THE EXPERIENCES OF MOTHERS AND NURSES IN CARE-BY- PARENT INTERVENTIONS IN A NEONATAL INTENSIVE CARE UNIT OF A REGIONAL HOSPITAL IN GAUTENG

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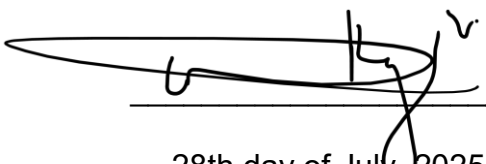
DECLARATION

I, Ntombikayise Gontse Kgosana, declare that this Dissertation is my own, unaided work. It is being submitted for the Degree of Masters in Nursing Science at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at any other University.



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28th day of July, 2025, in Pretoria, South Africa.

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DEDICATION

“From God, to God, and through God”

John Piper

ABSTRACT

Due to the age and vulnerability of neonates, family involvement in their care is strongly encouraged. Family-centred care (FCC) is a widely endorsed model in neonatal intensive care units (NICUs) as it reduces parental stress associated with neonatal admission and separation. However, in resource-limited settings, optimal FCC is often compromised due to financial, physical, and human resource constraints. Furthermore, when poorly implemented, FCC may have unintended negative consequences for both mothers and nurses.

This study explores the experiences of mothers and nurses in care-by-parent interventions at a regional NICU in Gauteng, South Africa. A qualitative descriptive design was employed, with data collected in two phases. In Phase One, purposive sampling was used to recruit thirty-three (n=33) mothers of admitted neonates, and data were gathered through focus group discussions. In Phase Two, total sampling was used to select seventeen (n=17) professional nurses, who participated in individual semi-structured interviews. Data were analysed using
Creswell's Method of Data Analysis, with strict adherence to ethical principles and measures to ensure trustworthiness.

Findings revealed significant barriers to effective FCC implementation in resource constrained NICUs, leading to suboptimal adherence and adverse effects on both maternal and professional nurse wellbeing. Additionally, these challenges may extend to impact paternal involvement and neonatal outcomes.

Based on these findings, the study provides recommendations for nursing education, policy development, and further research to enhance FCC implementation in regional NICUs.

Keywords: family involvement, care-by- parent interventions, neonatal intensive care unit, neonates, regional hospital.

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To my mother Hellen Kgosana: After God, everything I dedicate to you.

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CHAPTER ONE: OVERVIEW OF THE STUDY

1.1 INTRODUCTION AND BACKGROUND

The Neonatal Intensive Care Unit (NICU) is a specialised unit primarily for the treatment of ill and/or premature newborn infants (Altimier & White, 2019). Newborn infants, also referred to as neonates, can be categorised as patients aged 28 days or younger at admission (World Health Organisation, 2023a). Neonates in the NICU are ill or carry a high risk of illness and may require medical and surgical interventions, including invasive ventilation (Govindaswamy et al., 2023). Due to the age and vulnerability of this patient group, family involvement is often encouraged (Lyndon et al., 2017; Govindaswamy et al., 2023). One of the key models involving family systems in the NICU is Family-centred care (FCC) (Larocque et al., 2021; Reid, Bredemeyer & Chiarella, 2021).

Historically, after the admission of a child into hospital, parents were either prohibited or limited in their hospital visitations (Franck & O'Brien, 2019). This restriction left parents feeling misplaced and anxious (Brodsgaard et al., 2019). Health institutions justified the exclusion of parents from the units as an infection control measure, even though previous studies showed no discrepancies in infection rates when parental visitations were permitted (Lv et al., 2019; Reiter et al., 2022). Over time, parental separation and anxiety led to parent-initiated movements that introduced FCC in paediatric units in the United States and Great Britain. The introduction of the model increased parental access to health institutions and parental participation in caregiving duties, such as breastfeeding (Franck & O' Brien, 2019; Soni & Tscherning, 2020).

By 1993, Helen Harrison solidified the concept of FCC as a conceptual model or value system based on family consideration in the care of hospitalised loved ones. Harrison also developed guiding principles for integrating FCC in the NICU. This was prompted by the widespread dissatisfaction mothers voiced about their NICU experience. Today, these principles are practised worldwide as the foundation for neonatal FCC initiatives in hospitals. They include communication and information sharing, respect and dignity, collaboration, participation/involvement and a supportive environment (Harrison, 1993; Soni & Tscherning, 2020).

The primary purpose of FCC is to alleviate the parental stress associated with the separation of one's child, particularly maternal stress. Maternal stress is defined as elevated stress levels experienced by mothers in the perinatal stage (Zietlow et al., 2019). In the NICU, maternal stress is more prevalent than paternal stress in relation to neonatal admissions. Shetty et al. (2024) attributes this to the emotions involved in giving birth to a sick child. Regardless, the primary maternal stressor in the NICU is neonatal separation, followed by the displacement of parental roles. Secondary stressors included prolonged neonatal admission, neonatal diagnosis and prognosis, as well as financial and social problems (Mariano et al., 2022).

Maternal stress is associated with poor mental health outcomes, as demonstrated in an Australian study examining the psychological impact of NICU admissions on parents. The study included a psychological distress screening of 69 NICU mothers. Mothers were screened two weeks after their neonates' NICU admission, with the study finding that 26.8% of mothers exhibited clinical signs of anxiety and 24% showed signs of stress. The same mothers were screened again three months later, and 9.6% met the DSM-V criteria for generalised anxiety disorder. Clinical traits for major depression and post-traumatic stress disorder were also identified (Dickinson, Vangaveti and Browne, 2022).

Family-centred care practices in the NICU are associated with reduced maternal stress as they address mothers' desire to be involved in neonatal care (Rajabzadeh et al., 2021). However, improper implementation of FCC is linked to increased maternal stress, anxiety and depression.

Primary gaps in FCC implementation include information sharing and mistrust towards nurses. This is illustrated by Malepe, Havenga and Mabusela (2022): lack of information sharing as a challenge, along with perceived negative attitudes from the nurses. Mothers in the study expressed concern that if they were not in the units, their neonates would not be taken care of.

For optimal FCC, health institutions must provide a place for mothers to stay within the hospital (Goga et al., 2021). According to Oude Maatman et al. (2017), the NICU environment should include sleeping quarters for parents and all the daily necessities such as a bathroom, kitchen, washing machine, and a place where mothers can relax away from the infant and the NICU. The author justified these provisions by noting that

parents have limited reasons to leave the hospital premises. However, this environment is not feasible for many public NICUs in South Africa due to the scarcity of resources.

Mothers staying in the hospitals may also face challenges related to their financial and social situations (Mariano et al., 2022). Prolonged admission can lead to increased costs, as both the parent and the neonate are admitted. Moreover, social problems may arise, such as the inability to care for children at home during the mother's hospital stay (Mariano et al., 2022).

Even though FCC is considered the "gold standard" in paediatric care (Miller et al., 2021), some healthcare workers do not agree. The feasibility of FCC in developing countries and low-resourced NICUs is a challenge. In a study conducted in China by Xiang et al. (2020), the healthcare staff held mixed opinions on the necessity of implementing FCC in their units. The staff reported that they did not believe FCC would promote breastfeeding, shorten hospital stays or create better staff-parent relations. The study further identified three barriers for FCC implementation in their unit: lack of human resources; lack of infrastructure and physical resources and lack of financial resources. These findings suggest that FCC implementation may not be feasible or considered necessary in some institutions.

Beyond the feasibility and resource challenges associated with FCC, nurses hold positive attitudes toward patient-focused care compared to family-centred care. Shields (2015) and Wong et al. (2023) suggest that barriers to positive attitudes towards FCC include staff shortages, lack of time, inadequate communication skills and a lack of recognition for care coordination efforts. A study examining nurses' perceptions and attitudes toward family-centred care in acute paediatric settings in Jordan found that nurses exhibited more positive attitudes when working with children than with parents (Razeq et al., 2021). Nurses felt more comfortable, satisfied and generally positive when working with children, as compared to parents. Additionally, the nurses indicated that they lacked time and adequate training for implementing FCC principles (Razeq et al., 2021).

Effective implementation of FCC in developing countries and low-resourced NICUs remains a challenge. In the context of the chosen research setting, a regional hospital in Gauteng, a variation of FCC has been implemented that allows mothers to stay in

the hospital and participate in care-by-parent interventions within a twenty-four (24) hour period, under limited supervision from professional nurses. A regional hospital is a secondary level hospital that receives referrals from several district hospitals, community health centres, clinics and regional private facilities. While regional hospitals offer some specialty services, more complex patient cases are referred to tertiary hospitals for advanced care.

1.2 PROBLEM STATEMENT

In a regional hospital in Gauteng, mothers of neonates in the NICU participate in care-by-parent interventions under professional nurses' supervision. While this promotes maternal involvement, it also increases their responsibilities, requiring attendance every three hours for tasks such as feeding, nappy changing, and kangaroo mother care. These demands often lead to sleep deprivation, stress, and social strain, as mothers remain in the hospital for extended periods, leaving other children at home.

Staff shortages further challenge FCC implementation, placing additional pressure on nurses who must supervise mothers while managing clinical duties. This dual burden may contribute to burnout and compromise maternal and neonatal safety. Although FCC is widely advocated, its application in resource-limited settings remains underexplored. This study examines the experiences of mothers and professional nurses in a regional NICU, offering insights to inform healthcare policy and improve FCC implementation in South Africa.

1.3 RESEARCH QUESTIONS

What are the experiences of mothers regarding their involvement in the care of their neonates admitted to a regional NICU?

What are the experiences of nurses regarding mothers' involvement in the care of their neonates admitted to a regional NICU?

1.4 RESEARCH AIM

The aim of this study was to describe the experiences of mothers and nurses in care-by-parent interventions in a NICU at a regional hospital in Gauteng.

1.5 OBJECTIVES OF THE STUDY

- To describe the experiences of mothers regarding their involvement in the care of their neonates admitted in the NICU.
- To describe the experiences of nurses regarding mother's involvement in the care of their neonates admitted in the NICU.

1.6 THE SIGNIFICANCE OF STUDY

There is a substantial amount of international literature highlighting the benefits and limitations of maternal involvement in the care of their neonates in the NICU. However, research in low-resource settings, including South Africa, remains limited. This study aims to examine the implementation of FCC within the South African context and assess the overall feasibility of involving families in NICUs. Additionally, the findings of this research may contribute to health care policy development in such settings, with a focus on the wellbeing of both the mothers and nurses in NICU.

1.7 RESEARCH DESIGN AND METHOD

A qualitative descriptive design was employed to describe the experiences of mothers and nurses regarding the implementation of family-centred care in a regional NICU in Gauteng. This is discussed in detail in Chapter Three: Research Design and Methodology.

1.8 OPERATIONAL DEFINITIONS

1.8.1 Family-centred care

Family-centred care is a conceptual model focused on integrating families into the care of hospitalised loved ones through active participation and collaboration (Larocque et al., 2021). In this study, family-centred care refers to the involvement of mothers in the care of their neonates admitted in the NICU.

1.8.2 Care-by-parent interventions

These are caregiver tasks performed by the parent instead of a healthcare practitioner. These interventions allow parents to spend extended periods of time with their neonates during hospital admission. The interventions are influenced by hospital

resources, parental presence and institutional support (Reid, Bredemeyer & Chiarella, 2021). In this study, care-by-parent interventions refers to the engagement in tasks such as nappy changing, hygiene maintenance, feeding, umbilical cord care, eye care, kangaroo mother care and administration of oral, topical and inhalation medication every three hours in a 24-hour cycle.

1.8.3 Lodger mother

Lodger mothers who are authorised to continue residing in lodging facilities as their presence and caregiving are deemed to improve a patient's outcome. In the NICU, these mothers are the providers of care-by-parent interventions for the neonates in the NICU. In this study, lodger mothers are referred to as mothers.

1.8.4 Neonatal intensive care unit

The neonatal intensive care unit is a complex hospital environment with advanced equipment and experienced personnel who provide specialised care to neonates (Konukbay, Vural & Yildiz, 2024). In this study, the selected study site consisted of five sections offering different levels of care within an intensive care unit (ICU).

1. **ICU 1:** accommodates up to eight ventilated and/or critically ill neonates.
2. **ICU 2:** accommodates up to eight critically ill neonates requiring no or non-invasive ventilation.
3. **High care:** accommodates up to sixteen ill but stable patients, mainly consisting of neonates with low birth weight, jaundice, hypoglycaemia and neonates who have recovered from the ICU section.
4. **Isolation:** accommodates up to three patients with nosocomial infections and/or neonates from home under the age of 28 days.
5. **Kangaroo mother care (KMC) rooms**: Accommodates up to eight mothers and their neonates.

The unit had a prescribed bed capacity of 45 infants, excluding isolation; however, the unit regularly admits up to 60 patients due to the lack of similar units in the area.

1.8.5 Professional nurses

These are professionals who are qualified and trained to practice nursing to the prescribed level outlined by the South African Nursing Council (Nursing Act 33 of 2005). In this study, nurses refer to professional nurses working in the NICU, regardless of specialty qualification.

1.8.6 Maternal experiences

Maternal experiences in the NICU are considered emotionally stressful as mothers often have difficulty adapting to the NICU environment, the altered parental role and responsibilities and the condition and prognosis of their neonates. Mothers in the NICU often experience stress, anxiety and depression because of neonatal admission (Dressler, 2024). In this study, maternal experiences relate to the psychological and physiological impact that neonatal admission and parental involvement in neonatal care may have had on the mother.

1.8.7 Regional hospital

Regional hospital refers to a secondary hospital that receives patient referrals from several district hospitals, community health centres, clinics and regional private facilities (South African Legal Information Institute, 2019). In this study, a regional hospital refers to a setting with limited infrastructure, specialised equipment and personnel compared to academic and tertiary hospitals.

1.9 ETHICAL CONSIDERATIONS

Ethical clearance was provided by the University of Witwatersrand Human Research Ethics Committee, and all ethical principles were adhered to. Comprehensive description under Ethical Considerations in Chapter Three: Research Design and Methodology can be found.

1.10 OUTLINE OF CHAPTERS

This study is structured into six chapters:

Chapter One: introduces the study, outlining the background, problem statement, research aim, objectives, and significance.

Chapter Two: reviews existing literature on family-centred care (FCC), maternal involvement in NICUs, and challenges in resource-limited settings.

Chapter Three: details the qualitative research design, including sampling, data collection (focus groups and interviews), ethical considerations, and data analysis.

Chapter Four: presents findings from Phase One, exploring mothers' experiences, including stress, sleep deprivation, and family impact.

Chapter Five: discusses findings from Phase Two, focusing on professional nurses' perspectives, highlighting staff shortages, workload concerns, and FCC benefits.

Chapter Six: summarises the study, evaluates findings, and provides recommendations for nursing practice, education, policy, and future research.

Below is a visual representation of the chapter outline.

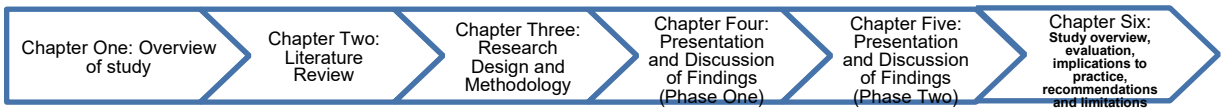

Figure 1.1: The outline of chapters

1.11 CONCLUSION

This chapter provided an overview of the research study, including the introduction, background, problem statement, research questions, aim, and objectives. It also outlined the significance of the study, research design and methods, and operational definitions. The next chapter will present a literature review on the phenomenon, exploring perspectives both locally and internationally.

