muscles contract, which leads to higher blood pressure and higher oxygen demand (Bernal 2017 n. p.).

Musculoskeletal demand for oxygen will increase as stress causes an increase in muscle contraction and activity (Bernal 2017 n. p.). The result of stress will create an ischemic effect in some selective parts of the body, resulting in reduced pH and increased acids in the body, this can result in more autoregulation that will increase the retention of acids again, creating a spiral effect. This autoregulation can reduce the capacity for oxygen absorption and excretion of carbon dioxide in the cells and will create a build-up of acids in the cells, contributing to more autoregulation. The effect to each system can be explained as follows: the respiratory system will reduce its affinity for gaseous exchange. This causes poor absorption of oxygen and poor excretion of carbon dioxide in the lungs, which results in poor oxygenation to the whole body. Resulting from this hypoxia is an increased probability of the intestinal system developing necrotising entero-colitis, which is a necrotising effect on the intestine in infants (Urden et al. 2014: 800-810).

2.2.3 Infant mental health, bonding and attachment

According to a study by Winston and Chicot (2016:12) human infants are born very dependent on their parents. Large amounts of brain development takes place in the first two years of an infant. According to those authors, the loving relationship and bonding with a primary caregiver, usually a mother or father, are the two primary factors that influence the aspects of brain development related to the infant's social, emotional and neurological development (Winston and Chicot 2016:12). Not allowing infants to experience a loving family environment might be the reason why they will have permanent emotional and psychological damage, and their intelligence and their ability to grow into their full potential will be jeopardised (Winston and Chicot 2016:14).

Overall potential and happiness of the infant is discussed in some new studies. The destructive effect of neglect, absence of care and love, and changes in primary caregiver can lead to long-term mental health problems. These statements have been discussed by studies done across the scope of developmental, psychological, neurobiological and animal epigenetic research. The most crucial development of the brain starts in uterus and continues until the first year of age, by three years of age the brain of a child is about 90% that of an adult. Neurological development that takes place in this period is described as 700-1000 synapse connections per second. During this time the experiences an infant has with the primary caregiver is of the utmost importance. Reoccurring experiences of communication and interaction result in patterns of connections made in the brain. Memories and expectations are formed which in turn lead to the development of perceptions and logic.

A study by Winston and Chicot (2016:13) states how sensitive and important the brain of an infant is. The study also implies that the longer a child is deprived of exposure to love and care, the more their ability to function normally is compromised. In Winston and Chicot's study, all the participants were assessed at the age of 6 years to determine who functioned normally. The results reflected that 69% of children adopted before the age of 6 months; 43% of children adopted between the age of 7 months and 2 years, but only 22% of the children who were adopted between the ages of 2 years and 3 ½ years could function normally. This emphasises the importance of infants being cared for by loving parents, and the importance of bonding with a primary care giver from an early age (Winston and Chicot 2016: 13). Discussing the lifelong effect of early bonding, leads to a discussion on its relationship with and development of emotional intelligence.

The importance of emotional intelligence and the development of the ability to cope better with stressful situations in life are supported by love from a primarily care giver. Emotional intelligence is

described in the Oxford dictionary (2018) as the capacity to be aware of, control, and express one's own emotions, to manage interpersonal relationships judiciously and empathetically. Therefore, emotional intelligence is key to personal and professional success.

In a study done by Winston and Chicot (2016:14) on epigenetics in mice, the following was found. Mice that were placed in the care of loving mothers were better mothers themselves when they grew up. These results were claimed to be accurate even over two generations, with granddaughter mice being better mothers too. The mice were also able to deal better with stress. These advantages were found to be due to a chemical change in the DNA of the mice. The exact similar effects, "methylation changes" in the brains of mice were found in the brains of humans. The same "chemical patterns" found on humans who were neglected as children and who committed suicide, were also found on neglected mice. In an article by written by Wan et al. (2014:1) the emotional and psychological influence of the mother's involvement on the infant is described. The study was performed on the neural basis of maternal bonding and compared and measured brain activity while a mother viewed her own infant and when she viewed another infant. Wan et al. (2014) demonstrated clear differences in brain activity when a mother viewed her own baby compared with someone else's infant. The relationship between sensitive emotional support and empathetic response of a mother towards her infant has proven to have a life -long influence on the infant's psychological development and state (Wan et al. 2014:2). In relation to a mother's compassion towards her infant, mothers were found to be more sensitive to the interpretation of the facial expressions of their own infants and more able to respond to the emotional and physical needs of their own infant, compared with infants who were not their own (Wan et al. 2014:9). This ability to take care and provide for the needs of the infant will provide a sense of security and safety that could influence the healthy psychological state and development of the infant (Wan et al. 2014:9).

In NICUs, families might be informed about the condition and progress of their infant, but not given the opportunity to be an active part of the physical care rendered and thus are not empowered as primary caregivers and so are unable to facilitate bonding and attachment (Woodhead et al. 2014:18). This results in the infant being "physically, psychologically and emotionally separated from its parents" (O'Brien et al. 2013:1). In an attempt to address bonding and the physical, psychological and emotional needs of the infant, as well as to relieve stress in families and to give them the opportunity to be actively involved in the care of their infant, three approaches have emerged in NICU practice. These approaches are: family centred care; developmental care and kangaroo mother care. Despite the

potential to integrate these approaches in the NICU, bonding and attachment between infants and families is often lacking (O'Brien et al. 2013:2).

As bonding also involves a sense of feeling in control and being comfortable with the bonding process, it is appropriate to refer to the study done by Bracht et al. (2013:115) where they describe the importance of providing parents with education and in doing so empowering them to be the primary caregivers of their own infant and thus strengthen the bonding process. The epigenetic experiments on mice performance described by Winston and Chicot (2016:13) closely mirror the response of humans in terms of the same chemical patterns detected in both mice and human brains. The response imparted an ability of the mice to become good mothers if they were cared for by good mothers. Furthermore, even if the mice's mother had been cared for by a loving grandmother, the ability of the mice offspring to have better stress management behaviour was also clearly visible. Bonding, therefore, is of great importance as it contributes and creates the ability to have better emotional intelligence, stress management and better life-long relationships (Winston and Chicot 2016:14).

Suggestions given by Winston and Chicot (2016:14) to parents to promote bonding with their infant are: skin-to-skin contact, early breastfeeding, making eye contact with the infant, and cuddling while performing verbal and non-verbal communication with the infant. According to a study performed by Wan et al. (2014:1) bonding is more likely to take place between the infant and the biological mother due to the genetic factors of similarity and the ability of the mother to recognise the facial expressions of the infant. The mother will be responding with maternal instincts and be able to determine the emotional status of her own infant better than anyone else.

As discussed by Wan et al. (2014:9) the neurological response of the mother that looks at her own infant is associated with intense experiences of maternal warmth towards her infant. This results in natural bonding between the mother and her infant as she is able to identify with, and care for, her infant. Bonding will also take place because the infant feels cared for and its needs are met, communication is experienced, and neurological patterns of good communication are established in the brain of the infant (Wan et al. 2014:9).

2.2.4 Being a parent of a premature or ill infant in neonatal intensive care units

The article by Heidari et al. refers to the alterations in the emotions of women who give birth to an infant. Women experience uncontrollable changes due to their new role as mother and when a new

infant is born prematurely, mothers are faced with even more challenges. With the impact of a premature birth, the natural process of maternal bonding is interrupted, resulting in what has been described as a painful destruction of balance. Parents confronted with the reality of a premature infant often experience a loss of control that causes more stress and can lead to psychological disturbances. Heidari, Hasanpour and Fooladi (2013) refer to the high levels of stress that are experienced by parents when their infant receives treatment, undergoes an invasive procedure, has an abnormal episode in breathing, change in skin colour, or appears to be in pain according to facial observations. The parents also experience more stress when the parent and infant are separated, and when the parent is helpless during a procedure where the infant appears to be in pain.

Three major reactions of parents of infants in an NICU were identified in the Heidari et al. (2013) study, namely: psychological, emotional and behavioural responses. In relation to psychological reactions, parents revealed behaviours such as crying, showing physical signs of not being comfortable, appeared psychologically unstable and were agitated. The second reaction described was emotional and at times parents exhibited feelings of fear and guilt if they thought they played any role in the baby being born prematurely. Thirdly, behavioural reactions of these parents included insomnia, loss of appetite, anxiety and in some instances, paranoia (Heidari et al. 2013:210-211).

A factor that also contributes to parental stress is the neonatal intensive care unit environment, where parents are more prone to be confronted by the appearance and the neurological condition of their infant and the even the end of life. According to Heidari et al. (2013) parents' stress levels reduce when they are educated, informed and invited to take part in the making of decisions regarding their infant and its treatment. In a randomised control study performed in Iran by Mianaei et al. (2014:94) stress and anxiety were found to be well-known aspects of the emotional experience of parents whose infant was nursed in an NICU, especially when born prematurely. The study further investigated the effect of parental empowerment to reduce these stress levels, particularly in mothers as they are that more likely to experience increased stress levels than fathers. The study documented stress and anxiety levels of the mothers after admission of their prematurely born infant and then again at two-time intervals after the first phase - introducing family integrated care - was introduced and again 2-4 days after the second phase was completed. In this study 45 mothers participated in COPE (Creating Opportunities for Parent Empowerment) and 45 mothers were in the comparison group (not exposed to the empowerment program) (Mianaei et al. 2014:95). The role that the nursing staff played in the education and support of mothers to reduce their levels of stress and concerns was noted (Mianaei et al. 2014:95). The stress levels of the mothers were measured by use of "The Parental Stressor Scale",

which measures stress in four areas according to: “sight and sound”, “infant behaviour and appearance”, “parental role alteration” and “staff behaviours and communication”. Parents used a rating scale to determine the stress levels of the mothers (Mianaei et al. 2014:95). The study discovered that stress levels increase during the time that the infant spends in neonatal intensive care, but that the stress levels in the mothers can be reduced. The study found that the mothers who were empowered by the COPE program not only showed a decrease in their stress and anxiety levels, but they were also more involved in the care of their infants. The comparison group who did not receive education and was not empowered, showed a significant increase in stress and anxiety levels, and they were also not as involved with their infants as the mothers who were empowered (Mianaei et al. 2014:95).

The definition of stress is described by participants in a study done by Heidari et al. (2014:210) as “significant experience which provokes a great sense of misgiving, nervousness, emotional tension or pressure and separation anxiety”. Mothers in the study discussed their disappointment in the birth of a premature infant as unexpected, overwhelming, and as an experience of feelings-of-loss. These emotions accompanied feelings of fear, psychological disturbance and stress. Heidari et al. (2014) intended to explore the experiences of parents with infants in an NICU to establish the meaning of stress to those parents and to determine the reaction of those parents to their experienced stress. The reaction was found to reveal emotional, psychotic and behavioural responses.

The Mianaei et al. study (2014) also demonstrated that high stress levels result in poor bonding abilities of the parents. The study highlighted the “deleterious effect” of stress on the mother-infant relationship, especially if the infant is born prematurely the mother may experience a challenge in bonding with her infant (Mianaei et al. 2014:95).

The stress levels of parents of infants in NICUs could be reduced if practices such as education and involvement were increased. According to Winston and Chicot (2016:14) parents can experience a sense of relief when they understand how much their infant needs them and does not place judgment on their behaviour, that the new infant is dependent on their involvement and the most important need of the infant is for their parents to love and care for them. Parents have at times unrealistic perceptions of what their children need, for example, they can be under the impression that they need to provide the best accommodation, toys or performances; but the need of an infant is mainly the love and attention, communication and affection, and cuddles and contact from their parents.

Parents should be made aware of these facts to enable them to relax and enjoy parenting their infant. Parents suffer from severe stress and anxiety and depressed parents can think that they are horrible parents. According to Winston and Chicot (2016:13) healthcare providers do have the opportunity to ensure parents that they, as parents, are able to take care of their infants and that their infant does not need complex things, but rather interaction from them as parents. Care and love are the most important aspect of their development.

2.3 OVERVIEW OF APPROACHES TO REDUCE STRESS OF INFANTS AND PARENTS

As discussed in previous paragraphs, the stress levels of a parent of a newborn infant can be very high, and healthcare workers are able to reduce these levels by evidence-based practices such as developmental care and family integrated care. In an attempt to reduce stress and promote the positive consequences of bonding and attachment during family integrated care, research has demonstrated that infants exposed to family integrated care gain more weight, experience less medication errors and accidental extubation, and less legal cases against hospitals are initiated. With the family as an integrated part of the multidisciplinary team, they understand what is practised, how, what, why, where and when, and they become the primary caregivers. Family integrated care has been expanded to several NICUs in Canada with consistently similar results (O'Brien et al. 2013:1).

According to the study performed by Wan et al. (2014:11) the response of a mother to her own infant's facial expressions and emotional needs is stronger than her response to another infant. The response is described to be compassionate and caring and the mother has the maternal ability to determine facial expressions due to neural responses of recognition of familiarity. Wan et al. (2014:11) found that the mother also responds better and with more empathy towards her infant than any other person can.

2.3.1 Family centred care in neonatal intensive care units (including family influence)

Family centred care emerged as a gradual, structured process of empowerment of families as caregivers in NICUs and takes place under the supervision of the neonatal staff. Families are educated, supported and involved in non-invasive activities such as basic care feeding, administration of medication to their infants and recording of care given from simplest to complex activities. (O'Brien et al. 2013:1; Bracht et al. 2013:115).

The family becomes an active part of the health team by participating in some physical care and informed decision making (O'Brien et al. 2013:1). The original perception of participants in this study on family integrated care was like the views of nurses in a study on involvement and responsibilities of nurses while family focussed care was rendered. The challenges were mentioned to be staff shortage, lack of equipment, the documentation responsibilities, the occurrence of noise in the unit, a problem with teamwork and the fact that they were not given the opportunity to educational programs to advance their quality of care (Montanholi, Merighi and Jesus 2011:305).

Family centred care is an approach to involve families in the care and decision making of their children while they are in hospital. This concept provides the family and patient with insight into treatment, procedures, tests, decision-making, alternative treatment and adopts a holistic involvement approach. Family members are involved in options of treatment, procedures and they have access to the files of their children. Similar as in the study, family integrated care includes the family being involved in nappy care, routine care, monitoring of vital signs such as temperature, breathing and heart rate, feeding of their infant and record keeping of observations and actions. These interventions allow the family members to be an active part in the infant's life and allow them to bond and care for their infant and get to know and understand their new infant's needs. Understanding and adhering to the needs of the infant results in bonding and attachment between the infant and family member(s) and benefits the infant for the rest of their lives (Galarza-Winton et al. 2013:335).

The above results point to aspects of family integrated care that are implemented by the nursing staff who are the pillars in the introduction and maintenance of family integrated care. This is probably why nurses in Mexico consider themselves to be in a powerful position, when they use their critical thinking skills, their decision-making abilities, their insight and knowledge to facilitate the interaction between infant and their families (Montanholi et al. 2011:306).

The importance of active family involvement in the care for the infant is again discussed in a study that was performed by Montanholi et al. in 2011. The study presents the results of an international study that highlighted the importance of family involvement and active participation in the care delivered to an infant in neonatal intensive care unit. The study mentions that care of an infant should focus on the development of the individual infant (Montanholi et al. 2011:305).

In a study done by Kemp (2011:3) the importance of the family, but especially the father is addressed. The father's involvement in the care of his infant has a direct influence on the confidence, stress

management skills, physical and emotional development of his infant. As a father to be, and when he is involved with his infant, the father undergoes hormonal changes which cause him to be more nurturing and protective. These hormonal change do not last forever and the time that the father is more perceptible to building a strong relationship with his new infant can be rewarded during the later stages of childhood.

Craig et al. (2015:S5) describe the involvement of the family in the care of an infant as the key to understanding the long-term benefits in the physical, neurological and psychosocial development of infants. Infants nursed in an NICU were included in this study. The importance of the family who are involved in decision-making and included as part of the multi-disciplinary team is stated and the active practice of family centred care is referred to. Craig et al. (2015:S5) recommend that all efforts to integrate family involvement by nursing staff, families and caregivers should be supported in policies written on care. Additionally, the need of the family to understand and comprehend the condition of their infant, and the provision of support for them as they prepare for discharge, needs to be documented (Craig et al. 2015:S5).

A study undertaken in Sweden fully involved the families of the infants in the NICU. The families provided most of the care to their own infants, resulting in many benefits to both family and infant. The involvement of the families reduces the stress levels of the mothers and they are more informed and empowered when discharged (Craig et al. 2015:S5).

2.3.2 Developmental care

Developmental care is defined as a specific method of viewing the newborn infant that focuses on the protection of the development of the infant. The concept of developmental care is built on the understanding of individual responses from each infant as seen by their behaviour and stress cues. The aim of the approach is to create an environment as close as possible to that of the uterus for the newborn infant (O'Brien et al. 2013:1).

The purpose of developmental care is to lower stress levels in the preterm infant by responding to the individual's developmental needs and readiness to interact with external stimuli (O'Brien et al. 2013:2). Developmental care includes involvement of families with their infants to manipulate external stimuli and use appropriate handling and touch. Family centred care is one of the principles of developmental care whereby the family members (especially the mother and father) are involved in some care-activities, but they are not part of the multi-disciplinary team (O'Brien et al. 2013:1).

The principals of developmental care include appropriate positioning, touch and handling, non-nutritive sucking, environmental manipulation (involving sound, light and smell), sleep-wake cycles and family centred care (if possible kangaroo mother care) (O'Brien et al. 2013:2). Developmental care has presented positive results for infants and families such as shorter length of stay in hospital, decreased stress levels in infants, less nosocomial infections, improved weight gain, less invasive procedures, improved bonding, improved breastfeeding and digestion and in the long-term, improved reaching of developmental milestones (Sizun and Westrup 2004:F385). The process followed to involve family in care activities is usually not well structured.

2.3.3 Kangaroo mother care

Kangaroo mother care is an approach that focuses on the physical involvement between family and infants, where the infant clothed with only a diaper is placed on the bare chest of the mother for as much skin-to-skin contact possible (Callister 2015:198). Kangaroo mother care refers the principal of growth and development of the kangaroo foetus outside the uterus of the mother kangaroo. Kangaroo mother care initially included the mother, but it can also include the father or another primary caregiver. The advantages for a human foetus to be placed in this position towards the mother are rapid weight-gain, comfortable breathing, emotional stability, increased bonding, increased growth and development, improved body temperature regulations, enhanced breastfeeding, earlier discharge from the hospital and the involvement of fathers in this practice (Callister 2015:198). The researcher's experience is that kangaroo mother care is usually not implemented in NICUs but is seen as a follow-up approach of care for stable premature infants.

2.3.4 Family integrated care

Family integrated care is defined as a gradual, structured process of empowerment of families as caregivers in NICUs and takes place under the supervision of the neonatal staff (O'Brien et al. 2013:1; Bracht et al. 2013:115).

Family integrated care encourages family members to be active members of the health team and to provide most of the care for their infant, while the caregivers teach and support the family members during this process (O'Brien et al. 2013:1). Family integrated care is also a gradual, structured process that evolves from uncomplicated to advance activities as the family members become competent and comfortable in taking care, touching and communicating with their infant. During family integrated

care the family members are present and actively involved during doctors' rounds, which differs from the other approaches. They are involved in nappy care, routine care, monitoring of vital signs such as: temperature, breathing and heart rate, feeding of their infant and record keeping of observations and actions. These interventions allow the family members to be an active part in the infant's life and allow them to bond and care for their infant and get to know and understand their new infant's needs. Understanding and adhering to the needs of the infant result in bonding and attachment between the infant and family member(s) and benefit the infant for the rest of their lives (Galarza-Winston et al. 2013:335).

Mianaei et al. (2014:94) state the reduction of parental stress levels when parents are educated on and involved in the care of their prematurely born infants compared with the significant increase in stress when parents are not educated and involved in the care of their prematurely born infants. The study is similar to and supports the concepts involved in family integrated care, but it was not called as such.

In Estonia in 1979, mothers were involved in the care of their own infants due to a nurse shortage and it was then observed that bonding and attachment occurred between the mothers and their infants. The involvement was referred to as parental integrated care or family integrated care (Sizun and Westrup 2004:F385). Gallo et al. (2016:333) describe the origin of family integrated care in Estonia as a humane care model, which provided mothers with the necessary support and education to help take care of their own infants in hospital while their infants were still admitted in the NICU. The results of family integrated care in Estonia, indicated advantages for infants and families such as: increased weight gain in infants, better bonding and attachment between infants and mothers, shorter hospital stays, less nosocomial infections in infants, better breastfeeding and less medication errors. Based on these observations studies were carried out in an NICU at Mount Sinai (Toronto, Canada) in 2004, and revealed the following results: 30% improvement in weight gain of infants, 30% reduction in infections, 20% reduction in NICU's length of stay and 50% reduction in utilization of nurses (Sizun and Westrup 2004:2).

During the initial studies done at Mount Sinai, O'Brien et al. (2013:1) reported that many concerns were raised by the medical team members about infection risks, liability, and the capability of family members. The results though were positive with reduced parental stress and the staff involved confirmed that family integrated care was safe and feasible to use (O'Brien et al. 2013:1).

2.4 IMPLEMENTATION OF FAMILY INTEGRATED CARE

The following sections discuss the structured involvement in care activities, the empowerment of mothers, fathers and family members, the role of healthcare providers and the implications of the implementation of family integrated care for an NICU.

2.4.1 Structured involvement in care activities

Family integrated care emerged as a gradual, structured process of empowerment of families as caregivers in NICUs. It takes place under the supervision of the neonatal staff. Families are educated, supported and involved in non-invasive activities such as: basic care feeding, administration of medication to their infants and recording of care given from simplest to complex activities (O'Brien et al. 2013:1; Bracht et al. 2013:115).

The family becomes an active part of the health team by participating in physical care, ward rounds and informed decision making (O'Brien et al. 2013:1) Challenges identified in the implementation of family integrated care are: staff shortages, lack of equipment, documentation responsibilities, increased noise in the unit, problems with teamwork and the fact that NICU nurses are not given the opportunity to participate in educational programs to advance their quality of care and role in family integrated care (Montanholi et al. 2011:305).

2.4.2 Empowerment of mothers, fathers and family

In a study done in Iran, Mianaei et al. (2014:95) found that parents, especially mothers, experience a high level of stress and anxiety when their infant is born prematurely. Because the stress and anxiety levels of the parents increase during the hospitalization period, the study aimed to investigate the effect on the stress and anxiety levels of the parents when they had been educated and empowered. The study was based on the assumption that high stress levels result in poor bonding ability of the parents. The study highlighted the deleterious effect of stress on the mother-infant relationship, especially if the infant was born prematurely and the mother had trouble bonding with her infant. To provide the parents with clear and sensible information is of high importance to establish maximum parental involvement in the care of their own infant (Mianaei et al. 2014:5).

In a study by Bracht et al. (2013), the role that education and support to the parents plays when family integrated care was implemented was assessed. Training was provided by hospital personnel and

previous parents of infants who had been nursed in the NICU. The parents also received support, especially during the time that infants were approaching discharge time. The aim was to empower the parents to be confident and to take responsibility as the primary care providers of their infant. The success of the training was measured by anecdotal responses and interviews that were conducted with the parents when their infant had been released from the hospital (Bracht et al. 2013:115). The findings indicated that the mothers felt supported to realise and identify their own strengths, had received the tools to be able to care for their own infants in the neonatal intensive care unit, and were prepared emotionally to face and solve challenges on their own. Education was found to be a valued and vital component of family integrated care in the NICU (Bracht et al. 2013:115).

Mianaei et al.'s. (2014:95) study in Iran demonstrated the effect of empowerment on parents with infants in the NICU. Education and support were used to empower the parents and to decrease the presence of stress and anxiety. The empowerment was performed in four phases: an introduction phase where mothers were educated about prematurity, the NICU and parental involvement in the care of the baby; a phase that focused on growth and development, infant behaviours and encouragement for mothers to participate; a phase to explain behaviours and communication and to start preparing the mother for post-discharge care; and a fourth phase to discuss interaction between mother and infant, growth and development and specific techniques to increase brain development such as songs and games. The outcomes of the study indicated that the involvement and empowerment of parents during the early stages of infancy in an NICU reduce parental stress and anxiety, encourage better parent–infant bonding, and equip parents to be competent primary caregivers (Mianaei et al. 2014:95).

Parents can also experience a sense of relief when they are educated to understand that their infant is not able to judge them and how much the sound of their voices can comfort their infant, and that their voices are the preference of their infant (Winston and Chicot 2016:14).

2.4.3 Role of healthcare providers

In a study done by Bahadori et al. (2014), reasons for the high workload of nursing were identified as high staff-patient equity, nurses allocated to do unnecessary jobs and orientation of new staff and the presence of students. In an attempt to reduce the workload, the following recommendations were made: to have clear understanding of expected duties, not admitting more patients than can be cared for, and using new technology and equipment that aid in reducing nursing staff workload (Bahadori et al. 2014:2).

2.4.4 Implications of the implementation of family integrated care in neonatal intensive care units

The fact that nurses are exposed to heavy workloads increases the level of work-related stress. If nurses are exposed to this stress for a long period, the effects can be harmful and potentially include cardiovascular and respiratory diseases. Work load and occupational stress also have a direct influence on an organization's effectiveness (Bahadori et al. 2014:2).

Two important factors that are often mentioned with regards to nurses' stress are the limited time for nurses to perform their duties and shortages of staff to perform those duties (Bahadori et al. 2014:2). These are two of the needs that family integrated care addresses. The involvement of the mothers and family in the care of the infant patients reduces the workload of nurses drastically. The mothers are tasked with the care of their own infant and should work hand-in-hand with the nurses, benefiting all the parties involved. The nurses' workload is reduced, the mothers are empowered and the infants bond with their own primary care giver who is their mother (Bahadori et al. 2014:2).

Bahadori et al. (2014) stress the fact that the workload of nurses has a powerful connection with patient quality care rendered. In a study that was performed to investigate factors that have an influence on nursing workload in intensive care units, the authors stated that nurses were found to have the highest level of job stress. Three sets of causative factors were identified, namely: structural, process and activity related factors.

Perceptions and work culture in a neonatal intensive care unit

In a study done by Patel et al. (2017:1), a professional challenge of family integrated care was discussed. The challenge identified was for healthcare professionals to evolve from being the main care provider to becoming a mentor and educator during the implementation of family integrated care. This can be understood through Carbon's study on perceptions, where he explains the most important purpose of perception to people is to strengthen and enlarge sensory inputs, to enable people to experience, orientate and react quickly, specifically and efficiently (Carbon 2014:566).

Humans prefer to experience something before accepting it as the truth. There is no better proof than when one has perceived and experienced something for oneself. The connection between a perception and relativity experienced by the senses is most strong in the visual context. If we do not

have previous understanding of a concept it is easy to miss detail in relation to that concept because there is no prior association with something providing insight (Carbon 2014:566).

The best way of increasing insight to any concept is to base the perception on a personal experience. The study claims that if humans could really become intrigued in something, they will spend time and effort to attempt to solve the "illusion's (Carbon 2014:566). Due to the power nurses have in the affective implementation of a new concept, the perception of nurses is of crucial importance.

As supported by Sepasi et al. power is created from the Greek word "pot ere" that means "ability to change". Nurses in the NICU are facilitators and key role players in the implementation of family integrated care, but the researcher of this study observed mixed responses and at times resistance and lack of enthusiasm, which might be due to their experiences. Therefore, it is assumed that their experiences might influence the way in which family integrated care is implemented in the NICU, leading to this study to explore their experiences (Sepasi, Abbaszadeh and Rafiei 2016:14).

The "power" of nurses should not be underestimated and their perception and attitude towards the successful implementation of a new concept is of the utmost importance. In a study by Sepasi et al. (2016:14), nurses were studied to explore their perceptions of the concept of power in nursing. The nurses who participated experienced power in nursing as an asset to nursing. Power was a means to portray good morals, improve quality of care and increase professional conduct.

Nurses are the first line of contact with the health system and they lead to the implementation of new programs and initiatives. Sepasi et al.'s article elaborates further, that if nurses believe a concept to be advantageous for the development of the profession, they would be more likely to successfully implement the new concept, which could result in: increased satisfaction, increased safety of patients, reduced hospitalization time of patients, or an improvement in the quality of treatment rendered to patients (Sepasi et al. 2016:14).

2.5 CONCLUSION

Studies on the implementation of family integrated care in NICUs in South Africa have not yet been conducted. The South Africa context is different from the settings where studies have been undertaken, as the country has a low-resource setting with staff shortages. Nurses are key role players in the implementation of family integrated care. The primary focus of this study is, therefore, to

explore and describe the experiences of nurses in an NICU in Northern Cape Province, South Africa, who have been exposed to, or involved in, the implementation of family integrated care.

CHAPTER 3: RESEARCH METHODOLOGY

3.1 INTRODUCTION

In the previous chapter, previous studies and literature were discussed regarding practises that attempt to involve family members in the care of patients and especially infants. Family integrated care was identified as being the most holistic approach to empowering family members and supporting their preterm or ill infants, and is the approach adopted in this study. Family integrated care has many benefits to the infant, the family, institution and medical staff. The important role that the nurses in NICUs play in the implementation of the practice of family integrated care was discussed. Consequently, the researcher views the experiences of NICU nurses during the implementation of family integrated care as crucial to the future implementation of family integrated care in South African NICUs.

This chapter focuses on the methodology the researcher used to collect, organise and analyse the data obtained.

3.2 AIM OF STUDY

The aim of the study was as follows: To explore and describe the experiences of nurses who work in a specific NICU in South Africa, on the implementation of family integrated care.
The researcher attempted to gain better understanding of this phenomenon to improve the future experiences of nurses, infants and their families, and to address the challenges associated with the implementation of family integrated care in NICUs in South Africa.

3.3 FRAME OF REFERENCE

The frame of reference of this study was based on the assumptions of a qualitative, explorative, contextual design from an interpretivistic paradigm. Botma et al. (2010:106) refer to assumptions as automatic, spontaneous convictions that belong to the researcher and that meta-theoretical assumptions refer to the more philosophical orientation of the researcher.

3.3.1 Ontological assumptions

Ontology aims at the science of how we view the world through the nature of reality during the research process (Polit and Beck 2017:8). Botma et al. (2010:106) indicate that interpretivistic research assumes that what one believes is constructed through meaning and understanding that was developed through what one has experienced. In this study, the researcher assumed that the nurses are key players in the implementation of family integrated care, but that they would construct their own meaning and understanding during their experience of family integrated care in a South African NICU. The meaning and understanding that they construct would determine their approach and relationships during the implementation of family integrated care. It was therefore considered important for the researcher to understand the experiences of the nurses working in the particular NICU in South Africa of family integrated care.

A clear need for the implementation of family integrated care in neonatal units in South Africa exists. The nurses are the implementers of the practice of family integrated care, their experiences and attitudes play a crucial role in the success of the implementation of family integrated care. The study sheds some light on the grey area of the perceptions of nurses, created by their experiences during the implementation of family integrated care in a particular neonatal unit in South Africa. The study was undertaken to understand the experiences of the nurses in order to be able to address the possible misunderstandings, misconceptions, negative attitudes, need for more information and training, and re-enforcement of current positive attempts in implementing family integrated care.

3.3.2 Epistemological assumptions

Epistemology focuses on the methods, theories and concepts on how one knows and understands something, rather than the knowledge itself. It looks at the structure of information, how one explains experiences, and how a social phenomenon can be known (Botma et al. 2010:40). In this study, an understanding of the experiences of nurses involved in the implementation of family integrated care in an NICU in South Africa was gained by means of interaction with the nurses to construct an understanding of their experiences.

3.3.3 Methodological assumptions

Methodology refers to the guiding structures in practicing research, to obtain the knowledge that the researcher wishes to study (Botma et al. 2010:41). This study was based on the assumption that nurses would construct meaning and understanding based on their experiences of family integrated care in

the NICU, and that they would be willing to share it with the researcher during interaction. By conducting a qualitative descriptive study, it was possible to obtain meaningful data regarding their experiences through focus group interviews, the data of which was interpreted through qualitative content analysis.

3.4 CONTEXT OF THE STUDY

The context of the study, the NICU of a particular South African hospital where family integrated care is implemented, was explained in Chapter 1.

3.5 RESEARCH STUDY DESIGN

A qualitative, descriptive, contextual design was used in order to enable the researcher to gain an understanding of the phenomenon under study.

3.5.1 Qualitative design

Qualitative research in itself is seen as post positivism, moving away from the focus on objectivity and controlling the components involved, to accepting more than one reality and acknowledgement of subjective values and critical theory (Roller 2014:3). Qualitative descriptive designs are often the choice of strategy in studies based on general premises of naturalistic inquiry when the researcher wants a direct description of something that took place as a phenomenon (Botma et al. 2010:194), which was the case in this study.