CHAPTER TWO: LITERATURE REVIEW

2.1 INTRODUCTION

A literature review establishes a theoretical foundation for the research to be conducted. It provides background information for readers and shows the researcher's understanding of the subject matter. A literature review also identifies the gaps and limitations in existing literature relating to a specific topic (Botma et al., 2022). The aim of this chapter is to introduce the concept of family-centred care (FCC) and its practices. The chapter explains the history of FCC and the principles developed by Helen Harrison. The chapter also discusses the impact of FCC implementation on neonates', mothers of neonates' and nurses' wellbeing. Finally, the feasibility and barriers to neonatal FCC implementation in South Africa are reviewed.

2.2 INTRODUCTION TO FAMILY-CENTRED CARE

Family-centred care is a conceptual model focused on family consideration and participation in the care of hospitalised loved ones. The model recognises that family systems play a crucial role in providing holistic, quality care (Franck & O'Brien, 2019). Often, healthcare practitioners focus on the physiological state of the patient and overlook the psychological and social challenges experienced by both patients and their families due to hospital admission (Reid, Bredemeyer & Chiarella, 2021).

In the context of the neonatal intensive care unit, when FCC is effectively implemented, parents are seen as collaborative and equal partners in the delivery of neonatal care (Lee, 2023). This collaborative partnership includes participating in decision-making, care-by-parent interventions, continuous education, and emotional support from healthcare practitioners (Chapko et al., 2022; Franck & O'Brien, 2019). This partnership is driven by the understanding that families, particularly parents, are constant in a child's life and should not be separated, even during hospitalisation (Harrison, 2010; Alsadaan et al., 2023).

2.3 THE HISTORY OF FAMILY-CENTRED CARE

World War II acted as a catalyst for changing the way paediatric nursing care was rendered. During this period, healthcare services became overwhelmed by the burden of infectious diseases and an increasing population requiring medical care (Reid,

Bredemeyer & Chiarella, 2021). This led to the prohibition and limitation of parental visitations in hospitals (Davies, 2010).

Outbreaks of tuberculosis, measles, diphtheria, and typhus were common at the time and hospitals feared that parental access to paediatric units would increase the risk of infections, even though previous studies indicted no discrepancies in infection rates when parental visitations were permitted (Bamm & Rosenbaum, 2008; Reiter et al., 2022). However, this concern was understandable as children, especially neonates, have a developing immunological memory, making them more likely to acquire an infection than adults (Chappell, Kelly & Rosenthal, 2021).

During the war, hospital administrators were seen as authoritative figures who strictly controlled paediatric care. (Reid, Bredemeyer & Chiarella, 2021). The restriction of parental access was so severe that Prugh (1953) reported that children admitted for ailments such as tuberculosis could spend up to two years in the hospital without seeing their parents. The prolonged separation led to parental anxiety and stress, and emotional distress in children (Brodsgaard et al. 2019).

Research pioneer John Bowlby (1953) conducted research on the negative effects of parental separation during paediatric admissions in World War II. Bowlby's research concluded that children required maternal affection for proper mental and social development; without it, their development could be negatively affected. Consistent maternal affection during child development was crucial in preventing delinquent behaviour and problems in adaptation. Bowlby also stated that the hospital staff were not adequate replacements for maternal affection.

In the same period, parent-initiated movements were introduced in Great Britain and the United States—namely, The Mother Care for Children in Hospital and The Citizens Committee on Children of New York City (Davies, 2010). These movements campaigned for the rights of families whose children were hospitalised. Notably, another research pioneer, Robertson alongside Bowlby (1952), published a book on the portrayal of children in hospitals and the implications of separation between mother and child. In the same decade, Robertson (1958) also produced a film series as a comparative review on parental presence. The series also portrayed a paediatric unit environment with windowless rooms, where patients' movements were restricted to

beds and cribs. The patients appeared distressed and were largely ignored by the nurses (Smith, 2018).

The efforts of researchers and the parent-founded movements led to the signing of the Welfare of Children in Hospital report (1959) in Great Britain. The report advocated for unrestricted parental visits and participation of mothers in the care of their children. It also recommended that nurses receive training focused on understanding the emotional needs of hospitalised children. The report served as a catalyst for increased parental participation and laid the groundwork for the creation of a family-centred care approach in paediatric units worldwide (Davies, 2010; Franck & O'Brien, 2019).

Despite these advancements, the active involvement of parents in the care of their hospitalised children took decades to implement. According to Davies (2010), a UK survey conducted by the National Association for the Welfare of Children in Hospital (NAWCH) in 1969 revealed that out of 67 hospitals surveyed, only 57% allowed unrestricted parental visitation. By 1982, this number had risen to 89%, with an emphasis on open visitations and the provision of overnight parental accommodation (Davies, 2010; Franck & O'Brien, 2019).

Unfortunately, discontentment among parents remained a recurring theme of parental experiences in paediatric units, particularly in Neonatal Intensive Care Units (NICUs). This led Helen Harrison (1993) to draft and publish recommended principles of neonatal family-centred care. The publication was prompted by "hundreds of letters and telephone calls" from parents who had previously had children in the NICU regarding the perceived negative treatment they and their hospitalised children experienced during admission. Parents expressed concerns about the lack of consistent and accurate information sharing, the absence of collaboration and participation in care decision-making, and an overall nursery environment that was deemed unaccommodating for parents (Harrison, 1993; Soni & Tscherning, 2020).

The historical evolution of FCC, shaped by pivotal research and advocacy efforts, laid the foundation for modern practices in neonatal care. Building on these advancements, Helen Harrison formalised a set of principles in 1993 that aimed to address persistent challenges in NICU environments and redefine the role of parents in neonatal care.

Harrison (1993) outlines the guiding principles of FCC in the NICU as follows:

- Communication and information sharing: Open dialogue between parents and healthcare staff is encouraged. Information sharing within the paediatric setting has been linked to reduced parental stress and fewer negative views towards the nurses.

- Respect and dignity: All stakeholders involved in neonatal care, including parents, should be treated with respect and dignity. Clarifying each person's roles and responsibilities in the unit leads to a sense of control in their respective area.

- Participation/Involvement: Parents are given the opportunity to participate in neonatal care duties. This helps alleviate feelings of hopelessness when a child is sick. FCC is founded on parental presence and care-by-parent interventions.

- Collaboration: Parents are recognised as part of the care team rendering neonatal care. This includes their inclusion in doctors' rounds and participation in decision making processes.

- Supportive environment: The NICU environment should accommodate parents in terms of space, time, needs and presence.

These principles have become universal standards for neonatal family-centred care, at times extending to paediatric care by the early 2000s. Nonetheless, the implementation of neonatal FCC remains inconsistent (Smith, 2018; Wong et al, 2023).

2.4 IMPACT OF FCC IMPLEMENTATION ON THE WELLBEING OF THE NEONATE

Family-centred care in the NICU was largely established to alleviate paternal stress and anxiety, however long and short-term positive outcomes have been observed in neonates as well. Moreover, available studies primarily report favourable results in NICUs that implement some form of FCC compared to traditional NICUs.

Firstly, parental presence and participation, especially in the care of premature neonates, have been linked with reduced hospital stay and lower morbidity. According to a Chinese study conducted by Lv et al. (2019), parents that were permitted to stay in the unit with their neonates experienced a reduction in hospital stay by 2.3 days compared to parents that restricted parental visitations and participation. The same

study also reported that parental participation led to reduced infant morbidity, most notably in cases of bronchopulmonary dysplasia. Bronchopulmonary dysplasia is a respiratory disorder that primarily affects the neonates' premature lungs (Sahni & Mowes, 2023). The study also found that there were discrepancies in nosocomial infections rates when parents were permitted to stay in the unit with their neonates compared to parents who were restricted in presence and participation (Lv et al., 2019).

Additionally, neonatal readmission rates have been observed to decline with parental presence and participation (Lv et al., 2019). This is likely because FCC provides a unique opportunity for mothers to be trained in neonatal care during their hospital stay. Mothers are empowered through education, supervision, and care-by-parent interventions, which in turn reduce neonatal readmission rates and promote neonatal survival. Essentially, mothers are equipped with special skills and knowledge to provide neonatal care at home (Ghorbani & Jabraeili, 2022).

FCC further reduces the risk of necrotising enterocolitis (NEC), a life-threatening neonatal condition that causes intestinal inflammation, leading to cellular death and sepsis (Altobelli et al., 2020). Neonates whose parents stay in the hospital have frequent breastfeeding sessions which promote weight gain and reduce the likelihood of NEC. Additionally, exclusive breastfeeding reduces the risk of infection in neonates as they are provided with the maternal immunoglobulins in the milk (Altobelli et al., 2020).

Parental presence in the NICU fosters a sense of safety for neonates, which reduces the occurrence of physiological stress. Physiological stress in neonates can be characterised by disturbances in the physiological and psychological processes, often influenced by components of the NICU environment, such as noise and light control, invasive procedures, handling by neonatal staff members and parental separation. Adverse effects of increased neonatal physiological stress include impaired cognitive, psychomotor, and behavioural development, which may manifest at an older age (Van Dokkum et al., 2021).

Direct parental participation in neonatal care promotes better sleep cycles, regular breathing and stabilised heart rates in neonates. Healthy sleep cycles in neonates

prevent increased immunological responses and maintain healthy neurological development. Parental presence is also linked to decreased neurological delays in premature neonates. In comparison, parental separation is correlated with shorter lifespans and an increased risk of developmental disorders.

Moreover, FCC promotes the use of kangaroo mother care (KMC), which provides numerous benefits for both the mother and the neonate. Approved by the World Health Organisation (WHO) as a standard of care for premature neonates, KMC involves placing an undressed neonate on the mother's bare chest to facilitate bonding and attachment between the mother and the neonate (WHO, 2023b). Consistent KMC has been shown to reduce physiological stress in neonates in the stressful NICU environment (Sarin & Maria, 2019). It promotes regular breathing and a stabilised heart rate in neonates, and decreases energy expenditure, which minimises weight loss and hypoglycaemic episodes. Additionally, KMC promotes thermoregulation, which essentially decreases energy expenditure caused by the cold. Thermoregulation is associated with weight gain and a decreased occurrence of hypothermia and hypoglycaemia (WHO, 2023b).

Conversely, traditional NICUs with restrictive parental visitations have been linked to negative long-term neonatal outcomes in terms of emotional, social and psychological wellbeing. For example, parental detachment from their neonates has been associated with a higher likelihood of eventual child abuse and abandonment (Taylor et al., 2020).

This is likely due to the disrupted bonding and attachment experienced by NICU parents post-delivery (Ghorbani & Jabraeili, 2022). A UK study found that premature infants were more likely to be placed on the Child Protection register, due to the hostile feelings and detachment parents develop from the child-parent separation experience during the long NICU admission (Rogers & Nurse, 2019).

There is overwhelming literature illustrating the benefits of FCC on neonatal care, health and development. No studies were identified that oppose the implementation of FCC or highlight significant disadvantages for neonatal wellbeing.

2.5 THE IMPACT OF FCC IMPLEMENTATION ON THE WELLBEING OF MOTHERS IN THE NICU

Family-centred care is known to have positive mental outcomes for parents, particularly mothers, who have been widely studied. Positive outcomes in the NICU linked to FCC include the alleviation of parental stress and other mental health benefits, such as reducing the risk of postpartum depression, anxiety and PTSD, which were discussed in this subchapter (Dickinson, Vangaveti & Browne, 2022; Rajabzadeh et al., 2021). However, there is limited literature outlining the positive and negative impacts of FCC implementation on maternal wellbeing in regional South African clinical settings.

The primary purpose of FCC is to alleviate the parental stress associated with the separation from one's child, particularly maternal stress. Maternal stress is defined as elevated stress levels experienced by mothers in the perinatal stage (Zietlow et al., 2019). In the NICU, maternal stress has a higher prevalence compared to paternal stress in relation to neonatal admissions. Shetty et al. (2024) attribute this to the emotions associated with giving birth to a sick child. Regardless, the primary maternal stressor in the NICU is neonatal separation, followed by the displacement of parental roles.

Mothers whose neonates have been admitted to the NICU are prone to negative mental health outcomes. In an Australian study, the impact of NICU admission on parental mental health was investigated. The study included a psychological distress screening of 69 NICU mothers. The mothers were screened two weeks after their neonates' NICU admission, and the study observed 26.8% of mothers showing clinical signs of anxiety and 24% exhibiting stress. The same mothers were screened three months later, and it was discovered that 9.6% met the DSM-V criteria for generalised anxiety disorder (GAD). The mothers were also observed to have clinical traits of major depression and post-traumatic stress disorder (PTSD) (Dickinson, Vangaveti & Browne, 2022).

The primary stressor related to NICU admission as perceived by parents is neonatal separation. A study conducted in Qatar that identified maternal stressors in the NICU found that neonatal separation was perceived as the primary stressor for mothers along with the inability to parent during neonatal admission (Mariano et al., 2022)

Rajabzadeh et al. (2021) and Zietlow et al. (2019) also identified neonatal separation as a stressor for mothers in the NICU, along with secondary stressors such as prolonged neonatal admission, neonatal diagnosis and prognosis, the general NICU environment and equipment, lack of information-sharing from hospital staff, displacement of parental roles, and financial and social problems.

However, components of FCC are known to minimise the stress experienced by mothers. A prominent care-by-parent intervention in FCC is KMC. WHO (2023b) states that parental participation in KMC reduces the risk of postpartum stress, anxiety and depression by 24%. The effectiveness of KMC on maternal mental health outcomes can also be seen in a study conducted in Iran. Mehrpisheh et al. (2023) assessed the introduction of a KMC intervention on maternal anxiety and stress. The KMC intervention was shown to significantly reduce the baseline anxiety and stress levels mothers experienced prior to the intervention.

In addition to the improved mental health outcomes FCC initiatives provide for mothers, FCC also improves parental role development and attachment (Mariano et al., 2022). Neonatal intensive care unit admission often strips mothers of their parental roles. The lack of engagement in neonatal care leads to role displacement, feelings of detachment towards the neonate and a decreased level of confidence in parental skills. As FCC provides the opportunity for parental participation through care-by-parent interventions, parents feel empowered and more in control during their child's NICU admission (Rajabzadeh et al., 2021). Empowerment is achieved through the education, training and support that mothers receive from the healthcare staff during their child's NICU admission. Parents are also empowered by partaking in decisions related to their neonate's care (Reid, Bredemeyer & Chiarella, 2021).

FCC in the NICU context is aimed at maintaining parental mental health during their child's NICU admission. FCC as a concept has been shown in literature to benefit mothers through the alleviation of stress, anxiety and even depression, as well as through the empowerment and confidence in parental skills, and maintenance of parental roles even during hospitalisation. However, inadequate implementation of FCC may lead to reduced mental, social and physical health outcomes for the neonates' family systems, particularly mothers.

FCC implementation in certain settings may cause ethical concerns involving parental presence and participation. Ethical concerns may arise from the over-reliance on parents in the NICU, with health practitioners leaving little to no room for negotiation of parental participation in neonatal care. Sir Roy Meadow (1969) coined the phrase *the captive mother* to describe the mother whose child has been hospitalised, and parental participation is imposed on her. The mother has little to no negotiation in their level of participation. Imposed parental participation affects the social, physical and emotional wellbeing of mothers as they have little control over their level of participation (Janvier et al., 2022).

Janvier et al. (2022) report in their study on the ethics of family integrated care in the NICU, that perceived parental guilt was a major theme. In the study, a third of parents experienced guilt when they were unable or unwilling to participate in care tasks requested by health practitioners. Parents also felt pressure to be more present. One participant stated that she had two small children at home to care for and wanted the NICU to also recognise that she needed family integrated care at home. The participant shared that she cried as a result of being separated from her children.

Shields (2015) also raised concerns in their review on questioning family-centred care, stating that parents are expected to stay in hospital during NICU admission without consideration of their home life and responsibilities. FCC involves an element of collaboration that imposed care does not. In some low resourced settings, imposed care may stem from an over-reliance on parents due to nurses' shortages experienced by institutions.

A study conducted in a Limpopo NICU found that parents who lodged in the hospital during NICU admission reported emotional and physical strains as a result of being present. Mothers yearned for the comforting environment that their own homes could provide. They reported lack of sleep and rest, attributed to their travel time between the NICU and the lodging facilities, as well as the continuous care-by-parent routine. Mothers experienced emotional strains exacerbated by the lack of information regarding their infant's wellbeing and prognosis, which were further complicated by perceived negative interactions with healthcare practitioners, including the use of improper language (Nyaloko et al., 2024).

In another NICU providing FCC, some mothers experienced stress, anxiety and even insomnia as a result of being exposed to their critically ill infants, which led to decreased participation in neonatal care. A mother in a Ghanaian study by Abukari and

Schmollgruber (2024) expressed that seeing her infant “struggling to breathe” worsened her emotional stress. Lack of nurses also created negative experiences for mothers. A mother complained that there were no nurses in the KMC during the night, which meant that she had to console her twin neonates alone, often neglecting one or the other. Moreover, inadequate facilities in the NICU prevented mothers from attending to their hygiene, which meant that personal hygiene needs were not met. Inadequate information sharing and negative staff attitudes towards families were also major concerns in the paper.

The implementation of FCC is inconsistent and ineffective in some settings, as certain principles of FCC — notably communication and information sharing, respect and dignity, and collaboration and decision-making — are not fully applied.

Inadequate information sharing and negative staff attitudes towards families were also major themes in a study conducted by Malepe, Havenga and Mabusela (2022). The primary caregiver participants reported limited communication and information sharing from the nurses, which negatively affected their experience in the unit. They identified little to no involvement in the decisions affecting neonatal care; they perceived themselves as being told what to do rather than being asked. This was illustrated by a participant who shared that they were informed to consent to a blood transfusion without proper education. The dynamics of the nurse-primary caregiver relationship appeared to be poor, as mistrust developed between the primary caregivers and the nurses. Caregivers believed that their children would not receive adequate care if they were not present in the units. FCC is best achieved when parents and healthcare practitioners have a collaborative and supportive relationship. Mistrust between stakeholders hinders the positive implementation of FCC. The physical structure of the units was also identified as a barrier to FCC as the NICU was viewed as an unwelcoming environment for families due to the lack of space and privacy (Malepe, Havenga & Mabusela, 2022).

2.6 THE ROLE OF NURSES IN FCC AND ITS IMPACT ON THEIR WELLBEING

Nurses play a pivotal role in the success of FCC initiatives in the NICU. In FCC, nurses act as mediators for families and institutions and also as facilitators for family consideration and involvement (Reid, Bredemeyer & Chiarella, 2021). Nurse support for FCC is linked to increased FCC compliance and reduced parental stress (Loutfy et al., 2024). Furthermore, nurse support is associated not only with increased, but also effective implementation of FCC in the NICU. Therefore, nurses' role and support of FCC are integral. However, the central role nurses play in FCC implementation results in a heavier workload for practitioners as the patient population increases to accommodate family members.

In the NICU, nurses' duties range from basic nursing care, such as feedings and nappy changing to technical skills, such as nursing critically ill patients and handling administrative duties. FCC adds to the nurses' duties by requiring intentional collaboration with patients' family systems. The increased duties involve training, educating and supervising family members, particularly new mothers. Nurses also take on the responsibility of providing support for the emotional, social and physical needs of family members present in the unit. Moreover, nurses must ensure the NICU remains an open, safe and conducive environment for family inclusion (Coyne et al., 2013; Gibbs, Boshoff & Stanley, 2016).

Even without the consideration of FCC, burnout is a common occurrence among neonatal nurses due to the physical and emotional demands of their work (Carton, Steinhardt & Cordwell, 2022). Burnout is a state of psychological and physical fatigue caused by long term stress and leads to dissatisfaction in life processes (Carton, Steinhardt & Cordwell, 2022). A participant in Vittner et al's (2022) study stated that providing neonatal care was barely manageable, and that having multiple families in the unit made their situation more difficult. This caused frustration as they did not want the families or patients to be neglected.

Nurses in the NICU are also at risk of compassion fatigue as they are continuously exposed to critically ill patients and families that require nursing support (Kutahyalioglu et al., 2022). Reid, Bredemeyer and Chiarella (2021) add that insufficient institutional support for nurses and other healthcare practitioners can further affect nurses' wellbeing and attitudes toward FCC. Moreover, some neonatal nurses interpret FCC

as a forced transition, which contributes to negative perceptions of the model (Gibbs, Boshoff & Stanley,2016).

A study examining nurses' perceptions and attitudes towards family-centred care in acute paediatric settings in Jordan pointed out that nurses registered more positive attitudes when "working with children than with parents" (Razeq et al., 2021). Nurses were more comfortable, satisfied and generally positive when working with children compared to parents. Shields (2015) suggests that staff shortages, lack of time, inadequate communication skills and lack of acknowledgement for care coordination efforts are barriers to positive attitudes towards FCC, contributing to a preference for patient-focused care rather than family integration.

Healthcare practitioners also do not agree on the feasibility of FCC in certain settings, particularly in developing countries. In a study conducted in China by Xiang et al. (2020), the healthcare staff held mixed opinions on the necessity of implementing FCC in their units. The staff reported that they did not believe FCC would promote breastfeeding, shorten hospital stays and improve staff-parent relations. The study further identified three barriers to FCC implementation: lack of human resources, lack of infrastructure and physical resources and lack of financial resources. These findings suggest that FCC implementation may not be feasible or considered necessary in some institutions.

Nurses working in the NICU experience a higher workload compared to other intensive care units (ICU) in a hospital. Azadi et al. (2020) examined the nursing workload in the NICU, adult ICU and coronary care unit, and found that while all these units had high workload scores, NICU nurses experienced the highest workload. This was largely attributed to the high level of reliance neonates have on nurses for activities of daily living. Increased workloads can lead to reduced quality of care, increased risk of medical errors, hospital acquired infections and patient deaths, while also causing stress, anxiety and burnout among nurses.

Even though FCC adds to the job description of the nurses, it has been argued that FCC may help reduce their workload. A study conducted in New Delhi, India, reported positive perceptions of FCC, with parental involvement in direct patient care being highlighted as a factor that contributed to a perceived reduction in nurses' workload (Maria et al., 2021).

However, parental involvement in patient care can also lead to an over-reliance on parents in the NICU. Coyne (2015) conducted a study that gauged the hidden expectations and unclear roles of families and healthcare practitioners in a children's unit, revealing that a severe form of parental reliance on delivering patient care existed. Parents also experienced a lack of negotiation in their level of involvement in patient care and little consideration for social responsibilities such as caring for other children at home or work obligations. The over-reliance on parental involvement led to dissatisfaction among nurses who felt "hopeless" about the possibility of change, especially since parents developed mistrust toward nurses. Parents felt that if they were not around, their children would not receive adequate care.

Mistrust can also be observed in Malepe, Havenga and Mabusela's (2020) study, which was set in a children's unit. Mothers viewed nurses negatively and were not comfortable leaving their children under their care. An environment in which families hold negative views and mistrust towards nurses is likely to negatively affect the wellbeing and job satisfaction of the nurses.

Nurses in the NICU experience high volumes of work, which have a physical and emotional impact on their wellbeing. Burnout is common and neonatal nurses often suffer from compassion fatigue and a lack of institutional support. While the integration of families in the NICU can have positive outcomes, in environments with inadequate human and physical resources, its introduction can yield negative effects on the nurses. The involvement of families, particularly mothers, increases the patient population that the nurse cares for, which is reflected in the nurses' preferences for patient-focused care over FCC.

2.7 CONTEXTUALISATION OF FCC IMPLEMENTATION IN SOUTH AFRICA

South Africa is considered an upper middle-class country and spends the most on public health delivery in Africa; nonetheless, the public health system remains overburdened due to a large influx of patients each year. According to Stats SA (2023), 7 out of 10 households in South Africa utilise public health facilities, and according to the SANC (2022), there is one nurse for every 231 people. These numbers do not account for the additional strain caused by illegal immigrants seeking healthcare. According to Aaron Motsoaledi, the appointed minister of health in South Africa, over 15000 illegal immigrants are deported each year (South African Government,2024)

South African hospitals face shortages of both human and physical resources, which creates a barrier for effective FCC implementation. Shokoane et al. (2023) identified inadequate provision of material and human resources as a challenge for family integrated neonatal care in a Limpopo district hospital. In the study, the ward infrastructure was described as congested, which restricted both staff and patient movement. The findings also reported a shortage of nurses to render neonatal care, let alone supervise mothers.

In another Limpopo study conducted in a resource-limited facility, Mahwasane et al. (2023) emphasised the need for direct supervision and close monitoring by the nurses, especially with KMC. In the study, mothers were portrayed as non-compliant with KMC, with instances of obstructing the nasal passages of their babies, which could lead to adverse effects. Parents were also observed with sleep deprivation and fatigue. Sleep deprivation was attributed to the high need for parental participation in neonatal care, compounded by preexisting anxieties and stress.

Mothers who stayed in hospitals with their children, also expressed a strong desire to return home, perceiving the lodging facilities and environment as unaccommodating and contributing to negative physical health outcomes such as inadequate rest and sleep (Nyaloko et al., 2024). Physical limitations persist in hospitals with a bed capacity of over 1 000, and primary caregivers reported the ward infrastructure as unaccommodating for caregivers. Concerns about the lack of space and privacy were also highlighted as barriers to FCC implementation (Malepe, Havenga &Mabusela, 2022).

The literature on FCC in South Africa spans multi-specialty units, including emergency departments, adult and paediatric intensive care units, medical and surgical units, general paediatric units and the neonatal intensive care unit. However, there is a gap in the literature regarding the overall experiences of FCC implementation in a regional NICU within low resource settings. Furthermore, existing studies on FCC in South Africa have largely focused on better resourced settings, such as private hospitals, tertiary and academic hospital institutions. These hospitals have more specialised equipment and staff to provide care and have bed capacity limits that do not increase the nursing workload. The Mahwasane et al. (2023) and Nyaloko et al. (2024) studies are among the few that examine resource-limited NICU settings in South Africa.

However, the Nyaloko et al. study focused solely on the experiences of mothers caring for preterm infants in a Limpopo NICU, while the Mahwasane et al. study assessed the support needs of parents of preterm infants. There is a need for studies to explore the feasibility and appropriateness of FCC in regional NICU settings in South Africa.

2.8 CONCLUSION

This chapter provided a literature review based on published international and local studies to explore the development of the FCC model, its current implementation in NICU settings globally and locally, and its impact on the wellbeing of neonates, parents and nurses. It also examined the feasibility and challenges of FCC implementation specifically in South African regional settings. The next chapter details the qualitative research design, including sampling, data collection, ethical considerations, and data analysis. Ethical considerations and trustworthiness are also discussed in the following chapter.

CHAPTER THREE: RESEARCH DESIGN AND METHODOLOGY

3.1 INTRODUCTION

This chapter provides an exploration of the research design and methods used for collecting and analysing the study data. The chapter outlines the respective research design, research questions, research approach and philosophy. The chapter also describes the research methodology employed. Particularly, the methodology section includes details on the site of selection, population, sampling methods and sample size, data collection, the role of the researcher in the study and the data analysis process. The chapter then follows ethical considerations and trustworthiness.

3.2. RESEARCH DESIGN

The research design can be defined as the detailed plan for conducting a research study. This includes the assumptions, philosophies, methods and strategies involved in the research; and can span from the formulation of ideas for data collection to the analysis and rigour of the data being collected (Botma et al., 2022). The research design is developed prior to data collection to ensure that the research questions are answered. A qualitative descriptive research design was chosen for this study.

3.2.1 Qualitative Descriptive Research Design

Qualitative research studies aim to understand the perceptions, experiences, attitudes, beliefs and behaviours of study participants regarding a phenomenon. Unlike quantitative research, which focuses on numerical data, qualitative research seeks to understand the non-quantifiable aspects. This is seen when qualitative research asks the questions “why” and “how” instead of “what” and “how much”. A qualitative research design relies on the observation of an environment and/or the dialogue between the researcher and participant(s) within that environment (Leavy, 2022; Creswell & Creswell, 2022).

Qualitative descriptive research provides comprehensive and straightforward descriptions of experiences, events and perceptions from participants to understand individual human experiences in its unique contexts. This means that the design is centred on subjective perspectives on the ‘who, what and where’ of experiences without prior assumptions or hypotheses. Part of the goal is to provide a rich

understanding on topics that have not been studied in-depth in a specific context or research area (Doyle et al., 2020; Hall & Liebenberg, 2024).

The choice of qualitative descriptive research for this study allowed flexibility in the collection of data to identify and understand patterns and themes in the implementation of care-by-parent interventions in a low-resourced Neonatal Intensive Care Unit (NICU) environment through participant-researcher dialogue. Additionally, allowed the provision of rich and straightforward descriptions of the experiences of mothers and nurses involved in care-by-parent interventions in these settings.

3.2.2 Research questions

1. What are the experiences of mothers regarding their involvement in the care of their neonates admitted to a regional NICU?

2. What are the experiences of nurses regarding mothers' involvement in the care of their neonates admitted to a regional NICU?

3.2.3 Research approach and philosophy

As the researcher aimed to provide new information regarding family-centred care, particularly the experiences involving care-by-parent interventions in a low resourced NICU environment, an inductive approach was adopted for the study. In an inductive approach, as opposed to a deductive approach, the researcher does not start with a clear conceptual framework. An inductive approach is beneficial when there is limited knowledge regarding a phenomenon or topic (Doyle et al., 2020; Hall & Liebenberg, 2024). As evidenced in the literature review, research on FCC in South Africa has largely focused on tertiary and/or academic hospitals, leaving a gap in understanding its implementation in regional NICUs with human and physical resource constraints.

Given the study's objectives of exploring participants' experiences with care-by-parent interventions in a NICU, the researcher adopted an interpretivist research philosophy. Interpretivism is a research philosophy aimed at interpreting the meanings, beliefs, values and ideas that participants have on a certain phenomenon. It is based on subjectivity and recognises that participants have individual interpretations of the realities in the world (Saunders, Lewis & Thornhill, 2019).

This philosophical approach led to the choice of a qualitative research methodology, as interpretivism aligns well with qualitative design methods. Therefore, this study adopted a qualitative descriptive design, guided by an interpretivist paradigm, to describe the experiences of mothers and nurses in the implementation of care-by-parent interventions at a regional NICU in Gauteng.

3.3 RESEARCH METHODOLOGY

Research methodology forms part of the research design and involves the data collection and analysis processes in a research study (Leavy, 2022). Data collection in this study consisted of the selection of the study site, population, sampling methods, data collection tools and data analysis procedures.

In this study, the research methodology was divided into two phases, as two population groups were chosen:

- Phase One - Focus group discussions with the mothers of the neonates admitted in the selected NICU.
- Phase Two - Semi-structured interviews with the professional nurses working in the selected NICU.

3.3.1 Selection of the study site

The study site is a crucial component in qualitative research methodology. It is the setting in which participants are enrolled, and the research data is collected. The proper selection of a study site is essential for ensuring high quality data. The study site must meet the appropriate population and sample size requirements to produce adequate data quality (Botma et al., 2022). Therefore, the researcher ensured that the site selected met the recruitment needs and was appropriate for the phenomenon being investigated. With this in mind, a regional hospital was identified as the study site. The hospital is located in a South African township community with numerous informal settlements (Moloisane, 2018) and serves as a referral hospital for secondary hospitals, clinics, and community health centres (CHC) in the region.