A qualitative approach focusses on aspects of meaning, experiences and understanding of the phenomenon from the viewpoint of the researcher participant in the context where the action takes place (Hyejin, Sefcik, and Bradway 2017:24). This study was qualitative of nature as it aimed at an in-depth understanding of the phenomenon of experiences of nurses regarding implementation of family integrated care in an NICU in South Africa.

To understand a phenomenon in qualitative research, the data is described as non-numerical or narrative data and is interpreted through thick or deep description of the unique contribution of each participant (Maxwell 2013:43). An explorative, descriptive design was used for this study, making use of data that was gathered through focus group interviews, which were audio-recorded and transcribed verbatim before being analysed and described in narrative form.

3.5.2 Explorative descriptive design

Exploratory research is research which begins with the phenomenon of interest and explores the dimensions of that phenomenon (Polit and Beck 2017:15). In addition, Polit and Beck (2017:15) state that exploratory research investigates the full nature of a phenomenon, how the phenomenon is experienced and the process by which the phenomenon evolves. Through the focus group interviews, the researcher explored all the participants' experiences as nurses in a particular South African NICU, of the phenomenon of the implementation of family integrated care.

3.5.3 Descriptive design

According to Boswell and Cannon (2017:114) descriptive research provides an accurate account of the characteristics of a particular individual, event or group in real-life situations for the purposes of discovering new meaning, describing what exists and categorising information. Burns and Grove (2009), as cited in Boswell and Cannon (2017:114), indicate that a descriptive design may be used to identify problems with current practice and rationales for current practice. Polit and Beck (2017:14) add that qualitative researchers study phenomena about which little is known and the in-depth probing nature of qualitative research, accompanied with in-depth understanding, which supports the objectives of this study, allow the researcher to describe what the dimensions or characteristics of the phenomenon are, which in this case, is the relatively new introduction of family integrated care in the field of neonatology.

3.5.4 Contextual design

This study focused on obtaining an understanding of a phenomenon through the experience, knowledge and perceptions from the people who are involved, who could voice their personal views and perceptions. This type of local knowledge is contextual, meaning the desired outcomes are specific and imbedded in understanding of how things work in a specific context and are bases to practical reasoning (Polit and Beck 2018:302).

The aim of this study was not to generalise the experiences and perceptions of the participants to the experiences of all South African nurses working in NICUs, but to obtain the specific experiences of the nurses working in this particular NICU in South Africa, because they have been exposed to the phenomenon of the implementation of family integrated care. Furthermore, the results are intended to be used in a follow-up study to make a difference in the particular context.

3.6 POPULATION AND SAMPLING

The population refers to the people with the characteristics, knowledge or experience of which the researcher was interested. Participants had to be well informed and to willingly agree to take part on invitation to the research study (Botma et al. 2010:52).

In this study the population was the nurses (registered nurses, enrolled nurses and nursing auxiliaries) working in an NICU in a selected public hospital in South Africa. Sampling criteria guided the sampling from the population, based on inclusion and exclusion criteria (Botma et al. 2010:200). The total number of potential participants was only nine permanent nurses and was thus too small to use a sampling technique. The total population who met the inclusion criteria, was therefore invited. The inclusion criteria were as follows:

- Nurses (registered nurses, enrolled nurses and nursing auxiliaries) permanently employed in the NICU, as they would have experienced family integrated care in the NICU.
- A willingness to participate voluntarily.

The following criteria applied to all nurses employed in the NICU:

- Participants were able to communicate in English and/or Afrikaans.
- Participants were above 18 years of age.
- Participants had been exposed to the implementation of family integrated care.

The exclusion criteria were any participants who did not meet the above criteria. Permission to perform this study in the specific hospital was requested and received from the Research Ethics Committee of the University of Pretoria, the Chief Executive Officer of the hospital and the Unit Manager of the NICU. Once permission had been granted, the nurses employed at the NICU were informed about the study during a staff meeting and were invited to participate voluntarily.

The participants in this study were all permanently employed nurses at the NICU of the hospital. They represented different categories and levels of nursing staff, different age groups, different cultures and backgrounds and had been employed for a variety of years. They all had been exposed to the implementation of family integrated care in the NICU. Once they agreed to participate, dates were negotiated for potential interviews that would suit most. Two weeks prior to the interviews, invitations were placed on the NICU's notice board as a reminder. Arrangements were made to

schedule two focus group interviews in order to ensure no interruptions of service delivery in the NICU.

The participants were well informed of their right to volunteer and to be able to withdraw at any time without any consequences. Their right to confidentiality was stated and they were made aware of the purpose of the information to be obtained in the interviews, and how the findings were to be used and documented on completion of the research.

Two focus group interviews were held, attended by four and five participants respectively. Their demographic data is discussed in Chapter 4.

3.7 DATA COLLECTION

Interviews are commonly used to obtain data in qualitative research. However, they are prone to being described as not being objective and susceptible to biases, because the researcher is the person who controls the interview process. Despite this, focus group interviews were considered the most favourable method to exploration of the actual experiences of the participants as they enabled the participants to speak freely (Boswell and Cannon 2017:315).

A focus group interview is a group of people brought together for a discussion which is facilitated by a moderator. The moderator guides the discussion according to written pre-set questions on a specific topic. Focus group interviews are regarded as carefully planned discussions taking advantages of group dynamics for obtaining rich information in an economical manner (Polit and Beck 2017:511). The advantages of a focus group include the following:

- Ability to obtain the viewpoints of many people in a short time.
- The fact that members react to what is said by others, thereby potentially leading to deeper expression of opinions (Polit and Beck, 2017:511).
- Stimulating to participants.

Polit and Beck (2017:511) raise concerns about focus group interviews such as:

- People not expressing their views as they may feel uncomfortable to speak in a group.
- The culture of the group may inhibit individual expression as “group think” takes hold.
- The data from focus group interviews might not be as “natural” as from individual interviews.

When done correctly, a focus group interview should provide a private, trustworthy, safe and comfortable environment, where the clear and truthful experiences and thoughts of the participants

can be discussed. The participants need to be viewed as partners of the research and not only a source of information or data (Boswell and Cannon 2017:318-319).

The focus groups were held in a meeting room in the hospital. The participants were familiar with the hospital and it was assumed that they would be comfortable and relaxed to describe and discuss their experiences. Comfortable chairs were placed in a circular format, which allowed the participants to see each other and for the voice recorder to record all participants' voices. The lighting and ventilation were adequate, and the room was clean and comfortable. A notice was placed on the door to inform people of the interviews and to request them not to disturb the interview process. Coffee and tea was available to the participants prior to the onset of the interviews and refreshments were provided after the focus groups were conducted.

Two focus groups were held, which were facilitated by an independent and objective interviewer who was familiar with group interviews as well as qualitative research and how to minimise the risk of bias. The researcher was present in the background to observe the focus groups and take field notes of her observations.

On arrival, the participants were received at the entrance of the room and introduced to the facilitator. They were invited to get something to drink. As soon as all the participants were present they were invited to take a seat. They were thanked for their time and interest to take part in the research project, the purpose was explained, and they were requested to read and sign the consent forms to indicate their willingness to participate voluntarily, to give permission to be audio recorded, and for the data to be used for the purpose of research. They were again informed that they were under no obligation and were free to withdraw at any time of the interview if they wanted to. They were also reassured that their identities would be kept confidential. The participants were informed of the time allocated for the interview of 35-50 minutes.

The term: *family integrated care* was clarified to ensure all participants shared a common understanding of the concept. The main question that was then asked was: *Please tell me about your experiences with the implementation of family integrated care in the NICU?* Further probing questions were asked by the interviewer to probe for clarification or more depth until saturation had been obtained and the interviewer was satisfied that the data gathered would provide a true understanding of the experiences of the participants on the implementation of family integrated care.

The probing questions were:

- *How do you see family integrated care?*
- *What works well regarding the implementation of family integrated care?*
- *What are the challenges that you experience with the implementation of family integrated care?*
- *What are the opportunities that can improve family integrated care?*
- *Do you have any other comments regarding the implementation of family integrated care?*

A total of four participants took part in the first interview and five participants took part in the second interview. Interviews were scheduled for 35 minutes to 50 minutes each. The first interview lasted about 35 minutes and the second interview lasted 50 minutes before data saturation had been obtained according to the interviewer. The participants were thanked for their participation and were invited to have refreshments.

The first interview was conducted predominantly in Afrikaans as most participants were Afrikaans speaking, but some participants did express themselves in English at times. The second interview was conducted predominantly in English with some Afrikaans in between. All participants stated that they were comfortable with the use of Afrikaans, English or a combination, during the interviews.

3.8 DATA ANALYSIS

Qualitative content analysis was used to analyse the true meaning of participants' experiences, and to understand the mixed responses observed by the researcher with regards to the implementation of family integrated care in the particular NICU.

Qualitative content analysis is the analysis of the collected data to identify patterns in the information discovered, to investigate those patterns, create conjectures, accept or deny those conjectures, and create meaning of the narrative data (Botma et al. 2010:221).

The aim of the study was the exploration and description of the true meaning of the participant's experiences in order to understand the mixed responses observed by the researcher and ultimately, to improve the implementation of family integrated care in the particular NICU.

The main instrument to analyse, interpret and describe the data is the researcher him or herself, who will do this according to their own understanding, experiences, values and knowledge of the subject.

The researcher cannot be separated from their own being and therefore will play a subjective role in the research process of qualitative research (Maxwell 2013:42). As described by Botma et al. (2010:221), the most important substances in qualitative analysis is that it must be systematic, sequential, verifiable and continuous.

The following steps, as described by Botma et al. (2010:223), were used in the data analysis process:

Step 1: Organise and prepare the data by transcribing interviews, capturing field notes and audio material in organised writing, sorting the data into order.

Step 2: Develop a general sense by reading through the information.

Step 3: Code the data by sorting it into parts or topics to get meaning.

Step 4: Describe and identify themes that refer to important findings.

Step 5: Present findings by discussion of the main themes in a narrative way, including audible, tables or adjuncts.

Step 6: Interpret data by finding meaning in the study from the researcher's personal interpretation and existing findings.

Step 1: Organise and prepare

The organising of the data for analysis requires the transcribing of interviews and optically gained information, typing of the field notes and the placement of the different forms of data into categories (Botma et al. 2010:224).

In this study the audio recorded focus group interviews were transcribed by the researcher and confirmed by a co-researcher for accuracy.

Step 2: Develop a general sense

This step describes the overall understanding that the researcher acquires from reading through the data (Botma et al. 2010:224). The researcher read thoroughly through the transcripts and made notes on the general findings and first ideas that came from the participants' contributions.

Step 3: Coding of the data

Coding is used to create a description of the setting or particulars, as well as themes from the categories. The coding process enabled the data to be separated into pieces or categories. It involved using specific or repeated words, phrases, sentences, paragraphs or images, to create headings for

further sorting (Botma et al. 2010:224). In this study the researcher made use of colour coding to initiate identification of themes.

Step 4: Describe and identify themes

The coding is used to create a description of the setting, or participants, as well as themes from the categories. The categories that are identified are turned into themes. Those themes usually represent five to seven major findings in the study and are used to create the subheadings of titles that are identified in the data. The themes should portray different experiences and perspectives from the different participants and be "supported" by "diverse quotations and specific evidence". (Botma et al. 2010:225) In this study, the researcher made use of colour coding to indicate themes identified.

Step 5: Represent findings

In this step, the identified themes are discussed in detail using subheadings and subthemes, specific illustrations, the participants' direct words and different perspectives. The themes should be interrelated and described making use of visuals, figures or tables of adjuncts (Botma et al. 2010:225). A colourful table was created to illustrate the findings and reveal the headings and subheadings for discussion.

Step 6: Interpret data

This step is the last in the process and involves the researcher interpreting and making meaning of the data. According to Botma et al. (2010) the researcher will be guided by the question: *"What were the lessons learned?"* The answer will be a combination of the researcher's personal interpretation and literature or theories. New questions can be developed for further research. The ending of the research will be determined by the type of design used by the researcher (Botma et al. 2010:225).

The researcher interpreted the true meaning of the data and true meaning of the experiences of the nurses in the implementation of family integrated care in the NICU. The data is discussed in a detailed description of the findings in Chapter 4 and the Conclusion presented in Chapter 5.

3.9 TRUSTWORTHINESS

Trustworthiness refers to the confidence of the accuracy the researcher has in the research (Polit and Beck 2017:559). In this study, the principles of credibility, confirmability, dependability, transferability and authenticity were adhered to as far as possible to enhance trustworthiness. By adhering to these

principles, the researcher aspired to disseminate the true meaning of the data and experiences of the implementation of family integrated care in NICU.

3.9.1 Credibility

Credibility refers to the confidence that the researcher has created in the truth of the findings under investigation (Botma et al. 2010:233). In this study, the researcher enhanced credibility using more than one source of data collection, namely two focus groups. The prolonged engagement of the researcher who was familiar with the context, as well as the discipline, also contributed to the credibility of the study. To prevent bias though, the focus groups were facilitated by an independent interviewer with significant experience with group interviews and understanding of qualitative research. The assistance of a co-researcher was sought to confirm the accuracy of the verbatim transcriptions, as well as the analysis and interpretation of the data.

3.9.2 Confirmability

Confirmability r**e**fers to applicability and relates to the extent that the results of a study can be applied to different populations and still reach the same conclusion (Botma et al. 2010:233). The confirmability of this study in other contexts has not been determined. To make confirmability possible, thick or dense description of the process followed was provided in order to make repetition possible, should there be an interest in repeating the study.

3.9.3 Dependability

Dependability refers to consistency and requires the findings to be similar if repeated (Botma et al. 2010:233). For the purpose of this study, the researcher created an auditable trail by providing thick description of the findings. The study was performed to gain better understanding of the experience of the implementation of family integrated care in the NICU. Most of the nurses in the unit were participants in the study and they were given the opportunity to give their experiences in full description. The researcher does expect the same results if the study were repeated.

3.9.4 Transferability

Transferability refers to the comparison of the findings to another similar setting (Botma et al. 2010:234). Thick description of the setting, sampling and process followed were provided to make it possible for a reader to decide what the possibility would be of transferring the findings to another setting.

3.9.5 Authenticity

Authenticity refers to the level of truthful reflection of the reality that is shown (Botma et al. 2010:234). To enhance the authenticity of the study, the original raw data (tape recordings and verbatim transcription) will be kept safe for 15 years as required by the Research Ethics Committee of the University of Pretoria and can be made available on request.

3.10 ETHICAL CONSIDERATIONS

When research involves interaction with human beings, the researcher has a responsibility to ensure that the study will not be harmful or disrespectful to the participants (Botma et al. 2010:56). Permission was requested and obtained from the Research Ethics Committee of the Faculty of Health Sciences (see Annexure E), University of Pretoria and the management of the institution and the NICU where the study was conducted. The ethical principles that were adhered to include: autonomy, justice, beneficence and confidentiality.

3.10.1 Respect for persons

The principle of respect for persons refers to decisions to protect a person's dignity and autonomy. Dignity is protected by means of confidentiality. Confidentiality indicates that a participant may decide with whom they share information and what information they keep to themselves. A researcher has the responsibility of maintaining confidentiality of all information obtained during research (Botma et al. 2010:17).

In this study, the data collected from the participants were handled and kept confidential in a safe place, interviews were conducted in private and the data were reported without making any participant's identity or personal information known.

Autonomy refers to the respect you show for a person by allowing a person to decide whether he / she wants to participate in the study once they are fully informed (Botma et al. 2010:3). In this study, the researcher obtained written, informed consent from the participants to participate voluntarily. Participants had the right to withdraw at any stage of the research study without any penalty or consequence, should they wish.

3.10.2 Justice

According to Botma et al. (2010:3) justice indicates that participants should be exposed to fair treatment. In this study, participants were all treated with respect and not judged on different beliefs, views, cultures, gender, background, economic status, race or any other characteristic.

3.10.3 Beneficence and non-maleficence

Beneficence is defined as a person's right to be protected from harm and discomfort, but also that one should do good and above all do no harm (Botma et al. 2010:20). The researcher hoped to gain understanding of and improve the implementation of family integrated care in the NICUs in South Africa. The study was not expected to have any negative outcomes for any participant, but it was expected that follow-up changes once the findings were known, would be beneficial to the newborns and their families, as well as the staff on NICUs.

3.11 CONCLUSION

In this chapter the methodology used was discussed. The findings will be discussed in the following chapter.

CHAPTER 4: RESEARCH FINDINGS

4.1 INTRODUCTION

In previous chapters the importance and need for this study were discussed as too the literature and previous studies done on family integrated care. The choice of method that was used to perform this study and an explanation of the methodology employed was discussed in the previous chapter. In this chapter, the findings and results discovered are presented and the interpretation of these discoveries and findings are discussed.

4.2 DISCUSSION OF FINDINGS

The aim of this study was to explore and describe the nurses' experiences of implementation of family integrated care in an NICU. Two focus groups were held with nine participants, as discussed in Chapter 3. The core question was: *"Please tell me about your experiences with the implementation of family integrated care in the NICU?"*

The probing questions were as follows:

- *"How do you see family integrated care?"*
- *"What works well regarding family integrated care?"*
- *"What are the challenges that you experience with the implementation of family integrated care?"*
- *"What are the opportunities that can improve family integrated care?"*
- *"Do you have any other comments regarding the implementation of family integrated care?"*

The focus groups were audio-recorded and transcribed verbatim and content analysis was done as described in Chapter 3. A summary of the three themes, eight categories and 30 sub-categories related to the experiences of implementation of family integrated care in an NICU are summarised in Table 4.1. A discussion of each of the themes, categories and sub-categories then follows, incorporating supportive quotations and literature.

Table 4.1: Overview of research findings

THEME	CATEGORIES	SUB-CATEGORIES
Initial implementation of family integrated care (Section 4.2.1)	Initiation of family integrated care (Section 4.2.1.1)	a. Perceptions regarding initiation of family integrated care
		b. Involvement of family
		c. Documentation by mothers
		d. Role of multi-disciplinary team
Advantages of family integrated care (Section 4.2.2)	Advantages for infants (Section 4.2.2.1)	a. Reduced stress levels and improved bonding
		b. Improved growth and development
	Advantages for mothers (Section 4.2.2.2)	a. Empowerment of mothers
		b. Obtaining emotional support
		c. Attention paid to mother's health
	Advantages for NICU staff (Section 4.2.2.3)	a. Sharing responsibility for care of infants
		b. Stress reduction of NICU staff
Challenges related to family integrated care (Section 4.2.3)	Challenges related to mothers (Section 4.2.3.1)	a. Effect on stress levels and exhaustion of mothers
		b. Effect of personal circumstances of mothers
	Logistical challenges (Section 4.2.3.2)	a. Unsuitable physical lay-out
		b. Infection prevention
		c. Lodging facilities
	Challenges related to staff (Section 4.2.3.3)	a. Perception and attitudes of staff
		b. Staff knowledge of neonatology

The following section includes a discussion of the themes, categories and sub-categories.

4.2.1 Initial implementation of family integrated care

The first theme identified was related to the initiation of family integrated care. The staff's experiences of the initiation of family integrated care are discussed in terms of their perceptions regarding the initiation of the phenomenon, involvement of the family, documentation by mothers and the role of the multi-disciplinary team.

4.2.1.1 Staff's experiences of initiation of family integrated care

a. Initiation of family integrate care

Participants in this study revealed that they initiated and practiced many aspects of family integrated care in an unstructured and spontaneous way, initially due to a shortage of staff. They did not have a name for their partially practiced and undocumented version of family integrated care, and they had their own unique initiation of family integrated care in the NICU.

The formal concept of family integrated care was later introduced in this setting and was then fully implemented. With formalisation thereof, there was also some negativity about the concept, but as the practice changed and as the staff experienced the positive results of family integrated care, so did their attitude about the formal concept of family integrated care.

Quotations from participants:
"Ja, at first you think, ai Sr. Swart, what is this, we don't have the time, we are too busy..." P2(1) *"It's not easy to start something new, but, once you are in it… Because for us it was: really?"* P1(1) *"No man Sr. Swart, what is this? But once now that we have seen it, there is a name for it. We've been doing it; you don't bring something new in. This is what we've been doing. We, we just didn't know what it is and how well it's working…"* P2(1)

In this regard Sepasi et al. (2016:14) mention that the attitude of nurses towards the power they hold can be a positive factor as they can use their power to support and successfully implement a new concept. The nurses are prone to be actively involved if they believe that the concept might be of advantage to their quality of care, to reduce hospital stay, to increase patient satisfaction, or to meet a moral obligation (Sepasi et al. 2016:14).

During the initial studies done at Mount Sinai, O'Brien et al. (2013:1) reported that many concerns were raised by the medical team members about infection risks, liability and the capability of family members. The results though were positive with reduced parental stress and the staff involved confirmed that family integrated care was safe and feasible to use (O'Brien et al. 2013:1).

Furthermore, participants described the process of family integrated care to be individually implemented. When the mother verbalised and was observed to be ready for more involvement, she would be introduced to more complex responsibilities. On the day of birth, the mother would only be introduced to the new infant and the staff. Emotional support would be given by the staff as she was

given the time to become more familiar with the circumstances and the new infant. The mother's introduction to new activities would then be determined by the individual cases according to the mother's readiness, needs and ability. The participants identified the emotional factors of the mother to be an important indicator for advancing to the next level of participation in the care of the new infant.

The structure of the process was at times altered according to the individual intellectual, emotional and psychological capability of the mother. The gradual implementation of the levels of involvement was also determined by the condition of the infants the process was introduced at a slower pace when the infants were critically ill as the mothers could only take part in some of the caring and activities that involve the new critical infant.

According to the participants, the mothers were given the opportunity to verbalise or write their need for more education on family integrated care. Each case was acknowledged as being unique, and the documentation completed by the mother and multi-disciplinary team portrayed the individuality of each case.

Supportive quotations:
"...so then we orientate the mommy there and we show them step by step where they have to write the feedings and thing." P4(1) *"The first day when the baby is admitted, depends on the condition of the baby...when the mother comes the first day we only just say, here is the baby...the orientation but without doing anything..."* P1(1) *"Then again after the third day can we maybe say, ok mother, every three hours you must come and change the nappy and make the temperature."* P1(1) *"There is a admission form that …step by step.*" P1(1) *"We orientate them about after the second day when they... we show them how the feedings are given.... When we come to medication, we encourage them ....to give the supplements."* P3(1) *"Where I had a problem when the occupational therapist started to this whole routine when she would become really strong about this whole maral and she would tell us, 'switch off the radio'. He, he, he! Things like this. I was like who is this woman? She is not even working here. But. At that stage I didn't understand from which view was doing it from and she a, mmt in-house training and she showed us how, and I also ever know, o, I even know I need to switch off the light, why should I switch off the lights.*" P1(1)

"...with this family integration we have now the forms that mothers fill in to say what is they are learning and, and ,and what it is they must learn how much did they learn..." P2(2) *"And there is a tick, not really writing work, they only tick off, that the mother feed, the mother did the fever, the mother changed the nappy and the mother did KMC ."* P3(1) *"Then we orientate mommy there and we show them now step by step where they must write in the feeds and thing. What it is to aspirate..."* P4(1) *"Yes, it is a very easy form."* P2(2) *"Who does the training and gives them the documentation of papers that they have to complete?" All of us."* P5(2)

The above correlate with descriptions of family integrated care in literature. Family integrated care emerged as a gradual, structured process of empowerment of families as caregivers in NICUs and takes place under the supervision of the neonatal staff. Families are educated, supported and involved in non-invasive activities such as basic care, feeding, administration of medication to their infants and recording of care given from simplest to complex activities and they become an active part of the health team (O'Brien et al. 2013:1; Bracht et al. 2013:115).

b. Involvement of family

Family integrated care was viewed by the participants as a process to involve the mother and when possible to include the father. Most participants viewed family integrated care as a sequence of activities with consideration of the mother as she indicated her readiness for involvement. The mother then was involved in activities related to the care of her infant and she became part of the multi-disciplinary team. The participants described family integrated care as a process that educates and involves the mothers so that they can be in touch with their infants and participate in their physical care, including: nappy care, feeding, monitoring of temperature, administration of oral medication, practising kangaroo mother care and documentation of their own activities.

Quotations from participants:
"Family integrated care with us is it now to involve the mother and the parents in the care of the baby, to equip them..." P3(1) *"...so then we orientate the mommy there and we show them step by step where they have to write the feedings and things"* P4(1) "*I needs to react, so they also picking up still, to add on this, so when they go home with the babies they already know that, ha-a, my baby is not right. I need to act, so, so without the act that they*

helping us, as also we are understaffed, they are also gaining more skill and they have put more effort in raising of their child in the hospital." P1(1)

"...you get her involved to understand the type of care we are giving during the hospitalization of the baby by ... by assisting her and explaining to her to give the feeding of the baby, changing of the nappies, caring of the baby." P1(2)

"...with this family integration we have now the forms that mothers fill in to say what is they are learning and, and, and what it is they must learn how much did they learn." P2(2)

"*Where I had a problem when the occupational therapist started to this whole routine when she would become really strong about this whole maral and she would tell us, 'switch off the radio'. He, he, he! Things like this. I was like who is this woman? She is not even working here. But. At that stage I didn't understand from which view was doing it from and she a, mmt in-house training and she showed us how, and I also ever know, o, I even know I need to switch off the light, why should I switch off the lights."* P1(1)

Similar experiences were observed during the initial studies done at Mount Sinai. O'Brien et al. (2013:1) reported that many concerns were raised by the medical team members about infection risks, liability and the capability of family members. The results though were positive, with reduced parental stress and the staff involved confirmed that family integrated care was safe and feasible to use (O'Brien et al. 2013:1). This safe practice of family integrated care encourages family members to be an active member of the health team and provide most of the care for their infant, while the caregivers teach and support the family members during this process (O'Brien et al. 2013:1).

An important aspect of involvement of the mother includes breastfeeding. The particular hospital of this study is a baby friendly status accredited hospital. This means that breastfeeding is encouraged, and formula feeding, bottles and pacifiers are only allowed in exceptional cases. Expressed breast milk is used in the unit and a donor human milk bank was started about four years ago. If a mother is not able to meet the demand of breast milk required by her infant, donor breast milk is utilised. In this way all the infants in the unit exclusively receive breast milk. Advantages of breastfeeding in this study was that it was affordable for everyone as it was free, it was available, sterile and easily accessible. Some mothers needed assistance and support with breastfeeding, but most infants were discharged on breastfeeding only.

Supportive quotations:

"And also sometimes they do, we do get mothers they don't allow us to touch the breast, because we have to help then expressing so, because in the beginning it's difficult. Not all mothers have that technique how to express, so some especially have inverted nipples it is difficult to get the milk out." P1(2)

"The mother also helps with the growth of the babies and also with the feedings etcetera, they also help us a lot with the breast feeding; they help us also with everything. We show them how the breastfeeding and everything is done, so they also do a lot with the growth of the babies." P4(1)

"...most of our little babies are discharged on only breast milk..." P4(1)

Breastfeeding is incorporated, facilitated and encouraged in the practice of family integrated care. As described by the World Health Organisation (2017), the benefits are endless and the practice facilitates bonding and attachment, provides the right nutrition to promote intellectual and physical growth, and protects against infections as it builds the immune system, -the composition is perfect for the infant and it is available and is cost effective.

Another aspect of family integrated care where mothers (and often fathers) were involved, was kangaroo mother care. Kangaroo mother care was introduced to the mothers whose infants were still in the NICU as soon as the infants were stable enough. When the infant's condition and weight was satisfactory according to the paediatrician, the mother and infant would be transferred to the kangaroo care unit. The mother would then be the main person responsible for the care of her infant. The infant would be nursed skin-to-skin and would only be removed from the mother's chest when she visited the bathroom or shower. Supervision was still done by the NICU staff and support was provided to the mothers. The participants indicated that it is easier to work with the mothers in the kangaroo unit than the ones in the NICU.

Quotations from participants:

"KMC is now the side where they are with the little babies the whole day. They only take those babies out for number one and number two toilet and when they go to wash, then they must get back in." P4(1)

"We are also understaffed and at times you find at times we have one person in KMC where you can't really monitor that everyone does the right thing." P1(1)

"If they are over one kilogram, they are encouraged, or if the babies are stable enough to KMC the baby." P3(1)

"It can be a beautiful something because my child is getting weighed today, if he gained this much, then we are going there, then we go to, then we will do this and we do that. You are so excited, so they really have more positive than mind, become positive, ok than at times when the baby does not drink and pick up. It's like ok. But she knows why I need, why I need to do this to keep on KMC, because on Wednesday. I need to weigh me baby, my baby must weigh 1, 6 before I can go home..." P1(1)

"The little babies that is in KMC, they are continuously with the baby, day and night. So, yea it is, it works well." P2(2)

"Especially with the KMC mothers we work better with them." P2(2)

Kangaroo mother care is an approach that focuses on the physical involvement between family and infants, where the infant clothed with only a diaper is placed on the bare chest of the mother for as much skin-to-skin contact as possible and breastfeeding is promoted (Callister 2015:198).

The participants referred to the fact that the infants are "continuously" and for "long hours" in the care of their mothers and they also referred to the disruption of kangaroo mother care only when the mother needs to visit the bathroom. The participants then mention that the infant will immediately be placed back in kangaroo mother care with the mother. Developmental care was also an aspect where parents are involved within the NICU of the study hospital. Nurses in the NICU involved in this indicated that initially they did not know about developmental care, but received training from the occupational therapist. Initially they described themselves to be resistant due to a lack in education and insight. They then became enthusiastic to participate in the implementation of developmental care as an integral part of family integrated care and to involve parents accordingly.

Quotations from participants:

"Where I had a problem when the occupational therapist started to this whole routine when she would become really strong about this whole maral and she would tell us, 'switch off the radio'. He,he, he! Things like this. I was like who is this woman? She is not even working here. But. At that stage I didn't understand from which view was doing it from and she a, in-house training and she showed us how, and I also ever know, of, I even know I need to switch off the light, why should I switch off the lights." P1(1)

"It's some things not really encourage in depth, you don't know because we didn't specialize in neonatology." P1(1)

"Yes, so the mothers know also not to play that music so loud."P4(1)

"Yes, they should not talk loud" P1(1)
"That little baby was still supposed to be in the mother's "stomach" and now it is to them like you, you still wanted to be inside the mother. So after the noise and now comes the doctor and also makes a mess or trouble [maak droog of moeilikheid]? You can just think for you how that little baby must feel." P4(1)

Developmental care is an approach to lower stress levels in the preterm infant by focussing on the individual's developmental needs and readiness to interact with external stimuli (O'Brien et al. 2013:2). Developmental care includes involvement of families with their infants to manipulate external stimuli and to use appropriate handling and touch. Family centred care is one of the principles of developmental care where the family members (especially the mother and father) are involved in some care activities, but they are not part of the multi-disciplinary team (O'Brien et al. 2013:1).

Developmental care has presented positive results for infants and families such as: shorter length of stay in hospital, decreased stress levels in infants, less nosocomial infections, improved weight gain, less invasive procedures, improved bonding, improved breastfeeding and digestion and in the long-term, improved reaching of developmental milestones (Sizun and Westrup 2004:F385); as well as: less medication errors and accidental extubations, and less legal cases initiated against hospitals (O'Brien et al. 2013:1).

Studies done in NICUs in Canada indicate that developmental care activities contribute to the family becoming an integrated part of the multidisciplinary team, understanding what was practiced, how, what, why, where and when, and to become the primary caregivers (O'Brien et al. 2013:1).

c. Documentation by mothers

Documentation by the mothers emerged as an important sub-category. Documentation on the process of family integrated care had to be completed by each mother on her activities and it increased as she became more and more involved with the care of her infant. The mothers received orientation regarding documentation, which was followed with support and continuous education. The documents included a letter of permission signed by the mother to take part in family integrated care, a form to be completed on the education they had received regarding integrated family care and what they still needed to be educated on, and the infant's documentation where they had to record their observations and activities.

This documentation was described by the participants as being easy to understand and complete and was a part of the implementation of family integrated care. However, it was also seen as a challenge, as there were mothers who were not dedicated to completing the documentation. Additionally, some mothers were illiterate and could not read or write to document their observations, findings and actions. Staff needed to give much more support to the illiterate mothers to empower them.