The hospital's neonatal ward consists of various compartments, including two intensive care unit rooms, two high care rooms, one isolation room, two kangaroo mother care

rooms and one lodger facility room Even though the lodger facility room in the NICU accommodates up to six mothers; it is unclear how many lodger mothers can be accommodated throughout the hospital. Lodger mothers were residing in several units such as postnatal, gynaecology and stepdown units. Lodger mothers are mothers whose neonates have been admitted in the hospital and have been authorised by the hospital to reside in the premises to provide care-by-parent interventions.Care-by-parent interventions are caregiver tasks performed by the parent instead of a healthcare practitioner, as per study findings these primarily included feedings and diaper changings.

According to the data collected, the unit should accommodate up to forty-five patients, however, the high patient demand often leads to an increase in bed capacity. This results in overcrowding in the unit's compartmental rooms and the hospital lodger facilities.

The neonatal ward accommodates both term and preterm neonates with varied medical, surgical and congenital conditions. Term neonates are those who have reached a minimum gestational age of 37 weeks, while preterm neonates have a gestational age under 37 weeks (World Health Organisation, 2023c). Most neonates in the unit are on various forms of supplemental oxygen, ranging from invasive mechanical ventilation to nasal prong oxygen therapy.

The length of a patient's stay is dependent on the neonate's condition. Neonates with extremely low birth weight, defined as a birth weight under 1 000 grams (World Health Organisation, 2023c), may remain in the unit for several months, while neonates with less critical conditions may stay for only a few days. The duration of mothers' stay in the lodger facility aligns with the stay of their respective neonates.

3.3.2 PHASE ONE: Focus Group Discussions

3.3.2.1 Population

Population, in research, refers to the group of elements — such as individuals, objects, substances and events—that the researcher intends to study (Leavy, 2022). Since this study followed a descriptive design; the aim was to identify participants who had experienced or were experiencing care-by-parent interventions in a regional NICU. The study population for Phase One consisted of the biological mothers of neonates

admitted to the regional NICU. These targeted mothers performed care-by-parent interventions for their neonates.

To determine the sample, it was necessary to establish the size of the population. It should be noted that for the data collection months of March and April 2024, a total of 216 neonates were admitted to the unit along with their mothers. This resulted in an estimated two hundred and sixteen (N = 216) mothers lodging at the study site over a span of 60 days.

Inclusion criteria:

- Mothers whose neonates had been admitted for a minimum of 3 days and who had experienced a minimum of two night-time parental visitations. This was to ensure that mothers had adequate experience with the unit routine and parental expectations in patient care.

Exclusion criteria:

- Mothers under the age of 16 years. This group requires parental consent, which may not be readily accessible (Botma et al., 2022).
- Mothers with intellectual disabilities, as participants needed to fully understand what participation in the study entailed and what they were agreeing to.
- Mothers of neonates with a poor prognosis, to sensitivity towards the wellbeing of the mothers.
- Mothers who volunteered to participate in the study, but on the day of data collection appeared or reported feeling ill. This was done to uphold the principle of beneficence.

3.3.2.2 Sampling and Sample Size

Sampling is the process of selecting a group from the study population that will contribute towards the actual study and act as a representative of the population (Botma et al., 2022). Since the study was a qualitative inquiry, purposive sampling was used. Purposive sampling involved choosing participants who had experienced the study phenomenon (Creswell & Creswell, 2022). Biological mothers of neonates admitted to the NICU were chosen according to the inclusion criteria. Therefore, when

sampling, the researcher invited all participants who met the inclusion criteria and were willing to participate in the study through informed consent.

Thirty-three (n = 33) participants were involved in the data collection process through FGDs. This sample size was determined when the researcher discontinued data collection due to data saturation. Data saturation was evident after six focus group discussions. In qualitative research, data saturation is the primary criterion for determining the adequacy of a purposive sample.

Data saturation is reached when the researcher identifies no further themes relating to the research question (Naeem et al., 2024), indicating that further data collection would not yield additional insights.

3.3.2.3. Data Collection Method

Given the researcher's inductive approach to the research, FGDs were adopted and served as the primary and sole method of data collection in Phase One. An FGD is a group activity whereby a specific phenomenon is thoroughly discussed by group members under the facilitation of the researcher. In line with the interpretivist approach to research in Phase One, the FGDs emphasised the participants' viewpoints on their realities and experiences. Compared to individual interviews, FGDs allowed for a more efficient collection of the participants' perceptions, and experiences in a shorter time frame (Akyildiz & Ahmed, 2021).

FGDs typically consist of four to eight participants, with the researcher asking openended questions on a particular phenomenon. Smaller groups allow for in-depth discussions of experiences, while larger groups are appropriate for sharing perceptions (Botma et al., 2022). In this study the focus group sizes ranged from four to seven participants. The researcher initially enrolled six to eight participants for each focus group, however, not every enrolled participant was able to participate on the date of collection. This will be described comprehensively in Chapter 4: presentation and discussion of findings (phase one).

3.3.2.4. Data Collection Process

Prior to data collection and recruitment:

The researcher obtained permission from relevant stakeholders indicated at table 3.1

Participant recruitment:

The population was purposively sampled based on the inclusion criteria and availability to participate in the research study. The researcher approached mothers in the lodging facilities and potential participants were provided an information sheet (Annexure E) that included the study information and the contact details of the researcher, the supervisor and the University of Witwatersrand's Human Ethics Department. Potential participants were given an opportunity to ask questions before deciding whether to participate in the study or not. Interested participants were provided a time sheet to join focus group discussions at allocated dates and times. All interested participants were approached at least two days prior to the data collection date to allow participants time to review their decision to participate in the study. Consent forms (Annexure F and G) were signed on the day of data collection.

During Data Collection:

The room where the focus group discussions were held was prepared prior to participant arrival. The researcher utilised an empty kangaroo mother care (KMC) room to facilitate the focus group discussions, ensuring air-conditioning was on for participant comfort. The outside door of the KMC room was marked with a note stating: "Focus Group Discussions in session". Upon arrival, participants were welcomed and offered refreshments.

Once all group participants arrived, the researcher read the study information sheet aloud and provided another opportunity for participants to ask questions. The researcher emphasised that participation was entirely voluntary and that no remuneration would be provided for participating in the study. The researcher further emphasised that participants could decline to answer any question or withdraw from the study at any time. The researcher also outlined the importance of respecting each participant's privacy. Participants were verbally asked not to share the other participants' experiences outside the FGD, even if confidentiality could not be guaranteed.

Each participant was provided with three sheets:

1. Consent form for participating in the focus group discussion as part of the study (Annexure F).

2. Consent form for audiotape recording of the focus group discussions to maintain accuracy during transcription (Annexure G). The transcriptions also served as evidence of findings for reviewers of the study.

3. Demographic sheet (Annexure H) for use during the discussion of findings.

Once the consent forms and demographic data sheets were completed, ground rules were discussed, and pseudonyms name tags were provided to participants to maintain confidentiality. The participants were informed about the distress protocol (Annexure K), which had been arranged with the hospital psychologist. Participants and staff members were informed that should they experience distress; they could be referred to the psychologist according to the hospital's referral policy.

The FGD was recorded on two separate voice recording devices and proceeded as follows:

- The researcher re-welcomed the group.

- The discussions all began with a description of the mothers' routine and care-byparent procedures

- The researcher then opened the floor with the central question of the study: "Based on your experience as a mother, what are your experiences of the care-by-parent interventions and family involvement in the NICU?".

- Probing questions were asked to explore the central question and routine procedures further.

- Additional guiding questions, based on the principles of family-centred neonatal care by Helen Harrison were discussed (Annexure I).

- Each focus group discussion concluded with a question regarding suggested improvements to parental integration in the unit.

- The participants were thanked for their time and contributions and given an opportunity to ask questions about the study.

- Refreshments were provided after the focus group discussion.

Field notes (Annexure J) were taken by both the researcher and a research assistant, the research assistant is a general professional nurse who assisted in drafting field notes during data collection; assisting participants in demographic data and consent forms; debriefing sessions to identify themes from the data collection; rendering psychosocial support for participants who exhibited distress during the data collection.

Field notes captured what was observed, heard and experienced by the researcher during the data collection phase. Field notes add to the richness of the data during analysis (Botma et al., 2022).

Distress Protocol:

A distress protocol refers to the systematic management of emotional distress exhibited by participants during interviews and discussions. Such protocols are necessary for ensuring participant wellbeing (Whitney & Evered, 2022).

The distress protocol (Annexure K) was applied in three of the six focus group discussions. This is discussed further under chapter 4: results and discussion of phase one data collection.

3.3.3 PHASE TWO: Semi-structured interviews (professional nurses)

3.3.3.1 Population

In Phase Two, the study population consisted of professional nurses working in a regional NICU. Professional nurses are healthcare professionals qualified by the South African Nursing Council (SANC) to practise nursing at the prescribed level outlined under the professional nurse category (Nursing Act 33 of 2005). The professional nurses in the selected NICU are directly involved in care-by-parent interventions, and act as facilitators and supervisors of these interventions. Thus, the choice of this population was appropriate as they could provide a holistic, rich understanding of the phenomenon through their experiences and perceptions (Botma et al., 2022).

In March 2024, the population consisted of twenty-seven (N = 27) permanent and contractual professional nurses, including the operational unit manager and two

community service professional nurses. The data collection phase extended into April 2024; therefore, it should be noted that in the month of April the population consisted of twenty-six (N = 26) professional nurses including the operational unit manager and two community service professional nurses (one professional nurse retired).

Inclusion criteria:

- Permanent and contractual professional nurses.
- A minimum of three months' experience in the hospital's NICU to ensure that the participants had enough time to adapt and become familiar with the unit's protocol and functions.

Exclusion criteria:

- Professional nurses with less than three months' experience in the hospital's NICU as they may not have been as familiar with the unit's protocols and functions to provide a rich description of their experiences.
- Nursing personnel in the unit who have not nursed neonates requiring intensive care such as enrolled and auxiliary nurses.

3.3.3.2 Sampling and Sample Size

Due to the small sample size, total sampling was used. Total sampling, a type of purposive sampling, involves sampling the entire population (Creswell & Creswell, 2022). This meant that the recruitment process aimed to involve every participant that met the inclusion criteria. A total of N=24 professional nurses were invited to participate in the study based on the inclusion criteria. Phase Two data was collected over two months (April and May 2024). The study concluded with seventeen (n=17) willing participants.

3.3.3.3. Data Collection Method

The researcher also applied an interpretivist's approach in Phase Two, emphasising participants' viewpoints on their realities and experiences. In Phase Two, semistructured interviews were used as the primary data collection method. Originally, the researcher planned to use FGDs, as they provide rich data from multiple

perceptions and experiences compared to one-on-one interviews (Nyumba et al., 2017; Botma et al., 2022). However, FGDs were deemed impractical during the recruitment process due to the ever-changing environment in the NICU and patient-ratios ranging from 1:3 to 1:8.

Therefore, the researcher selected individual semi-structured interviews as more appropriate for successful enrolment and participation. Semi-structured interviews are conversations between the researcher and the participant that capture individual beliefs, perceptions and accounts. These interviews follow an interview guide (Annexure L), which is a predetermined list of open-ended questions related to the research aim and objectives. Notably, these interviews allow flexibility to divert from the interview guide to explore emerging topics in greater depth (Botma et al., 2022).

3.3.3.4. Data Collection Process

Prior to data collection and recruitment:

The researcher was granted permissions from the Postgraduate Studies Committee at the Faculty of Therapeutic Sciences of the University of Witwatersrand (Annexure A), the Human Research Ethics Committee of the University of the Witwatersrand (Annexure B) and the study site (Annexure C). Verbal permission was granted by the NICU manager for participant recruitment and data collection within the unit.

Participant recruitment:

The population was sampled based on the inclusion criteria, with the aim of total sampling. The unit manager announced the study to the NICU staff and recommended that the researcher approach participants individually rather than in groups. The researcher then invited participants individually. Interested participants were provided a time sheet to indicate availability. The researcher provided each potential participant with an information sheet that included the contact details of the researcher, the supervisor and the University of Witwatersrand's Human Ethics Department. Prospective participants were given the opportunity to ask questions about the study before deciding whether to participate.

Data collection process:

The room where the interviews took place was prepared in advance. The researcher utilised an empty kangaroo mother care (KMC) room to facilitate the interviews. Airconditioning was turned on for participant comfort. A table and two chairs were prepared and the outer door of the KMC room was marked with a note indicating that a meeting was in progress. Upon arrival, participants were welcomed into the room and provided with a form to sign.

The researcher provided each participant with the following two forms:

- A consent form for the interview participation (Annexure M) attached to an information sheet (Annexure N) explaining the research and confirming that the interview would be recorded with an audiotape recorder. The information sheet also outlined the participant's rights, such as the right to withdraw or abstain from answering specific questions.

- Demographic data sheet (Annexure O) to enrich the data collected during the interviews.

The researcher read the information sheet to each participant and provided them with an opportunity to ask questions. Thereafter, the audiotape recording and interview commenced.

During the semi-structured interview:

- The researcher began the interview with a greeting and an enquiry into the nurses' care routine and the mothers' care routine within the unit. The researcher then continued to the central question: "*Based on your experience as a professional nurse in the unit, what are your perceptions of care-by-parent interventions in the unit?"*
- The researcher also had secondary questions that aligned with the principles of neonatal family-centred care by Helen Harrison.
- Probing questions were asked throughout the interview to explore the participants' expressed experiences in greater depth.
- After the interviews, the researcher thanked the participants and reminded them that they could contact the researcher via the email on the information sheet in case they had additional questions.

- No participants in the semi-structured interviews required the application of a distress protocol.
- The first semi-structured interview served as a pilot study to evaluate the appropriateness of the interview guide. The interview was transcribed by a thirdparty transcription service and sent to the supervisor to review. After the supervisor's approval, full data collection for Phase Two proceeded.
- The duration of the semi-structured interviews ranged from 21 minutes to 48 minutes.

Following the interviews:

- The researcher organised and securely stored the consent forms (Annexure M) and demographic data sheets (Annexure O). The interview recordings were saved on the researcher's laptop and a universal serial bus (USB). The consent forms were scanned and also saved on the researcher's laptop and USB. The USB was placed in a secure fire-resistant locker.

3.4 PILOT STUDY

A pilot study was conducted before data collection for both Phases One and Two to test the feasibility and appropriateness of the selected methodological approaches Pilot studies help to identify ambiguities in the research questions, and in qualitative studies, evaluate the facilitator/researcher's ability to conduct focus group discussions effectively (Lowe, 2019). The pilot study was conducted at the same research setting as Phase One and Two.

The Phase One pilot study involved conducting a focus group discussion with 6 participants who met the inclusion criteria for the study. The researcher and supervisor evaluated the session and determined that the pilot study met the research objectives of the study. As a result, the data collected from the pilot study was incorporated into the research study. The FGD was transcribed via a third-party transcription service along with other FGDs.

For Phase Two, a pilot study was conducted using one semi-structured interview. The interview was transcribed via a third-party transcription service and submitted to the researcher's supervisor for review. The purpose was to ensure the appropriateness of the interview guide in meeting the research objectives. Following evaluation by the

researcher and the supervisor, it was determined that the pilot study aligned with the research objectives. Thus, the data was included in the research study.

Both pilot studies followed the design, methods, trustworthiness and ethical considerations outlined in this chapter.