Quotations from participants:
" ...with this family integration we have now the forms that mothers fill in to say what it is they are learning and, and, and what it is they must learn how much did they learn." P2(2) *"And there is a tick, not really writing work, they only tick off, that the mother feed, the mother did the fever, the mother changed the nappy and the mother did KMC."* P3(1) *"Yes, it is a very easy form."* P2(2) *"Who does the training and gives them the documentation of papers that they have to complete? All of us."* P5(2) *" ... then Nellie will explain, this is the form. This is what you write on it and this is how you write it, and this is how the example is, say the child has a dirty nappy. Then they must exactly say what colour of the, of the..."* P2(2) *" ...and then you now get some of the mommies that does not know how to write."* P2(2) *"But they can make the 3 and the 6, but otherwise like with the other stuff, we then also write, this is what they showed us."* P2(2)

There are not many studies done on the effect and response of documentation of patient treatment or condition by family members in hospital. In a study done in Canada at Mount Sinai Hospital, a care plan and step-by-step to discharge documents are used to support family members with their documentation of their implementation of family integrated care. The study refers to the documents used as a tool for family members to track the involvement in the care of their infant and the progress of the infant (O'Brien et al. 2013:2).

d. Multi-disciplinary team

The role of the multi-disciplinary team emerged as another significant sub-category, specifically in relation to orientation and education, as well as the importance of team work. The participants in this study repeatedly referred to the good teamwork between the multidisciplinary team in the implementation of family integrated care in the NICU. The multidisciplinary team comprised the nursing staff together with the paediatrician, occupational therapist, speech therapist and dietician.

The occupational therapist took on the role of the project leader who communicated between the members of the multidisciplinary team, educated the staff on the aspects and structure of family integrated care, and guided education of the mothers in a daily structured process. The multi-disciplinary team's first responsibility was to introduce the mother to her new infant and to give her the opportunity to grasp what had happened to her, as most of these infants were born prematurely.

The mother was then orientated regarding her new environment and introduced to the NICU and the staff. Her role and responsibilities were explained to her and she was emotionally supported throughout the introduction of the process of family integrated care. The first level of involvement was for the mother to touch her baby. More advanced activities that increased her involvement were added when she was ready, such as: nappy changing, taking the temperature, administration of the nasogastric feeds, administration of oral medications and kangaroo care. During the whole process, important principles to practice were the involvement of the mother as an active participant in the multidisciplinary team, and the integration of developmental care with all activities. The mother would attend the doctors' rounds daily where the condition of the baby was discussed.

Quotations from participants:
"The occupational therapist started to this whole routine when she would become really strong about this whole meraai [issue] *and she would tell us 'switch off the radio'....and she had in-house training and she showed us how, and I also even know o, I even know I need to switch off the lights, why should I switch off the lights...were were like OK, it is working, ok it is working."* P1(1)
"...the doctor explains to, to, the mother, then we just assist that forms but even the occupational therapist they have their own part..." P1(1)
"Yes, our doctors are always involved. They are always there." P1(2)
"Yes, yes the therapist's dieticians are also there with the children." P5(2)
"When you involve them in the care of their child, then you get that confidence, then you get that confidence, I know what is going on with my baby, what is expected of them and mm, this is just also the care of the child is discussed with them." P3(1)
"The other mother had done everything for their babies, cleaned, wrote on the observation chart what they have done. So, I think the mothers are very involved with their little babies." P4(2)
"By assisting her to her and explaining to her to give the feedings of the baby, changing of the nappies, caring of the baby." P1(2)
"Those of them, when they are over a kilogram are encouraged, or when the babies are stable enough to KMC." P3(1)

"The consultant loves to explain to the mother. Mommy, this is what your child today, this is how your child is today. We are going to start your child on this type of medication..." P2(2)

Family integrated care includes family involvement in: nappy care, routine care, monitoring of vital signs such as: temperature, breathing and heart rate, feeding their infant and record keeping of observations and actions. These interventions allow the family members to be an active part in the infant's life and allow them to bond and care for their infant, and get to know and understand their new infant's needs. Understanding and adhering to the needs of the infant result in bonding and attachment between the infant and family member(s) and benefit the infant for the rest of their lives (Galarza-Winton et al. 2013:335). These similar results point to aspects of family integrated care that are implemented by the nursing staff, whom are the key role players in the introduction and maintenance of family integrated care.

As nurses are a valuable part of the multi-disciplinary team, it is no surprise that nurses in Mexico consider themselves to be in a powerful position, as they are able to use their critical thinking skills, their decision-making abilities, their insight and knowledge to facilitate the interaction between infants and their families (Montanholi et al. 2011:306). The participants of this study practice parental involvement for the same reason that staff in Estonia originally started to involve mothers in the care of their infants, namely: staff shortages. Family integrated care in Estonia emerged as a gradual, structured process of empowerment of families as caregivers in NICUs with activities such as: basic care, feeding, administration of medication to their infants and recording of care given from simplest to complex activities (O'Brien et al. 2013:1). The family became an active part of the health team by participating in physical care, ward rounds and informed decision making under the guidance, education, supervision and support of the neonatal staff (O'Brien et al. 2013:1). In the current study, teamwork was described by participants as a very positive experience, this is of great importance as if this was not the case, the successful implementation of family integrated care could not be possible.

4.2.2 Advantages of family integrated care

As mentioned in Chapter 1 and 2, there are many advantages in the practice of family integrated care. In the following section, some of the advantages discovered, as experienced by the nurses in the NICU, will be described and corroborated with literature. The advantages are related to the infant, the mother and the staff.

4.2.2.1 Advantages for the infant

As previously mentioned, the findings of previous studies on family integrated care have identified many advantages for the infant. In this section of the study, these advantages are discussed further.

a. Reduced stress levels and better bonding

In this study participants said that the emotional effect on the infants was well experienced by themselves and the mothers. They discussed the reaction of the infants when their mothers are involved and when they are stable enough to receive kangaroo mother care. The need of the infants to be with their mother was clearly stated as the infants were described as being 'naughty' when crying to receive their mother's affection and touch. The nurses further described the positive experience of seeing how the infants calmed down when their mother touched them. Participants talked about the bonding that took place and referred to the emotional stability that this practice brought to the infants and mothers.

Quotations from participants:
"When they get use they are getting use to the mother. He is bonding, yes." P1(2)
"All the love and attention." P2(2)
"Then the bonding must, they must bond. Much better than before because she now has contact with the baby for that half hour or hour that she spends with the baby. Eight hours all together." P2(2)
"The babies get better sooner, he's growing and his just very naughty, they cry a lot and as soon as they start getting that lots...KMC, yes because they want the mother, yes. It's nice to see, as soon as the mother is touching the baby, or she is with the baby, the baby calms down." P2(2)
"Usually it helps a lot, so and I mean, as they already said it's the bonding and they are helping us..." P3(2)

The birth of a new infant into a family is usually a very exciting experience. This exciting experience, however, will come to an end when an infant is born prematurely or sick and is admitted to an NICU. The normal bonding and attachment processes between parents and their infants are interrupted when they are separated. O'Brien et al. (2013:1) and Bracht et al. (2013:115-126) indicated that parents need to be involved in the treatment and care of their infants while they are still in hospital to facilitate bonding and attachment.

The importance of attachment of infants to a parent and the life-long effect this attachment has on trust, mental health, emotional coping mechanisms and emotional intelligence of infants, have been described (Schore 2001:7-66; Carmen et al. 2012:568-577). The lack of attachment is associated with attachment anxiety, depression, lack of emotional intelligence and emotional dysfunctional aspects (Lanciano et al. 2012:755-758).

As described by Winston and Chicot (2016:12) the most important time for brain development takes place in-uterus and then up to the first year of life. This involves the time of bonding and establishment of communication and patterns in the brain of the infant. If the infant cries and this form of communication is not addressed, the infant will not experience bonding, love and care. This could have serious repercussions in terms of future expectations in relationships and trust in people. If an infant is deprived of loving family experience, it can result in permanent damage to its emotional health, intelligence and ability to develop to its full potential. Love is described as the most important need for healthy infant brain development and bonding is encouraged by the practice of skin-to-skin contact between mother and infant, eye contact, cuddling, verbal and non-verbal communication, early breastfeeding and face-to-face contact (Winston and Chicot. 2016:14).

Montanholi et al. (2011:306) indicated that nurses are the facilitators of family integrated care and they view and understand the need for family and parental involvement, also because they wish to minimize suffering and sequelae of the infant and they hope to improve the affective bonding between mother, father and infant. An important aspect in the management of the health of the maternal mother is bonding with her new infant. Cheng, Fowles and Walker (2006:35) state that the new mother needs to go through a process of adapting to her new role as a mother, and part of this process is bonding with her new infant, developing confidence in her ability to provide for the needs of her infant and enjoy the interaction with her infant.

b. Growth and development

Involving the mother in family integrated care was viewed by the participants as part of the process of empowering the mother for the discharge phase, so that when the mother takes her infant home, she is comfortable and competent to take care of her infant and able to ensure its growth and development. According to the participants, the mothers would be so involved that they would be able to identify abnormalities or changes in the condition of their infant such as vomiting and they would report these abnormalities to the staff. Weight gain was viewed as very important to the mothers and was often the reason for their excitement or disappointment. The mothers would strive

for their infants to gain weight, anticipating the outcomes on the days their infants were scheduled to be weighed. Feeding was also discussed as a crucial part of weight gain and with that the importance of education and the involvement of the mothers in feeding their infants. Their involvement included breastfeeding or expressing breast milk if their infant was too small to feed from the breast.

Quotations from participants:
"The babies get better sooner, he's growing and just like ..." P2(2)
"Premature little baby, for their growth and development, this is now for, they must be healthy, they must be able to see. They must be able to hear, they must be able to walk." P4(1)
" You can see how lekker [delicious] *... It is not nice for them, the first time for the mother to see the baby like that, but they can see how" lekker" or nice/delicious/good that little baby becomes."* P4(1)
"...my baby is not right. I need to act, so without the fact that they are helping us, as also we are understaffed, they are also gaining more skill and they have, they put more effort in raising of their child in the hospital." P1(1)
"So, what we basically do is when we admit, admit the baby and the mother comes in we welcome the mother. They know where they are coming from and a, you show them this is where your baby's gonna stay here now." P2(2)
"When you involve them in the care of their child, then you get that confidence, then you get that confidence, I know what is going on with my baby, what is expected of them and mm, this is just also the care of the child is discussed with them." P3(1)
"So now to equip them, for when the little baby is discharged it is to be, to be working with the little baby, to work with the baby and to be able to care for them and it is now just to improve the care of the baby with the help of the parents and involved family." P3(1)
"The mother had done everything for their babies, cleaned, wrote on the observation chart what they have done. So, I think the mothers are very involved with their little babies." P4(2)
"The more the condition of the baby changes or regresses the mother is part of it, the mother is aware. When the baby vomits because, and the mother is feeding the baby....." P1(1)
"They gain so much, then...You are so excited, so they have more positive than mind, become positive, OK than at times when the baby does not drink and pick up. It's like OK. But she knows why I need why I need to do this to keep on KMC, because on Wednesday. I need to weight my baby, my baby must weight 1, 6 before I can go home..." P1(1)
"The thing is if we are busy, we don't really have chance to saying no we will go and feed. Maybe you find the time you were supposed to go, and feed has passed, but then when the mothers are

there at least they are meeting us halfway, by its time you go got the baby, they already done so much, they already fed the baby, they did the observations." P3(2)
"We orientate them so after the second day, as their feeds, we show how the feeds are given; show what to look out for." P3(1)
"Then we orientate mommy there and we show them now step by step where they must write in the feeds and thing. What it is to aspirate..." P4(1)
"When we give her a pass out. If she has enough milk, expressed enough." P4(1)

Family integrated care has many advantages, such as improved weight gain, improved breastfeeding on discharge, less parental stress and it is safe and feasible in an NICU (O'Brien et al. 2013:1). According to a study on the neural basis of maternal bonding done by Wan et al. (2014:1), they found the neural response of a mother who views her own baby is much more intense and complex that when she views a baby who is not her own infant. They further described the positive mother-infant interaction that takes place due to the stimulation and activation of specific parts of the brain and that mothers tend to focus less on directive parent behaviour and more on positive and attentive infant behaviour, which contributes to the growth and development of the infant.

This ability of recognition by the mother enables her to understand her own infant better than another infant. The special mother-infant emotional bond can be affected if the mother struggles with feelings of emotional closeness with her infant, which can continue into emotional difficulty in parenting (Wan et al. 2014:1). According to Gillian et al. (2011:541), separation can lead to abnormalities in motoric and neurological development of the infant, and lack of bonding and attachment. Lack of bonding and attachment in turn can have a lifelong negative effect on the infants, such as a lack of bonding, poor relationships with other people, poor development of psychosocial skills, and feelings of neglect and abandonment. Seyada et al. (2008: 61) indicate that bonding and attachment are involved in the development of emotional intelligence and psychological and neurological development; therefore, it is crucial to reduce stress levels, facilitate bonding and create attachment between family and infant.

4.2.2.2 Advantages for the mother

Some of the advantages that the implementation of family integrated conveys to the mothers are: a sense of empowerment owing to an increase in her mothering competencies and decision-making skills, the provision of emotional support and increased attentiveness to the health of the mothers.

a. Empowerment of the mother

The mother's initial overwhelming experience of having a new infant was discussed by the participants, as was the positive experience of the mothers who had be empowered during the process of family integrated care. The mothers who were involved in the implementation of family integrated care experienced a variety of advantages. As described by the participants they experienced the mothers to be more orientated to their environments, better informed, more self-assured and more competent in the care of their infants.

Mothers were part of the multi-disciplinary team which made them more informed and which resulted in them portraying better decision-making abilities. While being supported emotionally, the mothers benefited from the fact that they were guided and educated in a gradual structured and supported process to become involved, competent and responsible for the care of their own infant. The participants expressed that the experience of empowering the mothers of their patients (the infants) was a positive experience - the more the mothers of the patients became empowered, the better the teamwork in the unit between staff and mothers could be observed.

Orientation was viewed by participants as the first line of introduction to the process of family integrated care. Continuous education followed on a structured and gradual basis, as the mother indicated her readiness to advance to the next level. Education was given on the condition of the mother's new infant, visitors' regulations, on the routine in the unit, what was expected of her as the mother, the process of family integrated care, the levels of integrated family care and how it is implemented, the documentation that accompanies the process and the continuous support they can expect. Mothers were then educated on the various care activities of their infants. Special arrangements were made to accommodate illiterate mothers to ensure that information was not lost.

The documentation in the form of record keeping by the mothers was also described as a source of empowerment, as the mothers were guided in becoming more competent and more involved in monitoring and care of their infants.

Quotations from participants:
"When the mother comes in there, they have a very big shock, this little baby, she didn't even know that so has such a little thing". [As die ma inkom da, hulle skrik hulle boeglam, hierdie kleine babatjie, sy't nie eens geweet sy't so pikinini nie] P4(1)

"If you involve them in the care of the child then then they get that confidence, I know what is going on with my child, what is expected..." P3(1)

"...my baby is not right. I need to act, so, so without the fact that they helping us, as also we are understaffed, they are also gaining more skill and they have, they put more effort in raising of their child in the hospital." P1(1)

"Many educated mommies out there, because some mommies just get their babies, then they don't really know, but with this integrated care for the family, that education is so beautiful to me." P4(1)

"… if we are busy we don't really have chance to saying no we will go and feed. Maybe you find the time you were supposed to go, and feed has passed, but then when the mothers are there at least they are meeting us halfway, by its time you go got the baby, they already done so much, they already fed the baby, they did the observations." P3(2)

"I think I will name two sides, where it is working well for the mother and the baby, is like we said, the mother is part of all that is happening, she takes part in every step..." P1(1)

"Yesterday we received a 710 gram, it is cords and lines everywhere, so then we orientate the mommy there and we show them step for step where they have to write in the feedings and thing. What it is to aspirate, sometimes they don't even know about, little babies. Just even will attach the baby front to the back the nappy and, but afterwards what works well for me is that you can turn your back on that mother and then you know that mother is doing the right thing, behind your back, this is what works very well for me, yes." P4(1)

"When the mother comes the first day, we only say here is the baby, and the orientation but without doing anything, just knowing for her knowing to wash hands, spray your hands. After that then you come and stand this side to look at the baby a little bit." P3(1)

"So, what we basically do is when we admit, admit the baby and the mother comes in we welcome the mother. They know where they are coming from and a, you show them this is where your baby's gonna stay here now. You show them or tell them where they are gonna sleep now and you then start orientating them about the ward and hands." P4(1)

"During the doctors' round at about eight o'clock, preferably in the morning, so that they can be present, so that their doctor can explain to them or bridge the gap to stay informed of the progress of the baby." P3(1)

"Other is also equipped with skill because the mother might forever know that when the temperature is higher than 37, I need to report, so she will be alert to say that if my baby is like this I need to do, they even know now when if the machines goes off and it becomes red, I need to report, so they even getting skills. They know when the baby turns blue. I need to react, so they also picking up still, to add on this, so when they go home with the babies they already know that ha-a, my baby

is not right. I need to act, so, so, so with the fact that they helping us, as also we are understaffed, they are also gaining more skill and they have, they put more effort in raising their child in the hospital." P1(1)
"The mothers are attentive, and they help us. OK, they know to what we are... because we teach them what to look out for... yes they know the danger signs to look out for" P2(1)

Parental education is described by Bracht et al. (2013:115) as a valuable aspect of the implementation of family integrated care, the study elaborates on the important advantages that education holds to the parents. Winston and Chicot (2016:14) were of the opinion that when parents were informed, it could contribute to the parents being more relaxed and assertive.