3.5 ROLE OF THE RESEARCHER FOR PHASES ONE AND TWO

In qualitative research, the researcher serves as the primary instrument for data collection. This means that the researcher is integral to the research process, shaping the study through direct engagement with participants (Collins & Stockton, 2022). The following aspects outline the specific roles and responsibilities the researcher undertook during data collection:

- The researcher entered the research setting where the phenomena were being studied.
- The researcher secured the necessary permissions from relevant stakeholders mentioned under the data collection section and obtained ethical approval from the University of Witwatersrand after completing online ethics training.
- A private and comfortable venue was arranged for the interviews and focus group discussions.
- As a professional nurse registered under the SANC and employed in the regional NICU the researcher had direct experience and a clear understanding of the inclusion criteria, ensuring appropriate sampling. Furthermore, the researcher's involvement within the research setting helped establish rapport and relationships with the participants, making them feel comfortable enough to share their experiences and perceptions comprehensively.
- The researcher is multi-lingual in English, SeSotho, SeTswana, IsiZulu and IsiNdebele, which enabled participants to express themselves accurately in their home language. This added to the richness in the descriptions provided by participants.
- During the recruitment phase of the data collection, the participants were informed of the objectives of the study, what was expected of them and what kind of data

would be collected and for how long. The use of audio recording was fully disclosed to participants.

- The researcher handled ethical concerns with integrity and in accordance with the distress protocol. The researcher holds certificates in research ethics, including introduction to research ethics, informed consent and research ethics evaluation.

3.6 DATA ANALYSIS FOR PHASES ONE AND TWO

Data analysis involves finding meaning in the research data collected. It involves a systematic review and extraction of data to answer the research question (Creswell & Creswell, 2022). Creswell's (2017) method of data analysis blends general steps of analysis with a specified research strategy. The data analysis for both Phase One and Phase Two both followed the steps outlined in Creswell's method. The researcher began with the analysis of Phase One data, followed by Phase Two data.

Step 1: ***Organising and preparing data, such as transcribing interviews, scanning research material and typing field notes.***

- The consent forms (Annexures F, G and M) for the focus group discussions and interviews were collected and digitally scanned along with the field notes (Annexure J) and demographic data sheets (Annexure H and O). The scanned documents were stored on a universal serial bus (USB) for safekeeping along with the hard copies.

- The audiotape recordings of the focus group discussions and interviews were transcribed via a third-party transcription service. The researcher compared the audiotape recordings for each FGD and interview with the respective transcription sheet to ensure accuracy, making edits where necessary. The researcher also wrote additional notes on non-verbal cues, such as laughter, silence, sighs and cries, that were missed in the transcriptions.

- Verbatim transcription was used to ensure the totality of the interview or FGD was reflected during the data analysis. Quotations in vernacular were translated by the researcher and the co-facilitator.

Step 2: ***Developing the general sense; this is reading through all material to gain an overall understanding of the data.***

- The researcher read through the transcription sheets (Annexure Q and R) to obtain a general sense of the data. The researcher also used this time to reflect on the overall meaning of the data.

- Notes were written by the researcher while reading the transcription sheets. Notes were placed in the left margin of the transcription sheets to capture general thoughts and themes.

Step 3: ***Coding of the data***

Coding helps organise and analyse data (Creswell & Creswell, 2022). It facilitates the researcher's understanding of the data gathered and facilitates theory creation.

- The researcher used colour code scheming for the assignment of codes. Specific colours were assigned to key concepts and categories using Microsoft Word. The colour scheming provided visualisation of recurring topics/categories.

- Those categories were then grouped with other relevant codes to create themes.

- Coding was completed one transcript at a time, starting with Phase One, followed by Phase Two. With the codes generated, a list of major and minor topics was created per phase.

- Codes that were related to the same topic were grouped together to make categories for each phase.

The categories identified by the researcher were presented to the supervisor to initiate the identification of themes.

Step 4: ***Describing and identifying the themes of the data***

Themes represent the major findings and are used in the findings chapter (Botma et al., 2022).

- Themes were created by the researcher and supervisor from the generated categories.

- For the Phase One findings, four major themes with respective subthemes were identified.
- For the Phase Two findings, three major themes with respective subthemes were identified.

Step 5: *Presenting the findings*

The researcher used a narrative approach to present the findings, providing comprehensive descriptions of themes and sub-themes (Botma et al., 2022).

- The researcher included rich quotations from participants' perspectives in careby-parent interventions to provide a detailed representation of the themes and subthemes. Chapter Four presents the findings from Phase One, and Chapter Five presents the findings from Phase Two.

Step 6: *Interpreting the data*

Interpretation involves contextualising the findings within existing literature and theories (Botma et al., 2022). A detailed interpretation of data is presented in Chapter Five.

3.7 ETHICAL CONSIDERATIONS

Ethics are driven by the moral compass of doing no harm. Ethical considerations in research refer to researchers' strategies to ensure that the study is conducted in a way that is not harmful to participants. Ethical considerations were applied at every stage of data collection. Ethical principles inclusive of respect for people, justice, beneficence and integrityguide these considerations in research (Cacciattolo, 2015; Botma et al., 2022). Ethical principles are the founding truths for researchers in protecting the dignity, rights and wellbeing of the participants and include respect (World Health Organisation, 2025a).

3.7.1 Approval and permissions from relevant stakeholders prior to the data collection process

Research was only conducted following permissions from the stakeholders presented in Table 3.1.

Table 3.1: Permissions sought for the research

Approval from the School of Therapeutic Sciences' Postgraduate Research Committee at the University of Witwatersrand	Approved on the 26rd of June 2023	Annexure A
Human Research Ethics Committee (medical) Clearance Certificate	Cleared on the 17th of January 2024	Annexure B
Permission to conduct research from the hospital's research committee	Obtained on the 12th of December 2023	Annexure C
National Health Research Ethics Council (NHREC) GP number 202311_037	Submitted on the 17th of November 2023	Annexure D

Permission to conduct research in the NICU was obtained verbally from the unit manager and the nursing services area manager.

3.7.2 Ethical considerations during the recruitment process

- The researcher prepared study and audiotape recording consent forms for phases one and two (Annexures F, G and M). Information sheets (Annexures E and N) were also prepared, outlining the purpose of the research study, data collection procedures, and the benefits and limitations of participating. These documents ensured that participants had sufficient information for **informed consent**. Furthermore, during recruitment, the researcher verbally engaged with prospective participants who met the inclusion criteria, giving them the opportunity to ask questions about the study. The consent form(s) were only signed on the date of data collection.

- The researcher ensured that any individual who met the study criteria could participate in the study, regardless of race, age, class, language and religion. This

meant that if an individual met the inclusion criteria in the respective phases of data collection, they were permitted to participate. No participants required a language translator.

- The inclusion and exclusion criteria developed by the researcher considered ethics and sensitivity to the study population. In Phase One, populations with evident intellectual disability, minors under the age of 16 years, mothers whose neonates had poor prognosis and mothers observed to be ill on the day of data collection were excluded. In Phase Two, the criteria emphasised the need for participants to have experience in the NICU to ensure they could contribute meaningfully to the research. This criterion upheld the responsible conduct of research.

- Participants were provided with the contact details of the researcher, researcher's supervisor, and the Human Ethics Department in the information sheets (Annexure E and N). This ensured that participants had access to support and could address any concerns or complaints with the relevant parties.

- Participants in both phases were enrolled at least two days prior to the assigned date of data collection. This was done to ensure participants had ample time to make an informed decision if they still wanted to participate; this also gave them the opportunity to contact the researcher with any questions.

- Emphasis was placed on the voluntary nature of participation. The researcher clarified that no remuneration was offered.

- To encourage confidentiality and maintain privacy, pseudonyms were used on name tags for participants in both phases. Particularly in Phase One, where FGDs were involved, name tags with pseudonyms minimised the risk of participants using each other's actual names.

3.7.3 Ethical Principles applied for Phases One and Two

Respect for people

- Respect for people extends beyond anonymity and confidentiality. Anonymity refers to ensuring no identifiable participant data is collected or known, even by

the researcher (Botma et al., 2022). However, Kraft et al. (2020) add that respect for people is broader than participants acting as autonomous agents. Respect for people considers the participants' rights, emotions and interests (Kraft et al., 2020). In Phase One, during focus group discussions, participants could recognise one another, but they were asked to not disclose information shared by others out of respect. In Phase Two, face-to-face semi-structured interviews were conducted, and the researcher could identify who the responses belonged to during transcription and presentation of findings, but measures were taken to protect confidentiality and maintain respect.

- Confidentiality refers to measures taken to ensure that the data collected is only accessible to the researcher and the study team. The following measures were implemented to maintain confidentiality:

    1. Pseudonyms were assigned to participants to preserve confidentiality in the data collected, particularly for the tape recordings and presentation of findings. Consent forms were the only documents that contained personal information. The consent forms were scanned and stored securely on a USB stick along with the hard copies in a safe location. No identifiable data was stored on the computer.

    2. Access to the data collected was restricted to the researcher, research assistant, supervisor and the third-party transcriber (non-disclosure agreement signed: Annexure P).

    3. The researcher will hold the study date for a minimum of ten years and will be available for scrutiny, thereafter, the researcher will erase all identifiable data, including the audiotape recordings, unless guided otherwise by the University of Witwatersrand.

    4. In Phase One, one participant was distressed over a social problem involving other children being left alone at home during neonatal admission.

       The participant was asked to stay behind and a referral for social support was offered. It was explained that for the social support referral to be drafted, the researcher had to disclose the social problem to the unit manager and a referring doctor as the participant was a patient. The participant provided

verbal consent. No other incidents requiring breach of research participant confidentiality occurred in either phases.

- The role of the researcher in ensuring respect was to uphold participant autonomy through informed consent throughout the whole data collection phase (Botma et al., 2022). This means that participants were informed of all aspects of data collection, including audio recording, before providing consent. No interventions outside the participants' knowledge were conducted.

Justice

- Justice refers to the fair treatment of research participants (Botma et al., 2022). The role of the researcher in upholding justice was to ensure sampling from the population was inclusive and representative of the population without bias.

- The researcher followed the interview guides for both phases (Annexures I and L), as accepted by the Human Ethics Department at the university and the site research committee.

- Contact details for the researcher, supervisor and the Human Ethics Department of the University of Witwatersrand were provided on the information sheets (Annexure E and N) for participants to raise concerns/complaints regarding the study processes.

- The rights of the participants, outlined on the consent forms, were discussed prior to data collection. These rights included voluntary participation with no remuneration, the right to withdraw from the study at any time without explanation, the right to abstain from answering specific questions should the participant not wish to answer, and the right to complain if they felt their rights were violated.

- No complaints or concerns were received as of the study's conclusion.

Beneficence

- Beneficence refers to the principle of doing no harm (Botma et al., 2022). Participants should not experience harm or discomfort due to the study.

- Psychological or emotional harm was identified as the primary risk factor in the study. The researcher ensured that psychological support was available on standby during data collection. Participants showing signs of distress were managed according to the approved distress protocol. After each FGD and semi-structured interview, participants who appeared distressed were asked to stay behind, and referrals for support were offered. No participants accepted the psychology referrals. Nonetheless, the researcher pointed them to the contact details listed on the information sheet should they change their minds.

- The distress protocol (Annexure K) wasapplied in Phase One when participants expressed high levels of emotional distress or exhibited behaviours such as crying and trembling.

The following distress protocol was followed:

1. Stopping/pausing the focus group discussions and removing the participant from the group to receive immediate support from the research assistant.
2. Assessing the participant's psychological and emotional status, with the option to continue or leave the discussion.
3. If the participant preferred to be excused from the focus group discussion; they were permitted to leave, and were offered a psychological referral.

Integrity

- Integrity is an ethical principle that involves conducting research honestly and with transparency. Integrity required with adherence to moral and ethical standards during the entire research process. The research process spanning from the proposal to conduct research to reporting research findings (Armond, Cobey & Moher, 2024).
- The researcher promotes transparency of research findings. As per agreement with the research setting, the researcher will present the findings of the study to the research setting. The researcher also promoted that participants who are interested in the research findings maya contact the researcher's email.

- The researcher also discloses the limitation of the study, including the presence of bias as part of transparency and honesty. The limitations of the study are outlined in Chapter Six.
- The researcher utilised a third-party transcriber for accurate data recording, however the researcher to ensure accuracy as well reviewed the transcriptions while listening to the respective audiotape recordings.
- Throughout the research study, the researcher was under supervision to maintain integrity by the supervisor, this included regular meetings with the supervisor to discuss the data collected. Each chapter of the research study was reviewed by the supervisor for corrections.
- The researcher intends to disseminate the research study and findings in school, national and international platforms.

3.7.4 Ethical consideration after data collection

- Restricted data access – Collected data access is restricted to the researcher, supervisor and transcriber. The transcriber signed a non-disclosure agreement.

- Safe storage of data and erasing of identifiable data – The length of time for data storage is determined by the university.

- Non-disclosure of research site – The site of selection is not mentioned by name in the final submission of the research study to maintain a sense of confidentiality.

- Reporting of findings – The findings and discussions associated with the study will be reported to the hospital's clinical manager as requested by the site of selection after final submission of study.

3.8 TRUSTWORTHINESS

Trustworthiness describes the extent to which the researcher has confidence in the study's data (Stahl & King, 2020). Trustworthiness also enables readers to have confidence in what the researcher is reporting (Stahl & King, 2020). This study applied Lincoln and Guba's (1989) five criteria for trustworthiness.

3.8.1 Credibility

Credibility ensures that the study measures what it is supposed to measure. Several criteria were applied by the researcher to ensure credibility:

- Triangulation was rendered through the use of two population groups—the mothers of neonates admitted in the NICU and the professional nurses who work in the respective NICU. This added credibility to the data and allowed for data from different perspectives. Triangulation was also achieved through the use of primary and secondary sources of data: primary data were the focus group discussions and semi-structured interviews conducted in the study, which were analysed. Secondary data, including field notes and demographic data sheets, were not analysed but added richness to the research findings and discussions.

- Prolonged engagement was rendered in three ways:

1. The researcher collected data at the study site over a period of three months, which allowed for a range of data collection from varied contexts within the study site. Additionally, data collection continued until data saturation was reached. In Phase One, FGDs ranged from 38 minutes to 1 hour 4 minutes, and saturation was reached after six FGDs. In Phase Two, semi-structured interviews were conducted with the intention of total sampling; data saturation was reached after 17 interviews (ranging from 21 minutes to 48 minutes).

2. The researcher engaged in prolonged interaction with the data, reviewing and editing transcribed texts to ensure verbatim accuracy. This meant re-listening to all audiotapes before conducting data analysis. The researcher also had prolonged interaction with the study topic through literature reviews and the topic being part of the researchers' specialisation in work experience.

3. The researcher was employed at the study site which allowed prolonged engagement and understanding of the specific context.

- In Phase One, the researcher and research assistant held debriefing sessions after each FGD to discuss the major topics that were raised. Field notes were

also taken and reviewed after each FGD. Field notes included non-verbal cues and repeated themes that were emphasised.

- To add to credibility, the researcher attended courses on research ethics, methodology and data analysis provided by the university. Furthermore, the researcher conducted the research study under the guidance of an appointed supervisor.

- Member checks were carried out throughout the FGDs and semi-structured interviews. This was done to ensure that the researcher was interpreting the data presented correctly.

3.8.2 Transferability

Transferability refers to the extent to which study findings can be applied to different contexts. To validate transferability, the researcher implemented the following criteria:

- A dense description of data of findings is presented in the results chapters, accompanied by direct quotes from verbatim transcriptions.

- The researcher provided a detailed description of the methodology, including the methods and time frames for the data collection phase. This allows other researchers to assess the applicability of the findings to similar contexts.

- Purposive sampling was employed in both phases, which enhances the transferability of the findings. Unlike random sampling, purposive sampling strengthens the possibility of transferability as the findings represent a specific group affected by a phenomenon and could be applied to other similar groups experiencing the same phenomenon.

- Data was collected till saturation was reached. Data saturation is reached when the researcher identifies no further themes relating to the research question (Naeem et al., 2024). This was observed after six FGDs in Phase One and 17 semi-structured interviews in Phase Two. Achieving saturation ensures that the data collected provides sufficient representation of the phenomenon, making the findings more likely to be applicable to other similar contexts.