In an Iranian study by Mianaei et al. (2014:95), advantages of the parents taking part in an empowerment program were confirmed as reduce levels of stress and anxiety, and increased confidence to take care of their infant. They were taught about the condition, state, expectations and differences in prematurity, how to communicate, be the primary caregiver at home and to fulfil the needs of their infant.

b. Emotional support

Emotional support was given to mothers on an ongoing base, as they needed encouragement, support and/or education. The mothers would spend up to four months in the hospital, seldom exiting the hospital grounds. Participants referred to occasions where the mothers were emotionally supported and comforted. The staff also seemed sympathetic towards the mothers; they did not expect the mothers to perform activities that they were not comfortable with performing.

The participants also mentioned that mothers who were stressed about their home situation were given the opportunity to return home for a visit. The infant would then be taken care of by the staff for the time of absence. The mothers usually did not receive many visitors as they came from a large geographical catchment area with towns being far apart, and most could not afford the costs for transport. Those mothers relied more often on the staff for emotional support.

The overcrowded and small NICU could not accommodate visitors as there was barely enough space for the incubators and the mothers of the patients. The rooms provided for the mothers to stay in were double rooms, meaning that two mothers were sharing a room. This made it difficult for fathers and family to be accommodated.

Quotations from participants:
"We try to calm - because she - the mother down and to make her feel at home and to make her, so that she doesn't have to be you know, to worry that much about what's going on now, so yes." P2(2) *"Yes, and usually when the mother is a little incompetent. And they must, mmm, they feel, they feel a little emotionally down and they feel a little, how can I say, the, they, hmm, hmm, they are not very confident, but with the involvement ... If you involve them with the care of the child, then they get that confidence..."* P3(1) *"They will now just no I am not working with the child today and I feel too stressed and sister you must now just go on with this child and so on. This is also challenges that we deal with, and sometimes you must also just talk and encourage and say no everything is going to be oraait and so on."* P2(2) *"And then they get pass outs. So, if family maybe passed away or the mommy is a little stressed and she feels like she needs to debrief, then we give a pass out."* P4(1) *"…all the other family with her, they are there with us, but we allow just the father and the grandparents what, what, inside of the wards."* P2(2) *"Only a few fathers that actually get involved and we actually get them after a while..."* P3(2) *"There was a father... from Springbok....So every time that the mother comes, he's coming with her in the room and we do had a problem because during that time it's feeding time and the mothers have to expose their breasts to give, the mothers around must expose their breast to give the babies the breastfeeding. So that actually was a challenge..."* P1(2)

Heidari et al. (2013:210) defined stress as "a significant experience which provokes a great sense of misgiving, nervousness, emotional tension or pressure and separation anxiety". Mothers discussed their disappointment in the birth of a premature infant as an unexpected, overwhelming experience and a feeling of loss, and these emotions accompanied feelings of fear, sociological disturbance and stress. Heidari et al. (2013:210) further described the uncontrollable changes in the emotions of a woman who has given birth due to her new role as mother. When this new infant is born prematurely, she faces even more emotional challenges. The impact on the natural process when maternal bonding cannot take place, is described as a painful destruction of balance. The parents experience a loss of control that causes more stress and can lead to psychological disturbances.

Cheng et al. (2006:35) indicated that if the mother is not supported during this postnatal period, she might be unable to take care of the needs of her infant, and this can influence the bonding process and have future negative effects on the relationship of mother and infant.

c. Attention paid to mothers' health

The participants were passionate about the healthcare of mothers who had just delivered a newborn infant. They indicated that they would most likely be the first healthcare providers to discover if a mother had an abnormality or health risk such as infection haemorrhage, or even a mental issue such as depression. Early detection and treatment were seen as a great benefit of family integrated care because the close contact and continuous interaction with the mothers, made it easier to observe the mothers and to detect any changes in their health status.

Quotations from participants:
"You see the mothers there, you know I always tell them we are a mother, we are even the ones who can pick up that the mother is not doing well. That she's got pain, that she is not doing well, that she has something wrong. You will just smell something. You'll ask what's wrong, she will be like I got infection. She didn't even know that she will go to casualties [emergency department]. *You get such things. But then you as the sister, you will say, let me call casualties. Go to casualties, get treatment, and come back, she feels little better. Because we are there, but in this other hospital, when they don't even interact with the mothers continuously."* P1(1)

According to Cheng et al. (2006:35) the postpartum period is defined as the period from giving birth to six weeks after giving birth. This is the time that a mother needs to recuperate as her body has produced an infant, many physiological, hormonal and emotional changes have taken place, but she also has the responsibility of taking care of a new infant as well as recovering from the delivery. Maternal health care is often neglected if the international objectives and information on maternal health is considered. A more holistic approach to maternal health care is needed whereby family support is encouraged and educational projects are introduced. Longitudinal studies show that poor maternal physical health is related to a negative effect on the health of the infant in terms of: poor physical health, occurrence of tantrums and poor relations with other children. Mothers under these circumstances report on the many challenges of having to manage the behaviour of children up to the age of three years (Cheng et al. 2006:35).

One advantage that was discovered in this study, that as far as the author is aware has not been mentioned or discussed in any other available study on family integrated care, was the advantage of the care rendered to the mother's physical health.

4.2.2.3 Advantages for the NICU staff

Two advantages that family integrated care holds for the NICU staff are the sharing of responsibility for the care of the infant and stress reduction in the staff.

a. Sharing responsibility for care of infants

The participants indicated on numerous occasions that all parties involved in the relationship benefited: the staff, for receiving support in relief of the workload; the mothers in receiving emotional support as well as education and support in practicing their new skills under supervision; and all the benefit already discussed regarding the infants.

The participants initially expected that the implementation of family integrated care would add to their already heavy workload. The surprising reality was that the opposite was found following the implementation of family integrated care, as the mothers became part of the multi-disciplinary team and acted as an extension to the staff in performing many extra duties while taking care of their infants. The participants discussed their support in the care of the infants, when and where the mothers were tired, felt emotionally drained, or were not yet competent, or were unsure or unable to perform a task. The participants also talked about the need for emotional support of the mothers, as the staff was able to bring a level of comfort to the mothers.

Quotations from participants:
"...So, yes it works well. The mothers are observant and then they help us..." P2(1)
"It's got more positives than negatives and ... ,that everything has a negative somehow, somewhere." P1(1)
"They must practice family integrated care, because if I can see how lekker [nice] *the mommies work."* P4(1)
"Why is it , it works well for us at staff, it there, I will make an example of a day like yesterday, we were only two registered nurses, with two nurses with 18 children and then we had 3 admissions and as you admit, you don't get a chance to give to the other children. But the child ate, temperature was done, I even said at the end, just press the blood pressure that it may take and then I will come

to write later. So, it, they were, they are , they were a handle for us when we could not get to them and getting a new sick baby, I can go on so long, the mother..." P1(1) *"…helping with that workload of us that we are having." P3(2)*

Mianaei et al. (2014:95) found in their study in Iran on empowerment of parents of a prematurely born infant, that the nurses in the unit experienced a high workload and found relief in sharing the responsibility of care with the parents. The parents in turn appreciated the opportunity to actively take part in the care of their infant.

b. Stress reduction of NICU staff

Participants described the mothers as being helpful, supportive and an active part of the multi-disciplinary team. The participants referred in several examples of how the mothers helped them during very busy times. The short-staffed situation was at several occasions relieved by the responsible and dependable participation of the mothers. The mothers were even referred to as being a '*handvatsel*' [handle] that extends or can be held on to. The description is so appropriate and indicated a level of trust involved between the staff and mothers.

Quotations from participants:
"I need to act, so so without the fact that they helping us, as also we are understaffed, they are also gaining more skill..." P1(1) *"Maybe you find the time you were supposed to go, and feed has passed, but then the mothers are there at least they are meeting us halfway, by the time you go to the baby, they already done so much, they already fed the baby, they did the observations. So, really time saving for us, because sometimes you really find that we don't really have chance when we are having sick babies."* P3(1) *"...they also help us a lot with the breastfeeding, they help us also a lot with everything. We also show them also how the breastfeeding is done..."* P4(1) *"Then I told her, leave him, I will feed him, do the observations."* P4(1) *"...no, I can't work with the child today, I feel too stressed and sister you must now continue with this child now."* P2(2)

The heavy workload of nurses was discussed in a study done by Bahadori et al. (2015:2). The changing work environment of the nurse has left the occupation with many challenges due to the shortage of nurses, changes in hospital setup, the patient to nurse ratio, advanced technology and increased demands of patients, which in turn has left nurses feeling overwhelmed. The effect of long-term

exposure to stress can cause nurses to suffer from severe illnesses such as cardiac diseases, respiratory diseases and many more. Therefore, the implementation of family integrated care can address and relieve these challenges as the mother's involvement in the care of her infant reduces the workload of the nursing staff.

4.2.3 Challenges related to family integrated care

In the following section challenges related to mothers, logistics and staff are discussed.

4.2.3.1 Challenges related to mothers

a. Stress levels and exhaustion of mothers

Stress, fear, worry and uncertainty were identified by the participants as some of the emotions that the mothers experienced during their time in hospital, while taking care of their new infant. These emotions could have a negative effect on the mothers and could result in a negative impact on the infants. The mothers in this unit were faced with numerous challenges such as exposure to domestic violence, single parenting, lack of family support, lack of visitation, economic challenges, illiteracy, exhaustion and stress. The mothers were exposed to their own challenges and emotions; they were in a new environment and had just been through a delivery. They then were also expected to fulfil some expectations around the care of their baby and needed to learn skills to be able to perform those duties.

Participants appeared to be very empathetic toward the situation of each mother individually and provided emotional support. Staff communicated with the mothers continuously and would attend to the care round for the infant themselves should the mother need some time to rest and recuperate. The occupational therapist contributed daily physical or outdoor activities in an attempt to help the mothers to relax and prevent exhaustion and depression.

Quotations from participants:
"It is not easy to get up every three hours for feed every day for three months it is a challenge. Mmh, up to four months." P3(1)
"During that time the parents sleep inside, the mother sleeps inside the hospital for the full term." P3(1)
"They know now I have a baby, the mother is busy with the other little baby, she cannot get to this little one. So, I told her leave him, I will feed him, do the observations." P4(2)

"... the therapists come in also to hold sessions. She sit with the mommies and interview them one by one, I saw. Interview them, they take them out on walks here around the hospital and this is an income, then I saw the other day they have such games... Ask each other questions, it is supposedly to relax, and our mommies can sit and watch television with their little babies..." P4(1)

"...and then they feel so worked up and then they feel like they are not working with the child today." P2(1)

"...there are not really support, many of the mothers does not have support from outside, or there is always. Shall I say social problems, she sits alone with the sick baby, there is not really anyone that from outside..." P3(1)

"Sometimes the mothers are also always stressed." P2(1)

"We try to calm because, she the mother down and to make her feel at home and to make her feel at home, make her, so that she doesn't have to be you know, to worry that much about what's going on now, so yes." P2(2)

Haidari et al. (2013:210) referred to the high levels of stress that are experienced by parents when their infant receives treatment, undergoes an invasive procedure, has an abnormal episode in breathing, change in skin colour, or appears to be in pain according to facial observation. Parents also experience more stress when the parent and infant are separated.

Three major stress reactions were identified in a study by Heidari et al. (2013:2011), namely psychological, emotional and behavioural. In relation to psychological reactions, parents tend to reveal non-rational behaviour such crying, being agitated or even becoming psychologically unstable. Emotional reactions can include feelings of guilt and fear. Behavioural reactions to stress can include insomnia, loss of appetite and paranoia (Heidari et al. 2014:211). According to Heidari et al. (2013:212) it is the NICU environment where parents are more prone to be confronted by the appearance and condition of their infant and even end-of-life decisions, all of which contribute to parental stress. Parents' stress levels might not always reduce when they are educated, informed and invited to take part in the making of decisions regarding their infant and its treatment. However, according to Winston and Chicot (2016:14), parents can experience a sense of relief when they understand how much their infant needs them and does not place judgment on their behaviour, and that the new infant is dependent on their involvement, and that the most important way a parent can help their child is through their love and care of her/him. Parents have at times unrealistic perceptions of what their children need, and the parent can be under the impression that they need to provide the best

accommodation, toys or performance, but the need of an infant is mainly love and attention, communication and affection, and cuddles and contact from their parents.

Parents should be made aware of these facts to enable them to relax and enjoy parenting their infant. Parents suffer from severe stress and anxiety; depressed parents can have the experience of thinking they are horrible parents. According to Winston and Chicot (2016:13), healthcare providers should assure parents that as parents they are able to take care of their infants and that their infant does not need complex things, but interaction from them and care and love. Montanholi et al. (2011:2) describe the high demand involved in the care of neonates contributing to the overload of responsibilities on the nursing staff, but it could also contribute to an overload on parents.

In a study by Mianaei et al. (2014: 95) parental stress was discussed as being caused by the stressful event of the birth of a premature infant followed by admission and hospital stay in an NICU. This indicated that parents are already in a vulnerable state and therefore the introduction of family integrated care should happen in a gradual manner, so that the effect of the extra responsibilities given to the parents can be monitored to prevent exhaustion.

b. Personal circumstances of mothers

There were several personal circumstances of mothers that proved to be challenging with regard to the implementation of family integrated care, including: illiteracy, domestic violence, poor family support, substance dependency and a lack of the mother's involvement in her infant's care. The illiteracy of mothers in the unit was a challenge as the mothers needed to document their findings. The documentation involved a tick list that monitored the involvement of the mother in the care of her infant. The illiterate mothers needed someone to show them every time where to make a tick or to write information down on their behalf. These mothers then would still practice the activity, for example nappy care, and would show the nappy and content to the staff and the staff member would document the information on the daily activity sheet and the observation document.

Quotations from participants:
"Certain mommies, because many of them come and then they cannot, they are not educated, they cannot read or write, then you have to explain to them how to write..." P1 (2) *"Sometimes, then you get some of these mommies that now does not know how to write."* P2(2) *"For example, those who are now illiterate, that did not attend school. They will show us the nappy to see the colour."* P1(2)

"They can for example make a three and the six, otherwise as with the other things, then we write also, this is what they came to show us, so and they give their cooperation, see." P2(2)

Bhekimpilo (2015: 90) concluded that children from illiterate parents have more challenges to face in the future than children from educated parents. In the course of this research, no literature was found on studies relating to illiterate parents and the implementation of family integrated care.

A further important challenge to the successful implementation of family integrated care was substance dependency. Mothers, who were addicted to substances tended to abandon their new infants and sneak out of the hospital. These cases became complicated with involvement of social services and the police department.

Quotations from participants:
"The challenge that I have here, with myself, is that these days I get to have a lot to do with mothers that is on substance abuse things that..." P4(1) *"That the little baby is on substance abuse that just leaves the little baby like that. Then we must stand with these mommies."* P4(1) *"But then the Allied Health and Social Workers, social workers, then they come in. Many of us gets positive results there when they are rehabilitated. Some of them come take the babies back."* P4(1)

As discussed by Suchman et al. (2007:213), drug dependent mothers have the tendency to be less involved in the care of their infant and bonding and interaction between mother and infant is a serious problem.

Another serious challenge experienced was the reality of domestic violence. The mothers were often exposed to violence and abuse and the additional load of responsibility as well as the fear of taking the child to those circumstances added to the mothers' stress.

Quotations from participants:
"Sometimes they live an abusive life with the man or the only family and then they feel like now just no, I am not working with the child today..." P2(1)

According to Alhusen et al. (2015:101) abused mothers are more likely to miss the prenatal appointments and are more exposed to poor nutrition, alcohol abuse and substance abuse. These are

all predominant factors to delivering an underweight, small for gestational age, infant. Such an infant might be at a higher risk for early childhood developmental and behavioural challenges, cardiac disease, vascular incidence, diabetes mellitus, adiposity and metabolic syndrome in adults.
Additional literature was not found on the implications of domestic violence during the period of hospitalisation in the NICU or during implementation of family integrated care.