3.8.3 Dependability:

Dependability involves obtaining similar findings if the research were repeated with the same participants and methodology. To ensure dependability, the researcher implemented the following criteria:

- The researcher kept an audit trail detailing the records of all research processes, including data collection, analysis and representation of findings. This audit trail allows other researchers to follow the decision-making process used by the researcher.

- The research was conducted under the supervision of an academic supervisor. The supervisor is a PhD candidate and holds an MSc in Nursing along with qualifications in nursing education and a child nursing science speciality. The supervisor has nine years of work experience in the NICU and four years in academia. Continuous check-ins were conducted with the supervisor throughout data collection and analysis phases. This provided guidance and feedback, helping to verify interpretations, minimising biases, and strengthening the dependability of the findings.

- Triangulation — multiple data sources and data collection methods, as well as additional data in the form of field notes and demographic sheets— strengthened the dependability of the findings.

3.8.4 Confirmability

This involves maintaining objectivity, especially in data analysis and findings. Confirmability also ensures that the findings are solely the representation of the participants' perspectives and are as free from researcher bias as can be (Botma et al., 2022).

- Member checking was conducted during the FGDs and semi-structured interviews to confirm that the researcher's interpretation of the data collected was correct. If necessary, participants were asked for further clarification.
- Throughout the research process, the supervisor guided and reviewed the study.
- The researcher reviewed their decisions relating to the research process in a reflective journal to minimise personal biases. Even though the researcher is an

employee at the study site, efforts were made to dissociate from this role, and focus only on the research duties.

- Triangulation also contributed to confirmability by minimising personal bias, as data was collected from different sources—primary and secondary data— using multiple population groups. The use of a research assistant in Phase One further supported confirmability by providing debriefing sessions and reviewing the topics discussed during FGDs, helping to maintain unbiased interpretation of data.

3.8.5 Faithfulness

Faithfulness refers to how accurately the researcher portrays the realities of participants regarding a phenomenon, including their feelings, emotions and tone. Authenticity also aims to heighten reader sensitivity to the text and problem at hand. The criteria applied by the researcher to ensure faithfulness included:

- Verbatim transcriptions (Annexure Q and R) were used to analyse the data collected and to depict the findings of the study. Verbatim quotes in the findings heighten the quality of the study and allow for a rich portrayal of the participants' realities regarding the phenomenon being studied.

- Field notes were taken by a research assistant to document non-verbal cues such as perceived emotions and the tone of the participants. This adds a layer of sensitivity, helping readers better understand the context of the discussions.

- In both phases of data collection, participants were encouraged to provide descriptive examples of the topics that emerged from the discussed phenomena.

- All the raw data collected from the study is available for scrutiny if ever required.

3.9 CONCLUSION

This chapter provided a detailed description of the research design and methodology employed in the study. The research design was determined to be a qualitative descriptive design. The researcher followed an inductive approach, and the research philosophy was identified as interpretivism. The methodology detailed the population,

sampling, data collection methods and data analysis processes. Details were provided on how the researcher ensured trustworthiness throughout the study and adhered to ethical principles. The next chapter discusses the findings from the FGDs with the mothers involved in the care of their neonates.

CHAPTER FOUR: PRESENTATION AND DISCUSSION OF FINDINGS (PHASE ONE)

4.1 INTRODUCTION

This chapter aims to provide a detailed analysis of maternal experiences in Neonatal Intensive Care Unit (NICU) settings, focusing on communication barriers, relationships with professional nurses, and perceptions of care and maternal involvement. This chapter presents and discusses the findings from Phase One of data collection, addressing the following research question:

What are the experiences of mothers regarding their involvement in the care of their neonates admitted to a public regional NICU?

The chapter begins by presenting the demographics of the participants, followed by a summary of findings in a tabular format. It then outlines the themes and subthemes identified through thematic data analysis. A detailed description of four primary themes and their corresponding subthemes is provided. Each theme is introduced with an explanation and supported by evidence drawn from the raw data. Direct quotations from the transcripts are presented verbatim, italicised, and enclosed in quotation marks. To maintain confidentiality, participant pseudonyms, along with the respective focus group discussion number, are provided at the end of each quotation (e.g., *Participant 1, FGD1*). The demographic data of the participants in Phase One is also presented in this chapter followed by a discussion of the demographic data. The chapter ends with the discussion of identified themes and chapter conclusion.

4.2 FINDINGS FROM PHASE ONE DATA COLLECTION

4.2.1 DEMOGRAPHICS OF THE PARTICIPANTS

Thirty-three (n=33) participants participated in Phase One of the data collection process. The participants represented the biological mothers of neonates admitted in the NICU as per inclusion criteria. Data collection was conducted using Focus Group Discussions (FGDs), with a total of six FGDs held to achieve data saturation. The FGDs were conducted over a period of two months at the research setting and ranged from 35 minutes to 45 minutes in duration. Notably, as recorded in field notes, the

distress protocol (Annexure K) was initiated during FGDs 1, 3, and 6 due to mild displays of distress symptoms.

Table 4.1 illustrates the demographic data collected from thirty-three (n=33) participants according to the categories provided. The frequency refers to the number of participants whose demographic data falls into the allocated category. The percentage represents the frequency as a fraction of 100.

Table 4.1: Phase One demographic data

	Category	Frequency	Percentage
Age	16-17	3	9%
	18-29	19	58%
	30-40	10	30%
	over 40	1	3%
Marital status	Single	19	58%
	Cohabitating	8	24%
	Married	5	15%
	Rather not say	1	3%
Employment	Fulltime	7	21%
	Part-time	2	6%
	Unemployed	19	58%
	Student	5	15%
Nationality	South African (RSA)	22	67%
	Non- South African (RSA)	11	33% -54% Zimbabwe -18% Mozambique -9% Malawi -9% Lesotho -9% Not disclosed
Gravidity of mother (How many times have you been pregnant?)	1	13	39%
	2	8	24%

	3	10	30%
	More than 3 pregnancies	2	6%
Parity of the mother (How many children do you have alive?)	1	16	49%
	2	10	30%
	3 and more children	7	21%
Previous NICU admission, not	0	29	88%
inclusive of current NICU admission	1 and more	4	12%
Support system at home	Yes	31	94%
	No	2	6%
Birth weight of admitted neonate (inclusive of twin neonates)	0-799 grams	2	6%
	800-1 199 grams	9	27%
	1 200-1 799 grams	14	42%
	1 800-2 499 grams	4	12%
	2 500 grams and more	6	18%

4.2.2 DISCUSSION OF DEMOGRAPHIC DATA

The demographic data revealed that a large number of participants (49%) were first-time mothers. First-time mothers in the NICU often present with a fragile emotional state making them vulnerable to anxiety, depression, guilt and decreased confidence in caring for their neonates' post NICU admission (Gul & Hulya, 2024). Similarly, almost all participants (88%) had no previous NICU experience and were similarly vulnerable to the challenges faced by first-time mothers (Gul & Hulya, 2024).

The demographic data also showed that 88% of the participants' neonates were classified as low birth weight according to WHO criteria. WHO classifies low birth weight as neonates with a birth weight under 2500 grams; prematurity is also outlined as neonates born before 37 weeks gestation (World Health Organisation (2025b). Additionally, WHO Organisation states that low birth weight and prematurity are the

leading causes of death in children under five years old. This highlights both the neonates' need for NICU care and the vulnerability of their mothers' wellbeing. Low-birth-weight neonates in the NICU are linked to decreased maternal wellbeing. An American study on stress and maternal wellbeing found that mothers of low-birth-weight neonates experienced stress, fatigue, depression and poor quality of sleep during admission (Lee & Hsu, 2012).

Moreover, the vulnerability of the mothers' wellbeing could be exacerbated by the high unemployment rate (58%) and proportion of single mothers (58%) presented in the findings; this may indicate economic and social challenges. Economic and social challenges are also key factors contributing to maternal stress (Mariano et al.,2022). However, nearly all participants (94%) report a support system in place. Mothers with support systems during NICU admission report lower stress levels than mothers with poor support systems (Varma et al., 2019).

4.3 THEMES AND SUBTHEMES

Table 4.2 presents the themes and subthemes:

The data analysis revealed four emerging themes: 1) Communication barriers in the NICU: Impact on maternal experience, 2) Mothers' perceptions of relationships with NICU professional nurses, 3) Non-adherence to family-centred care principles/ collaboration between families and the unit, and 4) Implications of hospital stay on maternal wellbeing. Table 4.2 shows the themes and subthemes for Phase Two of the study:

Themes	Subthemes
4.3.1 Communication barriers in the NICU: Impact on maternal experience	4.3.1.1 Inconsistent communication practices between professional nurses and mothers
4.3.2 Mothers' perceptions of relationships with professional nurses	4.3.2.1 Perceived attitudes towards mothers by professional nurses 4.3.2.2 Perceived lack of trust and confidence in professional nurses' ability to provide adequate care

4.3.3 Non-adherence to family-centred care principles/ collaboration between families and the unit	4.3.3.1 Perceived nurse support and collaboration in the NICU 4.3.3.2 Rigidity of hospital rules 4.3.3.3 Restrictions on father and other family member visitations in the NICU
4.3.4 Implications of hospital stay on maternal wellbeing	4.3.4.1 Impact of hospital stay on maternal physical and mental wellbeing 4.3.4.2 Social implications of hospital stay on mothers: Impact on relationships, family, work, and personal freedom

4.3.1 Theme 1: Communication Barriers in the NICU: Impact on Maternal Experience

According to the Institute of Patient and Family Centered Care (2024), information sharing in FCC is the practice of actively communicating with family members in a complete, truthful and timely manner on the patient's condition and progression. This is done to increase family participation and decision-making regarding the patient's care. Conversely, the lack of information sharing occurs when communication is nonexistent, passive, incomplete, inaccurate and/or not delivered in a timely manner. This theme identifies the communication barriers and gaps experienced by mothers in the NICU and the implications of these barriers and gaps.

4.3.1.1 Inconsistent Communication Practices Between Professional Nurses and Mothers

This subtheme explores the perceived communication practices between professional nurses and mothers in the NICU. According to the participants, the primary contributor to a discomforting experience in the NICU was inadequate and inconsistent information sharing by professional nurses. The reported lack of information spanned from inadequate updates on the neonatal progress, explanations of the procedures and equipment used in neonatal care, to little or no active delivery of information by the professional nurses.

One participant explained that they had not received an update on their neonates' condition since admission. The participant explained that the information they received was limited to the basic care-by-parent interventions rendered in the NICU such as nappy changing and feeding:

"I just know hore [that] before I go to theatre that is what they said, foetal distress. From there, hhayi [no] I'm just feeding the baby, changing the nappy, life goes on. I don't know anything - I don't know progress - I don't know if there is progress or - they [professional nurses] don't tell us [mothers] anything!" (Participant 5, FGD2).

One participant stated that the professional nurses in the unit did not provide information on the neonates' progress, which made the NICU experience difficult:

"Difficult because amanurse [nurses] they don't tell you ukuthi [that] what is happening with your baby. Is there progress in some other things? Is there any update on how is your baby doing? We're not saying they should say and whatever we come for. But at least a day, tell us ukuthi [that] your baby today is doing much better. She is growing or kwenzakalani? [what is happening?]" (Participant 11, FGD 5).

Participant 11 continued to state that the lack of information sharing had affected their wellbeing: *"Then you get to a point manje [now] - you getting depressed"* (Participant 11, FGD 5).

Information regarding procedures performed on neonates was also not communicated with participants. One participant stated that they would often arrive in the NICU and find their neonate's head shaved or multiple peripheral intravenous lines inserted, without any explanation from the professional nurses:

"...Most of the time you go back to your resting place and when you come back, you find your child- it's either they've [professional nurses] shaved [his head] or a drip was inserted, but then they [professional nurses] don't explain what that drip is for, you understand me? Sometimes they insert two drips, and you don't know what they are for" (Participant 2, FGD2).

One participant had a negative emotional response because of the level of information sharing in the unit. According to field notes, Participant 21 began crying when speaking about their lack of knowledge regarding their neonate's condition:

"You feed the child while you are emotional. But every time, like, every time, I want to hold myself, but I cannot hold myself because I don't have information. At least if they would tell me that my child - that their problem is 1 2 3" (Participant 21, FGD 6).

Furthermore, some participants opted to obtain information about neonatal conditions and procedures from other mothers rather than consulting professional nurses.

One participant even shared with the focus group that they were not updated on why their neonate was placed under a phototherapy light, and instead received information from other mothers in the lodging facilities:

"... definitely we share information. Like it's there [in the lodger facility rooms] we get support, cause even you get hope. Because they tell you 'No, don't worry, this machine is for jaundice'. Definitely, they will be a mother who will say that machine is for jaundice. I think yeah it is scary. We cry about information" (Participant 7, FGD3).

Other participants expressed that the level of information sharing in the NICU had resulted in some family members being uniformed of their neonates' condition and progress. This, in turn, led to conflicts between mothers and other family members, as the latter were confused and frustrated by the mother's inability to provide updated information. Several participants associated the lack of information to their fear of communicating with professional nurses:

"They [professional nurses] don't tell you anything, yeah. I am afraid to ask what is happening with my child. They [professional nurses] don't tell you anything. They [professional nurses] tell you that your child is sick of what. My home is in Mozambique, I told them I am at the hospital… they [family] want to know how the child is, I don't know how I will tell them [family] - the child is sick of what" (Participant 10, FGD3).

According to the participants, the professional nurses did not actively approach mothers in the NICU to provide information on changes in neonatal care. Examples are highlighted in the quotes below:

"I don't feel like we are partners like the way we are supposed to be because sometimes you have to ask everything and the parent is not supposed to be asking- you should be informed. And the smaller things maybe it's not Important. But the important things should be informed without me asking about it - like about your child's condition" (Participant A, FGD1).

As stated by Participant A, the practice of little to no active information sharing affected the perceived role mothers held in the NICU. Participants did not view themselves as partners in neonatal care, as partners were considered well-informed. This is sentiment is reflected in the quote below:

"... I see it as they do not give us enough respect because when we [mothers] ask about the progress of our children, they [professional nurses] do not tell us, they tell us that the child is sick but they do not tell us what are they (children) sick of. I see that they [professional nurses] do not treat us well, if they [professional nurses] treated us well they would tell us what our children are sick of" (Participant 4C, FGD4).

Even when participants made efforts to approach the professional nurses for information, they reported being dismissed. A participant explained that mothers were dismissed when asking questions regarding procedures such as blood sampling:

"They [professional nurses] take blood without our knowledge, from our children. And then time will come when we ask questions. Some of nurses are a bit rude. It's like, yeah, 'why - why do you want to ask questions? It's not the time to ask questions.' When will there be a time for us to ask questions? If we go feed our children. It's the only time I see that it's reasonable for us to ask questions from the sisters…" (Participant 17, FGD5).

The data showed that there were communication gaps in information sharing regarding neonatal condition and progression. These findings are similar to a study conducted in

the Netherlands whereby parents identified significant gaps in communication relating to decisions made in neonatal care and treatment (Lorie et al., 2021). These gaps led to increased mistrust towards NICU staff. Contextually, correlation can be observed in a Limpopo study in which information sharing gaps related to neonatal wellbeing were identified by parents in the NICU; according to the findings the gaps in information sharing negatively altered the mental state of the participants (Nyaloko et al., 2024).

4.3.2 Theme 2: Mothers' perceptions of relationships with professional nurses

This theme outlines the perceptions mothers have towards their relationships with professional nurses in the NICU. The theme also outlines the perceived nurse attitudes and trust experienced by mothers in the NICU.