A further challenge identified during implementation of family integrated care in this study was the lack of involvement of the rest of the family other than the mother. The participants indicated that the implementation did not work as initial plans intended. The hospital could accommodate mothers to be close to their infants, and food and linen were provided without any additional costs. The staff attempted as much as possible to involve and give education to the father and grandparents when they came to visit, but it was not always realistic or practically possible, as the families were often from neighbouring towns and transportation was a challenge. It was also difficult to accommodate additional family members in the small NICU due to lack of space.

Quotations from participants:
"And when I see here comes the family in, we are now just the grandmother, father, but is works well for me if we with the father. Me well if we, the fathers also can KMC and the babies put inside." P4(1)
"Look, we can do, can do what we can in here, but is just lekker nice when the father come visit and understands what is going on here..." P3(1)
"It's difficult to get the whole family especially the fathers also who we would like to get involved. Most of them are working, but those of them who are coming, we try to, to, to show to, to, to do the KMC, how to put the baby on skin, but what, what the other stuff. The observation part of the baby, that is very difficult, so the mother is mostly the one that we can get so far to involve..." P2(2)
"It's only a few fathers that actually get involved and we actually get them after a while ... that they are interested they want to know, some ... even KMC, but it's not a lot of them." P3(2)
"What if the father said he wants to be more involved and yee, we can't accommodate, accommodate him with a place to stay, with the mother or with the baby for longer?" P2(2)
"Because the, the space it's all, it's not private, the space is not private..." P1(2)
"The family are not involved at, actually because some mothers, they don't get visitors, they are maybe not from Upington." P1(2)
"At this stage there is a lot of mommies that is awaiting KMC, waiting that now can't go to KMC. It is full, it's only a ten bedded ward, so to expand on our KMC are to put more in." P1(1)

"Some are from Keimoes, Kakamas … Come from far distances." P4(2)

"Sister said, the space is small, there's many babies, many mothers and we would like to get the father and the other family involved." P3(1)

"All the other family with her, they are there with us, but we allow just the father and the grandparents what, what inside of the wards." P2(2)

"Then we explain to them, all of them, what we're gonna do, what what's happening here now. What the mother's responsibility and you'll find out who's gonna come visit them. We take it from there we involve them as much as possible." P2(2)

"Some families from outside, they don't really know what is going on inside here. We don't always have time to always also explained to them, look, usually with visiting times, not know what what is, the mother then knows exactly, or she has at least a little knowledge, then she can again explain to them, then again it takes that little off us again." P3(1)

"Family integrated care with us is now to get the mother and father involved in the care of the baby...it is now to advance the care of the baby with the help of the parents and involved family, yes." P3(1)

Montanholi et al. (2011:305) stated the importance of family involvement and active participation in the care delivered to an infant in an NICU, as well as the importance of focussing on the individual developmental needs of the infant. Kemp (2011:3) emphasised the importance of the family's involvement, but especially the father. The father's involvement in the care of the infant has a direct influence on the confidence, stress management skills, and physical and emotional development of the child.

The father undergoes hormonal changes when he is a father to be and involved with his infant, which leads to nurturing and protective behaviour. Craig et al. (2015:S5-S8) described the involvement of the family in the care of an infant as the key to understanding the effect on the long-term benefits in the physical, neurological and psychosocial development of infants. The authors recommended that all efforts to integrate family involvement by nursing staff, families and caregivers should be supported in policies written on infant care, as it reduces stress levels of the mothers and they are more informed and empowered when discharged. In some cases in this study, there was a challenge with a lack of maternal interest and involvement. As much as some mothers experienced family integrated care and the involvement with their infants as positive, there were some mothers who did not appreciate the involvement and responsibilities of nursing their infants. These mothers would then not be active in the process and needed more education and encouragement.

No literature could be obtained on mothers who were not interested in the implementation of family integrated care because previous studies have been based in hospitals where all infants and family members were exposed to the implementation of the process. The family members understood that the NICU to which their infant was admitted practised family integrated care. No negative attitudes or experiences were documented in any studies obtained.

4.2.3.2 Logistical challenges

Logistical challenges were related to the unsuitable physical layout of the NICU, infection prevention and lodging accommodation of the mothers.

a. Unsuitable physical layout

The NICU was described by the participants as too small and overcrowded. This placed a challenge to the practice of family integrated care, preventing and limiting the participation of family members.

Quotations from participants:
"The space is limited and there are many babies, many mothers..." P3(1)
"The space is so limited..." P3(1)
"There's not spacious." P1(2)

In the studies performed on family integrated care, parents and family members only spent up to eight hours in the neonatal intensive care unit per day. The hospitals therefore did not have the need for overnight facilities and the physical layout was not discussed as a challenge to accommodate family members during the implementation of family integrated care (O'Brien et al. 2013:1).

b. Infection prevention

The participants were very passionate about infection prevention. Handwashing was the main infection prevention method and everyone who entered the unit was educated and expected to practise proper handwashing.

Quotations from participants:
"Especially in the infection risk, it's high, but a, we tried with the hand washing everything, but, yes..." P2(2)

"Keeping the rooms and ward clean is the only thing we can do, but it might be not enough at the end of the day...so. Yes." P2(2) *"Before we had gowns, but it phased out, so we are not using the gown any more for the visitors, because we don't have for each, each..."* P1(2) *"There are no gowns..."* P4(2) *"They must wash their hands when they enter the room, before touching anything."* P1(2) *"So, the important is hand washing."* P1(2) *"When the mother comes the first day, we only just say, here is the little baby, is here and the orientation, but without doing anything, just knowing for her knowing to wash hands, spray your hands." P1(1)*

In relation to infection control and the effect that overcrowded areas have on the increase of infection risk, Julian et al. (2015:1174) discussed the impact of NICU bed configuration on late onset bacterial infections and concluded that hand hygiene had the most important influence, regardless of room configuration and whether there were single or shared rooms.

c. Lodging facilities

The lack of accommodation for fathers at the lodging facilities was a concern and was seen as hampering the full inclusion of the fathers in family integrated care. As the mother's in the hospital were provided with shared accommodation, the study participants identified a lack of privacy as a concern. There were at times arguments or differences amongst the mothers, which might have been a result of confined space and lack of privacy.

Quotations from participants:
"What if the father said he wants to be more involved and yee, we can't accommodate, accommodate him with a place to stay, with the mother or with the baby for longer?" P2(2) *"Because the, the space it's all, it's not private, the space is not private..."* P1(2) *"A lot of sheep in one camp doesn't always work so well, but he he till to steal milk."* P4(1) *"And the other mommies in, from the ICU that sleeps in the rooms, they sharing with other mothers. So, they, it's not private."* P2(2)

O'Brien et al. (2013:1) describe the use of comfortable soft chairs during the long hours that the family members spent with their infant in kangaroo mother care positions. The mothers were not provided with private rooms, but only with comfortable chairs next to, or close to, the incubators used. The

hours spent with the infants were described to be about eight per day. The family members would then return home to return the next day, understanding that the family did not spend the night in the hospital (O'Brien et al. 2013:1).

4.2.3.3 Challenges related to staff

The challenges related to staff have an impact on the implementation of family integrated care because it is the staff who implement the practice. Therefore, the perceptions, attitudes and knowledge of neonatology held by the staff is discussed in the next section.

a. Perceptions and attitudes of staff

The participants referred to their initial perceptions of family integrated care, then described several experiences that had caused them to alter their perceptions on the process. Family integrated care was initially not fully implemented in this NICU; therefore, the pre-existing perception of the nursing staff was that it would lead to an increased workload. However, once they had experienced family integrated care, they realised that the implementation thereof actually reduced their workload and improved the outcomes of the infants.

Quotations from participants:
"We're also understaffed and at times you find we have one person in KMC where you can't really monitor that everyone does the right thing." P1(1)
"Whole Meraai and she would tell us 'switch off the radio', He, He, He! Things like this. I was like who is this woman, she is not even working here?" P1(1)
"Yes, at first you think, ai Sister Swart, what is this, we don't have time, we are too...(Laughing)....busy, o so tired." P2(2)
"No man, sister Swart, what is this? But once now that we have seen it, there is a name for it." P2(2)
"...We, we just didn't know how well it's working, yes, so yes...the baby gets so much advantage out of it, so much advantage, just like us." P2(2)

Carbon (2014:566) indicates that the purpose of perception is to enhance sensory inputs to enable a person to experience, orientate and act fast, specifically and effectively. The best way of perceiving something is to experience it in order to perceive it as reality and factual. Sensory experiences like viewing, feeling or touching something will make the perception more accurate.

Montanholi et al. (2011:305) describe the challenges of those nurses to be factors hampering delivery of high-quality care to the infants and their families, such as shortage of staff, lack of essential equipment and stocks, overwhelming paper work, noise in the unit, problems in teamwork and the lack of professional development of staff.

b. Staff knowledge of neonatology

The staff working in this study's NICU were not specialised in neonatology. Therefore, the concept and advantages of family integrated care were seen by the participants as new and strange. Consequently, the understanding and subsequent implementation of family integrated care was initially a challenge.

Quotations from participants:
"We need to understand form which few she was doing it from and she had a … uhmm in-house training and she showed us now, and I also even know, o, I even know I need to switch off the light, why should I switch off the lights." P1(1) *"We don't see things not really encourage depth, you don't know because we didn't specialize in neonatology mostly."* P1(1)

Montanholi et al. (2011:305) stated that the need for education and continuous professional development in nurses who works in an NICU is viewed as important to provide quality care to infants and their families in the NICU. In their study, the nurses verbalised that they were not specialized in the field of neonatology and confessed to obtaining insight after in-house training. The lack of education and the resulting lack of appreciation of the multiple benefits of family integrated care, could be a reason why it was not successfully implemented or maintained in the neonatal intensive care unit where study was performed.

4.3 CONCLUSION

This chapter provided the findings of this study regarding the experiences of nurses with the implementation of family integrated care concerning initial implementation of family integrated care, advantages for infants, mothers and neonatal intensive care staff and challenges related to mothers, logistics and staff. The next chapter will be on the conclusions and recommendations.

CHAPTER 5: CONCLUSIONS, RECOMMENDATIONS AND LIMITATIONS

5.1 INTRODUCTION

In this chapter the conclusions, recommendations and limitations of the study will be discussed for the use of future or similar studies and references.

The aim of the study was to explore and describe the experiences of nurses in the implementation of family integrated care in a particular neonatal intensive care unit in the Northern Cape province of South Africa. Family integrated care is an internationally recognised and practice, but a fairly new concept in the field of neonatology. This concept has many advantages as discovered in studies undertaken in the NICUs of Canadian and Iranian hospitals. Unfortunately, family integrated care has not been implemented in the South African neonatal field. Only some aspects of family integrated care have been adopted in some neonatal units in South Africa. Nurses are the key to the implementation of family integrated care, but resistance to the implementation of the process in the South African context, has been observed in some nurses. One of these units is the neonatal intensive care unit at The Hospital in the Northern Cape.

Situated in a particular hospital in the Northern Cape where the gradual structured process of family integrated care has been implemented in the NICU, this study explored and described the reasons for resistance against the implementation of family integrated care by nurses and to identify the challenges and benefits of implementing the process to the nursing staff, infant patients and their parents.

5.2 CONCLUSIONS OF FINDINGS

Family integrated care had been implemented in the study's NICU for a period of three months, before this research commenced. A qualitative study was then conducted using two focus group interviews with voluntary participation from nursing staff/caregivers that had experienced the implementation of family integrated care in the unit.

The researcher found that in the initial phase of implementation, caregivers were very resistant and were of the perception that the process would contribute to an even heavier work load. However, over the three-month period, the caregivers experienced and identified many advantages to the infants, the mothers and also to the caregivers, or nurses, themselves. They observed that the infants bonded better, that mothers were more involved in the care of their infants, that infants had lower stress levels and could be easily soothed by the mother, and that the infants experienced kangaroo mother care for longer periods of time. The study participants referred to the increased growth and development and increased incidence of infants to be breastfed when family integrated care in practised.

The participants observed many advantages to the mother. They discussed the obvious empowerment of the mothers, and how the mothers were orientated and educated towards the care and condition of their own infants, but also the benefits of greater parenting competency and an increased ability in good decision-making skills were identified.

The mothers benefitted from the emotional support they received from the caregivers in the unit, and because they had access to the caregivers 24 hours a day, the support was unlimited and given as needed. The identification of the benefits of family integrated care to maternal health had not previously been discussed in similar studies performed in Canada and Iran.

During this study in South Africa, the participants discussed their observations and role in the implantation of family integrated care in the NICU, as well as the ability to have faster diagnoses owing to the mothers' input, and how the process affected the mothers' health. The participants also faced challenges and attempts were made to overcome some of these challenges. However, there were some challenges that could not be addressed yet. These included the poor involvement of fathers and other family members. Limited space in an overcrowded NICU and the lack of overnight accommodation for additional family members might contributed to the fathers and other family members not being involved in the implementation of family integrated care in this unit.

Additional challenges faced with the implementation of family integrated care in the NICU were the shortage of staff and initial attitude of overworked nursing staff towards the implementation of a new structured process in an already very busy unit.

5.3 RECOMMENDATIONS

The following recommendations are presented by the researcher. Recommendations are presented with regards to neonatal nursing education and practice, general NICU hospital management and then conclude with suggestions for future research. Recommendations are aimed at the implementation of family integrated care, the provision of education for healthcare workers, especially neonatal intensive care nurses, and the use of media to educate and inform the public about the many benefits of family integrated care.

5.3.1 Recommendations for nursing education

- Education to be given to NICU nurses in the private and government sector in South Africa on the implementation and practice of family integrated care.
- Educational material to be incorporated in the speciality training at Educational Nursing Institutions in South African universities and colleges.
- Continuous education should be provided to parents of infants in NICUs in South Africa.
- Incorporation of family integrated care educational teachings to occupational therapy students in South African Universities.
- Ongoing education of student doctors at South African universities with regards to family integrated care.
- Practical demonstrations and regular educational sessions to the multi-disciplinary teams involved in neonatal intensive care units in South Africa with regards to family integrated care.
- Educational presentations on family integrated care at international and national conferences on Neonatal Care.
- Continuous practical demonstrations to, and by parents, and opportunities to demonstrate competency at the bedside of the infant by parents.
- Initiation and creation of educational material on family integrated care as pamphlets to be distributed at public health education events and in maternity and neonatal units in South African Hospitals.
- Distribution of education material and health education with regards to family integrated care at antenatal health clinics in South Africa.
- Display of posters and educational material on the implementation and benefits of family integrated care at health institutions in South Africa.
- Continuous educational sessions with parents of infants in a neonatal unit to reinforce involvement, skills and empowerment.

- Nurses and caregivers to experience the implementation of family integrated care and to influence and promote the practice of family integrated care in a positive way.
- Educational reading material should be made available to parents and family members of infants involved in family integrated care.

5.3.2 Recommendations for nursing practice

- Educate caregivers in NICUs in South Africa to be able to practice family integrated care in their units.
- Train the caregivers in NICUs to be able to implement family integrated care gradually and in a structured manner with the parents, in accordance to the displayed ability of the parents to advance in the complexity of care of their infant.
- Neonatal intensive care units should not be overcrowded or too small, the overfull and crowed units hold infection risks and make the participation of additional family members, especially the father, very difficult or impossible.
- The South African Department of Health should be made aware of the benefits of family integrated care to actively get involved in this practice.
- Occupational therapists at all health care facilities should be included in the implementation of the process of family integrated care.
- The benefits and success stories should be published in local and national media to inform and educate the public on the practice and benefits of family integrated care.
- Mothers and fathers should be empowered to take care of their infants while still in hospital. They should be supported and encouraged to actively take part in all decisions that are made.
- Healthcare providers should be encouraged to share their experiences of integrated family care with other healthcare providers. The participants in this study were advising other nurses and advocating for other hospitals to implement family integrated care in their units.

5.3.3 Recommendations for nursing management

- Management of hospitals should be made aware of the benefits of family integrated care to their staff, patients and families so they can implement the practice of family integrated care in their neonatal units.
- Hospital management should be made aware of the studies that have found a lower incidence of neonatal practice law suits concerning neonatal care provided by hospitals where the parents are

involved in family integrated care. The practice of family integrated care could save hospitals millions of rands.