4.3.2.1 Perceived attitudes towards mothers by NICU professional nurses

The subtheme consists of the perceived attitudes towards mothers by professional nurses. The perceived attitudes largely consisted of the experienced support and respect in the NICU. Disrespect and a negative attitude towards mothers by professional nurses were identified by participants as a major concern in the NICU.
This also affected the mothers' perceived support in the NICU. Participants expressed that the manner in which the professional nurses spoke to them and other mothers did not align with the treatment they expected in the hospital. This is shown in the following statements:

"Cause sometimes they [professional nurses] just take you - they just talk to you like they are talking to each other, when you are the parent. So, the way they are treating us is very bad…" (Participant 5, FGD 2).

"They [professional nurses] add stress. The way they talk with you, it is like you are a small child" (Participant 6, FGD2)

Even though participants experienced negative attitudes and comments from the professional nurses, it was also communicated that this was not the case with all the professional nurses in the NICU:

"I can say it's the least of them [professional nurses]. Others they just here- are here because they are working. They don't care if we - what they say hurt you or - they just respond as much as they want" (Participant 18, FGD6).

"Because they [professional nurses] don't - don't - talk with us nicely, they are rude. But not all of them, some of them. Some are good, some are not good" (Participant 4D, FGD4).

Interactions with professional nurses resulted in impaired emotional and mental wellbeing for the participants. The following participant expressed discomfort with their hospital stay as a result of the manner in which a professional nurse spoke with them:

"When they [professional nurses] are talking, they - are speaking something that you can touch mothers. And it's not nice. Sometimes I'm feeling like I can cry when they are speaking to me. Umm eish angazi… I'm not feeling happy to be here" (Participant 4E, FGD4).

In the same FGD, a distress protocol (Annexure K) was initiated after another participant recounted an incident in which she witnessed a professional nurse scolding a mother over an unspecified machine. The participant expressed confusion and distress, as they did not understand why the other mother was being reprimanded for something outside their knowledge:

*"She does not know the machine, she does not know the machine - when it speak to you, How would we know about the machine? I don't understand anything. So this brings me pain" (*Participant 21, FGD6).

The subtheme described the perceived negative interactions and disrespect from professional nurses by mothers. The perceived negative interactions and disrespect were primarily related to the manner in which professional nurses communicated with

mothers. Similar perceived negative interactions can be observed in Malepe, Havenga and Mabusela's South African study (2022), also based in Gauteng.

4.3.2.2 Perceived lack of trust and confidence in professional nurses' ability to provide adequate care

The subtheme describes the perceived lack of trust and confidence mothers had in the professional nurses' ability to provide adequate neonatal care. In the findings, participants questioned whether their neonates would be cared for in their absence. Professional nurses are described as negligent to neonatal wellbeing.

Participants reported nurse negligence in the NICU; according to statements, the neonate and the neonatal environment were not kept safe and clean. The following participants expressed that neonates were found in a condition that led them to believe professional nurses were not caring for the neonates in their absence:

"Most of us when we come here we find our babies vomited and then the baby lays on their backs. And then you tell the sister - the sister tells you - they shut you off like "Yeh wena [you] hey hey hey as long as the baby is breathing it's fine" (Participant 17, FGD6).

The participant also shared the dismissive approach that was mentioned in Theme 1, however, instead of information sharing, this was regarding neonatal care.

"...you arrive and you find your child passed stools, they [professional nurses] didn't even check or whether the child is wearing - what do they call it? like oxygen whatsoever. They didn't even check. They don't even check the important things" (Participant 11, FGD5).

The participant shared concerns that professional nurses did not consistently check on neonates for tasks such as nappy changing, and that critical tasks such as the placement of oxygen apparatus were also overlooked.

"...the baby is vomiting or the oxygen is out. They say "Ah just leave your baby. I'm gonna do it". When you go, you gonna find that the nurse didn't put that thing in, the oxygen is still out…" (Participant 22, FGD6).

The participant described an incident involving the misplacement of the oxygen apparatus and neonates' vomiting, similar to Participant 11's example. However, Participant 22 pointed out that the professional nurses were apparently not resolving the issues.

"... You arrive there [in the NICU], when they prick an injection into the child, they don't change. The entire hand is full of blood. They [child] not positioned well. Okay, the drip is out, it's leaking, it's leaking water the other day. They [child] are lying there where it is wet, they [nurses] opened the door, so the child is not being dressed. Yeah. It hurt me" (Participant 12, FGD5). The participant stated that the neonates were presented to them in a manner that disturbed their emotional state.

In addition to the alleged negligence in keeping the neonate and neonatal environment clean, participants expressed a general distrust and reluctance to leave their neonates solely under the professional nurses' care. One participant expressed that they would rather sleep outside the hospital building to be there for their neonate than leave their neonate in the professional nurses' care:

"... Because I know what the nurses do. So, we do see it. So being at home, knowing your baby is here, you just think of yoh, those people are sleeping now, those people- who are shouting at them, not being taken cared of" (Participant 12, FGD5).

The participant also viewed the idea of not being in the NICU as a contributor to stress. One participant in the same FGD affirmed the feelings of Participant 12 with a similar perception when describing that they found themselves tired of the prescribed parental routine but felt obligated to continue as no one else would care for their neonate:

"If you're not going there, who will feed him? No one. So, you must sacrifice yourself" (Participant 14, FGD5).

Participants also reported the recurrent issue of the professional nurses sleeping on duty, which left participants unsettled. This was illustrated in the following quote:

"At night you go there, you will find nurses asleep at 3, 6, 6 in the morning. It's not nice" (Participant 11, FGD5).

The sub-theme illustrated that the mother-nurse relationship may be strained as participants describe mistrust and negative interactions with professional nurses including scolding that impacts maternal emotional wellbeing. This is similar to the findings in a study in Gauteng conducted at a tertiary institution. Primary caregivers voiced mistrust over the nurses' ability to care for paediatric patients and account negative attitudes experienced from nurses (Malepe, Havenga & Mabusela, 2022). This highlights that these interactions are not isolated to the research setting.

4.3.3 Theme 3: Non-adherence to family-centred care principles/ collaboration between families and the unit

The theme focuses on the non-adherence to FCC principles observed in the unit. FCC is also guided by principles, namely communication and information sharing; respect and dignity; collaboration; participation/involvement and a supportive environment (Reid, Bredemeyer & Chiarella, 2017). In the findings, non-adherence to FCC principles is observed in the unit in collaboration, information sharing and family participation.

4.3.3.1 Perceived professional nurse support and collaboration in the NICU

In the study, participants were asked whether they felt supported as mothers in the unit. The responses revealed that perceived support was often equated with the provision of information, which has been acknowledged as lacking. Those responses regarding information sharing have already been discussed in Theme One. Therefore, this sub theme focused on the participants' perceptions regarding emotional support from professional nurse, as well as their perceptions of support and collaboration in care duties.

Perceived support from the professional nurses appeared inconsistent. A minority of participants verbalised positive support from the professional nurses. One of the participants expressed that the professional nurses had become a shoulder to cry on and provided a supportive environment for them when their neonate was admitted:

"...I was not fine with it and I didn't understand what they said was going on. But some of the sisters [professional nurses] gave me a shoulder to cry on and then they gave me at least hope that I can cope" (Participant 21, FGD6).

Another participant explained that they did not feel as though they were taking care of their neonate on their own and that the professional nurses ensured mothers carried out their care duties effectively:

"I feel alright cause I'm not watching over my child alone. You know they [professional nurses] help me, they check whether my child is alright, how they [neonate] are and that I am doing the correct things for them [neonate]. So it's alright" (Participant 9, FGD3).

However, the same participant 9 verbalised that the perceived support was inconsistent:

"[sigh] *Some they [professional nurses] give me support, some they don't give me support… some eish you can see they don't care about you"* (Participant 9, FGD3)

Majority of the participants perceived lack of support in the unit. One participant also verbalised that being in the hospital had affected their mental health because, in contrast to the emotional support they would have received at home, the professional nurses were issuing orders that evoked additional stressors instead:

"... it affected me cause sometimes when you are home, you have someone comforting you, No here - you have the sister [professional nurse] asking you to do this and that, and then they will have ideas… So when you are here sometimes you have more stress - more than before" (Participant E, FGD 1).

Another participant who exhibited emotional distress during the FGD, said the following when discussing support from the professional nurses:

"I will tell the nurse that I have a headache, she will shout, tell me that you don't sleep, you always on the phone. So, I would feel like, how should I sleep? My baby not well, like knowing my baby is not okay" (Participant 19, FGD6). The participant perceived a lack of support and empathy from the nurses when reporting ailments.

The professional nurses lacked patience towards mothers as expressed by this participant, which affected the overall NICU experience for mothers:

"... Okay, it's not nice to be here. And sometimes some of the nurses are not patient to the mothers" (Participant 4E, FGD4).

Participants verbalised that the lack of support in the NICU had created a community in which mothers provided emotional support to one another. This was evident in the following statements:

"… they [mothers] are the only people you have at that time. So, you will just express your feelings amongst them. So, I think the most support we get is amongst each other" (Participant 2, FGD2).

"*Yes, because yoh, at least we laugh, and forget that we laugh a lot, and forget about your problems sometimes"* (Participant B, FGD1).

Aside from the emotional aspect of perceived support, participants also expressed a lack of support and collaboration in care duties. Some participants reported that the professional nurses did not assist in basic care for the neonates. One participant described an event where they had asked a professional nurse for linen to replace the old linen during care; the professional nurse responded by telling the participant to go to the other rooms in the NICU and search for the linen. The participant was dissatisfied with the response as they were preoccupied with breastfeeding, and the neonate was

crying. The mother believed that the professional nurse was supposed to bring the linen to them instead, as the professional nurse was allegedly on their cell phone:

"... I mean I'm breastfeeding. I need to change the linen. I don't have it. Bathi ngishiye umntwana [They [professional nurse] say I must leave the child] she's crying. I have to leave my baby. And I have to go to the other side. How is that possible? Wena uhleli phansi [You [the professional nurse] are sitting down], You're watching me. Ubusy ngephone yakho [You [the professional nurse] are busy with your phone]. Is that fair? It's not" (Participant 11, FGD3).

Another participant shared similar sentiments, expressing frustration that while mothers were actively caring for their neonates, the professional nurses—who were being paid to work—were not fulfilling their duties as expected:

"… What I see is like, they [professional nurses] are acting like we [mothers] are getting paid. So that's what they are doing. It's like they [professional nurses] are getting paid, but they are not working" (Participant 12, FGD5).

The arrangement also made participants view their role in the NICU as merely feeders and diaper changers as reflected in their testimonies. This perception emerged in response to being asked whether they felt like partners in neonatal care and part of the team responsible for caring for the neonates:

"Like, just to go and feed the baby. And change the pampers" (Participant 22, FGD6).

"... Partnership, I don't see partnership here... So if I go there, just change the nappy, and then breastfeed, go back" (Participant 5, FGD2).

As stated perceived nurse support was correlated to information sharing and collaboration in neonatal care duties. Even though some mothers expressed adequate nurse support in the NICU, many described the professional nurses as having no partnership with the mothers nor rendering of emotional support. As per Loufty et al (2024). Increased perceived parental nurse support is associated with increased parental satisfaction and reduced parental stress. This can be seen in the findings as

mothers who perceived adequate nurse support had greater parental satisfaction in the NICU.

4.3.3.2 Rigidity regarding the routine care provided by the mothers

The subtheme outlines the prescribed parental care mothers should adhere to in the NICU. Mothers in the selected NICU followed a set of assigned rules in their role as mothers. All FGDs mentioned a prescribed routine in which mothers performed careby-parent interventions. The routine occurred every three hours for an hour in a 24hour cycle from the time of neonatal admission to the time of discharge. Participants mentioned that the routine involved nappy changing, feeding neonates prescribed amounts of milk, and using surgical spirit, cotton balls and wipes. Kangaroo mother care was practised when mothers were not breastfeeding:

"Iyenzeka [it happens] 24 hours cause it's during the day and during the night" (Participant 8, FGD3).

Participants expressed dissatisfaction with the prescribed routine as it resulted in a lack of sleep and rest. One participant explained that they slept for 10 to 30 minutes between the routine intervals because they struggled with expressing breast milk:

"We express milk, how do we do- we- cause sometimes the time it's 30 minutes, I sleep 10 minutes cause the milk does not come out. When I go back [to the NICU], I am sleepy, I am even afraid to hold my child because I might cause them to fall"

(Participant 3, FGD2). The same participant also noted that they found themselves sleepy and afraid of dropping the neonates when holding them as a result of inadequate sleep.

In a different FGD, one participant explained how the lack of sleep between the routine intervals had resulted in them falling asleep while holding their neonate and even spilling milk on them:

"... I spilled the milk on my baby so many times coming for that 3am, I would like carry this syringe like this, then start sleeping, the only time I will wake up is when that syringe falls on my baby, and I'd spill that milk, sometimes it's not even enough, you spill that milk, now you didn't feed the baby but you will be like tired" (Participant A, FGD1).

On the matter of sleep, participants mentioned that being the biological parents of the neonate did not mean that they should be deprived of adequate rest. One participant explained that mothers gave birth to their neonates and were immediately expected to care for their neonates without the support system they would have had at home. The participant found this transition difficult:

"... Cause remember, you had the child then two hours later, they [professional nurses] tell you to go check on the child so you never rested - cause what we know is that when you finish delivering the child, they discharge you, you go home. When you arrive home, they [support system] give you time - okay rest; we [support system] will care for the child until you are physically alright. Cause it is not easy to push out a person then you care for them on the spot. yah. it's no" (Participant 2, FGD2).

In addition to the hospital's expectation for parents to attend three hourly visitations, participants also pointed out that their right to decide on whether to provide breast milk was not regarded:

"...I am tired of expressing, yesterday I had stress… I don't know what to do, if I was at home I was going to take money and buy milk at Shoprite. Let them [neonate feed], when I am here- I don't know what I will do with them [neonate]" (Participant 10, FGD3).

One participant felt that mothers should have the option to sign a form that allows mothers to provide formula feeds for their neonates. The participant was struggling to produce sufficient breast milk, which led to a negative perception of themselves as a mother:

"... Why can't we like sign or something, that what's so ever happens , I know like , that I took the risks of whatever that happens with the baby… and the baby suffering of not getting the milk and there is already another option you can try outside of

breastmilk - formula… but now you are under pressure the baby is crying you can't do anything and as a mother you feel like your body is failing you" (Participant A, FGD 1).

Lastly, one participant made a statement that the assigned FGD agreed with, indicating that the mothers were not allowed to leave the hospital premises:

"There's no sense. You go to the ward [lodging facility], you go to the child, you are not allowed to leave and buy a drink or something, you drink water and go" (Participant 5, FGD2).

The findings illustrated the current policies and procedures impact the level and quality of FCC practice implemented in the NICU. Larocque et al. (2021) indicates without institutional support in aligning policies and standard of procedures to FCC principles, adherence to policies by nurses will result in conflict between families and nurses in the NICU.

4.3.3.3 Restrictions on father and other family member visitations in the NICU

The subtheme points out the experienced restrictions fathers and other family members have as per mothers' perspective. Participants reported that the NICU does not have designated visitation hours and that family members, apart from the mother, were only allowed a single visitation lasting up to 5 minutes during the entire neonatal hospital stay. This is conveyed in the following quotes:

"…neonatal, it's neonatal, they [professional nurses] say there is no visit at all. You just come and drop something and go back… Only the father, mother, maybe your dad neh? So, they came once and that is it" (Participant 5, FGD2).

"... They [professional nurses] only want to see the father and my mother. They [father and grandmother of the neonate] see them [neonate] one time" (Participant 9, FGD3).

"No. Cause the only thing they [professional nurses] tell you is that when they [father] come in, they [father] have two minutes or five minutes" (Participant 11, FGD3).