- Management of NICUs, maternity wards, health clinics, antenatal clinics and all neonatal or infant related health care facilities, should be informed of the practice and how they can involve the parents and families of infants to become part of the multi- disciplinary team.
- Management of health institutions in South Africa should initiate and encourage, fund and implement, more research studies on the implantation of family integrated care in their organisations.
- Accommodation facilities should be created for the mothers, fathers and family members to be able to stay close to the NICU, so that they can be involved in the care of their infant through the practice of family integrated care.
- NICUs should not be overcrowded or too small for the number of infants supported by the unit. Where space is limited space, the implementation of family integrated care becomes very difficult or even impossible, and at best is limited to the mother.
- Management should facilitate regular educational updates and courses on family integrated care and provide the support for caregivers to implement this practice.

5.3.4 Recommendations for future research

- More research needs to be performed on the implementation and benefits of family integrated care in the South African health sector.
- Study results should be presented at national and international neonatal health related events.
- The findings of the positive impact family integrated care has on the neonate, the family and the staff need to be published.
- The advantages of family integrated care need to be presented to the South African Department of Health

5.4 LIMITATIONS OF THE STUDY

The findings of this study are based on the real-life experience of a phenomenon and the data was validated as trustworthy. The limitation is that these findings originate from one study only, in a single neonatal intensive care unit and as such, cannot be generalised. However, the experience of the participants could serve as a guide to implement or improve family integrated care in other South African neonatal intensive care units.

5.5 CONCLUSIONS

The study addressed the experiences of nurses in the implementation of family integrated care as a gradual structured process, integrating the families in the care of their infants. It was found that family integrated care poses benefits as well as challenges for the mothers of infants and staff.

The implementation and practice of family integrated care was described by the nurses/participants in this study as positive and sustainable in the neonatal intensive care unit of this study.

If the principles of family integrated care are practised, the family is allowed to play an active role in the multi-disciplinary team during the care and treatment of their infant, which helps to overcome feelings of loss and helplessness and being excluded from the care process. Family integrated care empowers parents and optimises opportunities for bonding and attachment of the infant to a parent. This bonding and attachment have life-long benefits in the development of trust, mental health, emotional coping mechanisms and emotional intelligence of infants.

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ANNEXURE A

- **Declaration regarding plagiarism**

DECLARATION OF ORIGINALITY

UNIVERSITY OF PRETORIA

The Department of ...University of Pretoria..... places great emphasis upon integrity and ethical conduct in the preparation of all written work submitted for academic evaluation.

While academic staff teach you about referencing techniques and how to avoid plagiarism, you too have a responsibility in this regard. If you are at any stage uncertain as to what is required, you should speak to your lecturer before any written work is submitted.

You are guilty of plagiarism if you copy something from another author's work (eg a book, an article or a website) without acknowledging the source and pass it off as your own. In effect you are stealing something that belongs to someone else. This is not only the case when you copy work word-for word (verbatim), but also when you submit someone else's work in a slightly altered form (paraphrase) or use a line of argument without acknowledging it. You are not allowed to use work previously produced by another student. You are also not allowed to let anybody copy your work with the intention of passing it off as his/her work.

Students who commit plagiarism will not be given any credit for plagiarised work. The matter may also be referred to the Disciplinary Committee (Students) for a ruling. Plagiarism is regarded as a serious contravention of the University's rules and can lead to expulsion from the University.

The declaration which follows must accompany all written work submitted while you are a student of the Department of ...University of Pretoria..... No written work will be accepted unless the declaration has been completed and attached.

Full names of student: ...Emma Elma Swart.....

Student number: ...10320866.....

Topic of work: ...Micro 300.....

Declaration

1. I understand what plagiarism is and am aware of the University's policy in this regard.

2. I declare that this ...assignment..... (eg essay, report, project, assignment, dissertation, thesis, etc) is my own original work. Where other people's work has been used (either from a printed source, Internet or any other source), this has been properly acknowledged and referenced in accordance with departmental requirements.

3. I have not used work previously produced by another student or any other person to hand in as my own.

4. I have not allowed, and will not allow, anyone to copy my work with the intention of passing it off as his or her own work.

SIGNATURE .....

ANNEXURE B

- INFORMED CONSENT FROM NURSES

INFORMATION LEAFLET AND INFORMED CONSENT FOR NON-CLINICAL OPERATIONAL RESEARCH

TITLE OF THE STUDY: EXPERIENCES OF NURSES OF FAMILY INTEGRATED CARE IN AN NICU IN A PUBLIC HOSPITAL

Dear Participant

1. INTRODUCTION

We invite you to participate in a research study. This leaflet has information about the study. Before you agree to take part you should fully understand what is involved. If you have any question that this leaflet does not fully explain, please do not hesitate to ask the researcher.

2.THE NATURE AND PURPOSE OF THE STUDY

The overall aim of the study is to explore your experiences of family integrated care in the NICU.

3. EXPLANATION OF PROCEDURES TO BE FOLLOWED

In this study you will be invited to participate in a focus group interview with three to seven of your colleagues. The main question that you will be asked is "What are your experiences of family integrated care in the NICU". The focus group interviews will be scheduled when you are not on duty to prevent interruption of the services, but it will be done at the most suitable time possible for all.

4. RISK AND DISCOMFORT INVOLVED

We do not foresee any risk during participation in the study. The only discomfort might be the time that you sacrifice to participate, which will be approximately 45 minutes. If you experience any other discomfort during your participation, please inform us about it. If you feel uncomfortable during the focus group interview, you do not need to answer anything if you don't want to. The interview will take place in a private room in the hospital at a time that we will agree on.

5. POSSIBLE BENEFITS OF THIS STUDY

Participation in this study will give you an opportunity to share your experiences of family integrated care in the NICU. You will not be paid for your contribution, but the information that you contribute will assist us with recommendations to improve on the implementation of family integrated care to benefit parents, babies and the healthcare team involved in family integrated care.

6. WHAT ARE YOUR RIGHTS AS A PARTICIPANT?

You participation in this research is entirely voluntary - it is your choice to participate or not. If you wish not to participate you do not have to do anything in response to the request. The choice that you make will have no effect on your status as an employee, or any other way. If you agreed to participate in the study you can still withdraw at any time.

7. HAS THE STUDY RECIVED ETHICAL APPROVAL?

The proposal will be reviewed and approved by the Research Ethics Committee of the Faculty of Health Sciences of the University of Pretoria and the Ethics Committee of the Hospital. Copies of approval letters are available if you wish to view these approvals.

8. INFORMATION OF CONTACT PERSONS

If you have any questions about the study, after discussion.

You may contact any of the following persons at any stage.

- The researchers: Em-Esna Swart at [redacted]
- The supervisor: Carin Maree at [redacted].
- The co-supervisor: Seugnette Rossouw at [redacted].
- Research Ethics Committee: Manda Smith at (012) 356 3085

9. COMPENSATION

To participate in the research is voluntary, no compensation will be given.

10. CONFIDENTIALITY

All information that you give will be kept confidential. Once we have analysed the information no one will be able to identify you. Research reports and articles will be written for scientific journals but will not include any information that may identify you**.**

CONSENT TO PARTICIPATE IN THIS STUDY

I confirm that the researcher has explained to me the nature, process, risks, discomforts and benefit of the study. I have also received, read and understood the above written information (Participation Information Leaflet) regarding the study. I am aware that the results of the study, including personal details, will be anonymously processed into research reports. I consent voluntarily to participate in this research. I have been given an opportunity to ask questions and have no objection to participate in this study. I understand that there is no penalty should I wish to discontinue with the study and my withdrawal will have no bearing on my status as an employee of the hospital. I am aware that my experiences regarding the implementation of family integrated care will be explored during the focus group interview. Only the researchers and the supervisors will have access to this material.

I have received a signed copy of this informed consent agreement.

Participant's name …….. (Please print)

Participant's signature…… Date.....

Investigator's name ..... (Please print)

Investigator's signature .....Date…....

Witness's Name..... (Please print)

Witness's signature .....Date……..

VERBAL INFORMED CONSENT

I, the undersigned, have read and have fully explained the participant information leaflet, which explains the nature, process, risks, discomforts and benefits of the study to the participant whom I have asked to participate in the study. The participant indicates that s/he understands that the results of the study, including personal details regarding the interview will be anonymously processed into a research report. The participant indicates that s/he has had time to ask questions and has no objection to participate in the focus group meeting. She/he understands that there is no penalty should s/he wish to discontinue with the study and his/her withdrawal will not affect his/her as an employee at the hospital. I hereby certify that the client has agreed to participate in this study.

Participant's Name .....(Please print)

Participant signature .....Date……..

Witness name .....……..... (Please print)

Witness Signature ……Date……..

ANNEXURE C

- Interview schedule -

INTERVIEW SCHEDULE OF FOCUS GROUPS

The focus group interviews are planned as follows:

- Participants will be welcomed
- The purpose of the focus group will be clarified
- Informed consent need to be signed and permission will be requested to switch on the audio-recorder
- The following questions will then be asked:
    - “How do you see family integrated care?”
    - “What works well regarding family integrated care?”
    - “What are the challenges that you experience with the implementation of family integrated care?”
    - “What are the opportunities that can improve family integrated care?”
    - “Do you have any other comments regarding the implementation of family integrated care?”
- The discussions will be concluded and all thanked for their participation.

ANNEXURE D

-Ethics Letters of approval -

The Research Ethics Committee, Faculty Health Sciences, University of Pretoria complies with ICH-GCP guidelines and has US Federal wide Assurance.
- FWA 00002567, Approved dd 22 May 2002 and Expires 03/20/2022.
- IRB 0000 2235 IORG0001762 Approved dd 22/04/2014 and Expires 03/14/2020.

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Health Sciences Research Ethics Committee

6/11/2017

Approval Certificate
New Application

Ethics Reference No: 366/2017

Title: Nurses experiences of implementation of family integrated care in a neonatal intensive care unit

Dear Mrs EmEsna E Swart

The **New Application** as supported by documents specified in your cover letter dated 1/11/2017 for your research received on the 1/11/2017, was approved by the Faculty of Health Sciences Research Ethics Committee on its quorate meeting of 6/11/2017.

Please note the following about your ethics approval:
- Ethics Approval is valid for 3 years
- Please remember to use your protocol number (**366/2017**) on any documents or correspondence with the Research Ethics Committee regarding your research.
- Please note that the Research Ethics Committee may ask further questions, seek additional information, require further modification, or monitor the conduct of your research.

Ethics approval is subject to the following:
- The ethics approval is conditional on the receipt of **6 monthly written Progress Reports**, and
- The ethics approval is conditional on the research being conducted as stipulated by the details of all documents submitted to the Committee. In the event that a further need arises to change who the investigators are, the methods or any other aspect, such changes must be submitted as an Amendment for approval by the Committee.

We wish you the best with your research.

Yours sincerely

Dr R Sommers; MBChB; MMed (Int); MPharMed,PhD
Deputy Chairperson of the Faculty of Health Sciences Research Ethics Committee, University of Pretoria

The Faculty of Health Sciences Research Ethics Committee complies with the SA National Act 61 of 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 and 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes, Second Edition 2015 (Department of Health).

☎ 012 356 3084 deepeka.behari@up.ac.za / fhsethics@up.ac.za http://www.up.ac.za/healthethics
✉ Private Bag X323, Arcadia, 0007 - Tswelopele Building, Level 4, Room 60, Gezina, Pretoria

ANNEXURE E

- Declaration of professional editor -

ACADEMIC EDITING, FORMATTING AND WRITING SUPPORT
POST-GRADUATE SERVICES: STATEMENT OF WORK COMPLETED

31May, 2019

To whom it concerns,

This confirms that the following work was undertaken by myself on behalf of the client.

Client: **Ms Em-EsnaSwart**

University of Pretoria, Dpt. Nursing Science

Thesis: **Nurses' experiences of family integrated care in a neonatal intensive care unit**

	Service	
1	Proofreading and language editing	**x**
2	Proofreading, language editing and formatting	
3	Proofreading, language editing, formatting and logic	
4	Full rewriting of pages / sections	
5	Referencing check	**x**
6	Compilation of Bibliography	

Please note that no assessment has been undertaken of the academic credibility of the submitted work.

Kind regards,

Dr Christine McGladdery MSc (UCT), PhD (UP),
HDEchristinemcg01@gmail.com

ANNEXURE F

- Letters of approval from CEO of The Hospital -

Vir Aandag: CEO [redacted] Hospitaal

2 Augustus 2017

Aangaande: Navorsing toestemming vir studie gedoen deur Universiteit van Pretoria te [redacted] Hospitaal in Neonatale Intensiewe Sorg Eenheid.

TEMA VAN NAVORSING: Ervaring van Verpleegpersoneel met die implimentering van Family Geintegreerde sorg in NICU te [redacted] Hospitaal.

Family Geintegreerde Sorg word reeds in prakryk vir jare toegepas in [redacted] Hospitaal, die proses daarvan is meer gestruktureer gedurende die afgelope maande om dit moontlik te maak om die ervarings van die personeel in die Suid Afrikaanse konteks te bepaal aangaande die internasionaal beoefende konsep.

Die studie is 'n beskrywende qualitatiewe studie en die data insameling behels 2 fokus groep onderhoude met verpleeg personeel in NICU, groepe is 4-8 lede en onderhoude duur 30-40 min. Die name van personeel word vervang met nommers en hul identiteit sal nie bekend gemaak word nie. Slegs die data wat gebruik sal word om die ervarings in die S.A. konteks sal gebruik word.

Geen data ten opsigte van pasiente of hospital dokumentasie dien as deel van die studie nie.

Hiermee versoek ek vriendelik dat ek Sr E Swart toestemming ontvang van u om die ervarings van die personeel in NICU te gebruik in die MCur studie te Universiteit van Pretoria aangaande die onderwerp van Familie Geintegreerde Sorg.

By voorbaat dank

E Swart

Studente no [redacted]

Tel [redacted]

Referred to CEO 02-08-2017

Approved Acting CEO 02/08/2017

DEPT. VAN GESONDHEID
[redacted] Hospitaal / Hospitaal
2017 -08- - 2
OFFICE OF THE CEO (CEO)
DEPT. OF HEALTH

Permission to access Records / Files / Data base at the [redacted] Hospital

To: Chief Executive Officer/Information Officer
[redacted] Hospital
Dr _____

From: The Investigator
University of Pretoria Hospital
Dr _____

Re: Permission to do research at [redacted] **Hospital**

Drs Carin Maree and I are researchers working at the University of Pretoria Unit, Department of Nursing at UP Hospital. I am requesting permission on behalf of all of us to conduct a study on the Orthopaedic Hospital grounds ~~that involves access to patient records.~~

The request is lodged with you in terms of the requirements of the Promotion of Access to Information Act. No. 2 of 2000.

The title of the study is: Family Integrated Care

The researchers request access to the following information:

~~Access to the clinical files, record book and the data base.~~

We intend to publish the findings of the study in a professional journal and/ or at professional meeting like symposia, congresses, or other meetings of such a nature.

We intend to protect the personal identity of the ~~patients~~ staff by assigning each ~~patient~~ staff a random code number.

We undertake not to proceed with the study until we have received approval from the Faculty of Health Sciences Research Ethics Committee, University of Pretoria.

Yours sincerely

~~Signature of the Principle Investigator~~

Permission to do the research study at this hospital and to access the information as requested, is hereby approved.

Chief Executive Officer

[redacted] Hospital
Dr _____

Signature of the CEO
01

DEPT. VAN GESONDHEID
[redacted] Hospital / Hospitaal
Hospital Official Stamp
2017 08 -2
OFFICE OF THE CEO (CEO)
DEPT. OF HEALTH

ANNEXURE G

- Declaration of data storage-

Principal Investigator's Declaration for the storage of research data and/or documents

I, the Principal Investigator(s), Em-Esna Swart of the following trial/study titled Nurses experiences of implementation of family integrated care in a neonatal intensive care unit

will be storing all the research data and/or documents referring to the above mentioned trial/study at the following non-residential address:

Department of Health - locked in safe
Clinic Ventersdorp (South Africa)
In form of password protected usb.
At: Buffelo Building, Van Riebeek steet

I understand that the storage for the abovementioned data and/or documents must be maintained for a minimum of 15 years from the end of this trial/study.

START DATE OF TRIAL/STUDY: 01 / 01 /2016 END DATE OF TRIAL/STUDY: 31 / 12 / 2017

SPECIFIC PERIOD OF DATA STORAGE AMOUNTING TO NO LESS THAN 15 YEARS:

Jan 2016 until Jan 2032

Name Em-Esna Swart

Signature _____ Date 7/9/2017