All participants held negative perceptions of the restrictions on family visitations, particularly the limited visitation for their neonates' fathers. Participants expressed feelings of injustice regarding the limited visitation for the fathers, as they were only allowed to visit the neonate once during the hospital stay regardless of the length of stay. One participant emphasised the importance of fathers engaging with their neonates through touch and conversation, highlighting that such interactions are essential for fostering a connection between them:

"... It's not fair. I want him [the father] to touch him [the baby] and talk to him [the baby] so maybe he'll grow up or they are known to each other. Because if he knows me, only me, it's not fair…" (Participant 14, FGD5).

The participant viewed the visiting restriction as a barrier to father-child bonding. This barrier was also perceived by another participant in a different FGD:

"I feel like the opportunity of the baby getting to know the father has been taken away" (Participant 11, FGD3).

Participants believed that involving fathers more in the care would improve maternal wellbeing, as mothers would receive more support:

"... If they [professional nurses] allow some of them to come inside and support us inside and see our babies - our mothers you baby daddy. I think it would be easy for our emotional need…" (Participant 4A, FGD4).

The visitation restriction has led mothers to use deceptive strategies to provide more opportunities for fathers to see their neonates. Participants reported bringing fathers into the unit when different professional nurses were on duty and falsely claiming that the father had not yet seen the neonate, despite the fact that he had already visited:

"... Sometimes we check them [professional nurses]. Like if they were not here the last time, they never asked, say 'they never saw the baby so', unless the father asks, and

then the nurse asks 'has he never seen the baby', so I'm like, 'no'" (Participant A, FGD1).

However, this does not always work as some professional nurses would recognise the father. One participant reported that nurses complain when they recognise the father visiting more than once:

*"... They [fathers] can't just come here every day, because the nurses complain 'I saw this one, why he come again?'" (*Participant C, FGD1).

The findings highlighted the visitation restrictions experienced by fathers and other family members at the hospital. These restrictions have not onlyv affected paternal bonding but also influenced negative views towards professional nurses by mothers in the NICU. As stated above, without institutional support in aligning policies to FCC principles, adherence to policies by nurses may could result in conflicts between families and nurses in the NICU (Larocque et al., 2021).

4.3.4 Theme 4: Implications of hospital stay on maternal wellbeing

This theme describes the implications hospital stay had on maternal wellbeing. It is well documented that NICU admission, along with neonatal separation, may result in impaired maternal wellbeing. Impaired wellbeing can range from maternal stress to an increased risk of generalised anxiety disorder (GAD), major depression and post-traumatic stress disorder(PTSD) (Dickinson, Vangaveti & Browne, 2022). Family-centred care has been shown to alleviate maternal stress through open visitations, collaboration in decision making and participation in direct neonatal care. However, when FCC implementation is not centred on family consideration, it can lead to adverse effects on maternal wellbeing.

4.3.4.1 Impact of hospital stay on maternal physical and mental well-being

This subtheme describes the implications of hospital stay on maternal physical and mental wellbeing. The participants solely described the negative implications hospital stay had on maternal wellbeing, largely due to the inadequate sleep experienced

because of the prescribed parental routine that occurs every three hours in a 24-hour cycle.

Participants explained that the routine affected their physical and mental wellbeing, as they experienced inadequate sleep: *"Eh experience is very good and also it's very bad for myself. It's good because I can take care of my child and it's bad because of the hours, because I'm getting extremely exhausted"* (Participant 8, FGD3).

"It's both because physically my body is tired! But also mentally my brain, it's not working also, because - from the stress- I'm stressed and I'm physically tired" (Participant 1, FGD2).

Other participants experienced physical ailments as a result of their hospital stay. One participant verbalised experiencing headaches and fatigue due to the lack of sleep:

"... also that I had a lot of headaches because of not getting enough sleep. Because of my body is used to wake up, especially not getting, when I get to bed, I'm not getting enough sleep. So I'm always tired" (Participant 18, FGD6).

Another participant mentioned that her blood pressure remained elevated because of their hospital stay: *"... I am not alright because my BP [blood pressure], it is always up. I am not alright"* (Participant 9, FGD3).

Among the mental implications on maternal wellbeing, participants voiced that exposure to the sick neonates in the NICU had a negative effect on their mental state. One participant found it traumatising to witness a critically ill neonate being suctioned by staff members:

"It's not even a nice experience you go through, because, especially when you're in the ICU one. When you're in the ICU one and find that they are suctioning the baby, you know, You don't know what's going to happen. You find the kids crying. It's very traumatic. And mentally, it is really, really not" (Participant 11, FGD5).

A similar experience was shared by another participant who saw a neonate with breathing difficulties on a machine, describing the experience as scary to witness:

"Sometimes it is scary, you see that they put a machine on the child next door - I don't know about it - they [child] are breathing somehow, like it's extremely scary. but then you see your child and they are not on the machine, it gives hope that my child is better" (Participant 8, FGD3).

Another participant found that being exposed to her premature neonate as a first-time mother was emotionally draining, because the neonate's condition was not consistent:

"... He is small, he is premature, udla nge-tube [he eats with a tube], uyangiunderstanda [you understand me]? Like okay, like she said, days are not the same. Sometimes you go there, and you find your baby is okay, then the next day you find your baby is critical. That is very very emotionally draining, like emotional" (Participant 2, FGD2).

The subtheme findings illustrated the physical and mental impact NICU stays have on maternal wellbeing. The mothers report sleep deprivation, stress ailments such as fatigue, headaches and increased blood pressure.The findings are similar to a study conducted by Nyaloko et al (2024), which also described mothers providing direct care to neonates experiencing sleep deprivation and fatigue from the hospital routine prescribed for mothers whose neonates have been admitted.

4.3.4.2 Social implications of hospital stay on mothers

This sub theme focuses on the social implications of the hospital stay on mothers. Participants largely expressed their inability to care for their other children left at home during the hospital stay. Participants held negative perceptions of the situation:

"...Imagine leaving a child of seven years, not knowing how is it, not knowing whether they go to school. Yoh it's very depressing" (Participant 5, FGD2).

"...She's 2 years old, and I feel like she is too young, because she usually cuddles with me, I don't spend the day without seeing her, so this is like, sometimes, that thing comes back that I am away from my daughter, and sometimes it's painful" (Participant B, FGD 1).

"…As a mother it's nice to take care of your child. Not someone else. To look after him each day, when she is crying… She cannot even visit me. How does that make you feel?" (Participant 4E, FGD4).

Other participants noted that being at the hospital had induced stress related to their children's wellbeing. One participant reported that the situation had resulted in them leaving their child alone at home; the participant worried that the child might be taken away:

"...A lot of stress over the one [child] at home. How will they [child] be at night. The house has not been cleaned. The child is sleeping in the house alone, what if they [outsiders] enter the house and they [outsiders] take and go with them [child] when I am here?" (Participant 10, FGD3).

In the same FGD, another participant also reported leaving their child alone at home, while their husband goes to work:

"... Cause you leave them[child] alone, the father went to a piece job. They [child] are left alone. So my heart hurts. When I am sitting, I say my child is at home. My heart hurts" (Participant 11, FGD3). The participant held negative emotions over this situation.

Another participant shared feelings of distress, as their older child at home became ill and needed to be taken to the clinic. The participant expressed not only concern for their child's health, but also frustration that the child's father had to leave work, which impacted their financial situation:

"Eish, for me it is hard because sometimes they [home] call and say this one [child at home] is sick. Eish, so for the father to leave work- to leave- we won't have food. So, another person needs to be found to go with the child to the clinic. You see, that is also very painful" (Participant 4, FGD2).

The study findings illustrate the mental and social implications of hospital stay on mothers' wellbeing. In a Canadian study, Coyne (2015) highlights that mothers perceive nurses are often unaware of the implications of maternal involvement in the unit has on the psychosocial wellbeing of the mother and their family systems. The study was conducted in a unit whereby nurses described themselves as over-reliant on the participation of mothers in caregiving tasks to mitigate the workload experienced by nurses. This emphasises the high dependency on mothers to provide care is not solely marginalised to developing countries.

4.4 DISCUSSION OF FINDINGS (PHASE ONE)

The study aimed to describe the experiences of mothers regarding the implementation of care-by-parent interventions at a regional Neonatal Intensive Care Unit (NICU) in Gauteng. The findings presented above illustrated the experiences and perceptions of mothers involved in care-by-parent interventions at a regional NICU. The major themes were identified and outlined under Table 4.2. after thematic analysis and will also be discussed below along with the demographic data collected in Phase One.

4.4.1 Theme 1: Communication barriers in the NICU: Impact on maternal experience

In the study, participants experienced little to no active information sharing from the professional nurses, which was regarded as the primary contributor to a discomforting experience in the NICU. This experience was also perceived by some participants as a sign of mistreatment and disrespect. Participants felt that if the professional nurses had respected them; active information sharing about their neonates would be a norm. This situation was escalated by communication barriers, such as being dismissed when initiating communication and the participants' fears of interacting with professional nurses. Some participants even expressed that they would prefer to remain uninformed rather than interact with the professional nurses.

As seen in the findings, insufficient communication between mothers and the professional nurses had a significant negative impact on maternal wellbeing. A distress protocol (Annexure K) was initiated in FGD 6 when a participant discussed the perceived lack of information sharing regarding their neonate. The communication barriers also affected the confidence participants had in their perceived parental roles. Participants did not view themselves as partners in the NICU as a result of inadequate information sharing. Moreover, external family members lost confidence in the participants' parental roles as participants did not have information regarding their neonates' health status.

Comparing the study findings with existing literature illustrates a historical trend of communication barriers and inadequate information sharing in the NICU and paediatric setting, even in units that initiated the FCC philosophy. In 1993, Harrison published the recommended principles of neonatal FCC after receiving "hundreds of letters and telephone calls" detailing the experiences of previous NICU parents. Lack of consistent and accurate information sharing was a major theme experienced by NICU parents. This occurred decades after the inclusion of families in paediatric healthcare settings.

Similarly, a Ghanaian study on perceived barriers to family-centred care in the NICU revealed that lack of information sharing from nurses to mothers was a major theme. The severity of this issue was illustrated when participants noted that they were not aware of their neonates' reason for admission days after NICU admission (Abukari and Schmollgruber, 2024). This situation correlates with the findings in Theme 1 of the current study, where Participant 5 reported not receiving any information regarding their neonate since birth.

Contextually, a South African study on barriers to family-centred care in a paediatric ward setting showed that caregivers reported little to no communication from the nurses regarding their children's care, medication and treatment (Malepe, Havenga and Mabusela, 2022). Caregivers also expressed that communication was often limited to consenting for certain procedures. Similarly, in the current study, communication was inconsistent and often limited to education on care-by-parent interventions, like nappy changing and feedings.

In a Limpopo NICU study, participants (mothers) also identified lack of information sharing regarding their neonate's condition as a major theme and contributor to a

negative emotional state. This was exacerbated by negative interactions with nurses, including the use of inappropriate language towards the participants (Nyaloko et al., 2024). Similarly, in the current study, lack of information sharing negatively impacted the emotional state of the participants, particularly when coupled with negative interactions with professional nurses. One participant recounted an incident of “unnecessary” shouting from a professional nurse when asking a question regarding their neonate’s care.

The findings are consistent with current literature, which highlights that a lack of consistent, active and adequate information sharing leads to barriers in communication and hinders effective FCC implementation in the NICU and paediatric settings. Lack of information sharing also negatively affects maternal emotional wellbeing. However, the findings of this study contribute new knowledge, especially regarding FCC implementation in low-resourced settings, which has not been extensively studied in terms of its implications for maternal wellbeing.

The study also introduces the notion that insufficient information sharing not only affects maternal wellbeing but also impacts the integrity of the entire family system. The findings suggest that a lack of information sharing affects the perceived image of the mother by family members. In the NICU, selected family members, including fathers of the neonate, are limited to one 5-minute visit during the entire neonatal admission. This places the mother as the sole and primary access point for information regarding the neonate, leading to conflicts between the participants and family members when they are not able to relay information about the neonate's condition.

4.4.2 Theme 2: Mothers’ perceptions of relationships with NICU staff

The relationship between the professional nurses and parents influences the overall NICU experience. The current study revealed that there was little to no trust in the professional nurses’ ability to render effective neonatal care; this is largely due to the current practices and professional nurse attitudes in the NICU.

Even though some participants account positive experiences and support from the professional nurses in the NICU, majority of mothers perceived disrespect and mistreatment from the professional nurses, which created an unwelcoming and unsupportive environment for those mothers. This contradicted the FCC principle of

creating a supportive environment, as outlined by Harrison (1993) in their recommended principles of neonatal FCC.

Many participants expressed negative perceptions of the professional nurses, believing that professional nurses did not respect nor view the mothers as parents of the neonates being cared for. Furthermore, some participants felt that the professional nurses did not care about their wellbeing and were unaware of the impact that their communication style had on maternal wellbeing. Additionally, mothers experienced public scolding from the professional nurses. A Limpopo study conducted by Nyaloko et al. (2023) exploring cultural determinants in the NICU found similar perceptions of NICU staff interactions with mothers. Participants (mothers) in the study were actively involved in the direct care of their preterm infants and the interactions were mostly positive. However, some interactions with nurses were described as rude and unsupportive. For example, one participant described being sworn and shouted at by a nurse. The participants also stated that these altercations worsened the pre-existing maternal stress of having a sick child.

These findings are similar to those in the current study, where participants reported verbal assaults from professional nurses, such as shouting and public scolding. Similar accounts are seen in the Abukari and Schmollgruber (2024) study, where participants (families) even considered leaving the hospital because of the disrespect experienced in the NICU. The findings of the current study suggest that even when mothers are integrated into the care of neonates, a strained relationship between mothers and professional nurses contributes to a hostile environment filled with mistrust. This environment adversely affects maternal wellbeing, increasing stress and exhaustion. Mothers are unable to rest properly if they feel their neonates are not receiving adequate care from the professional nurses.

4.4.3 Theme 3: Non-adherence to family-centred care principles/collaboration between families and the unit

In the research study, inconsistent perceived nurse support was observed among participants. Some participants held positive perceptions on nurse support and collaboration in the unit, explaining that caring for neonates with the professional nurses made them feel they were not alone. Moreover, participants stated that the professional nurses served as emotional stability and encouragement agents for some

participants. Increased perceived parental nurse support is associated with increased parental satisfaction and reduced parental stress (Loutfy et al., 2024). This is evident in the current findings, where participants experienced reduced stress as the professional nurses provided a shoulder to cry on and participants felt a sense of collaboration and support from the professional nurses. Perceived nurse support was also linked to increased trust in the professional nurses.

Participants who experienced nurse support reported a positive attitude toward their NICU stay. However, those who reported inconsistent or no nurse support held a negative attitude towards both the professional nurses and their NICU stay. Some participants felt that the professional nurses lacked empathy, patience and the encouraging spirit they had expected in a hospital setting. Moreover, participants felt isolated in caring for their neonate to the extent that they performed nursing responsibilities, such as stocking linen in the cubicles, instead of the professional nurses. Participants believed that the professional nurses did not care about the mothers in the NICU, which led mothers to rely on each other for emotional support. This aligns with the results from a study by Loutfy et al. (2024), which found that reduced nurse support correlated with lower FCC practices in the NICU, including the adherence of FCC principles, and higher levels of maternal stress.

Non-adherence to FCC was evident in the limited involvement of fathers in the unit. As noted in literature, fathers do not receive as much nurse support in FCC practices in the NICU as mothers (Konukbay, Vural and Yildiz, 2024). The current study showed that fathers were not prioritised in neonatal visitations and care, with professional nurses even complaining when a father was seen more than once in the NICU. This frustrated the participants as they believed fathers should be given opportunities to bond with their neonates.

The rigidity of hospital rules regarding maternal visitations in the NICU also caused discontentment among the participants. They experienced continuous interrupted sleep cycles and an overall reduced sleep duration due to the prescribed and mandatory maternal visitations implemented in the unit. Additionally, struggling to express breast milk exacerbated the sleep problem. According to Suni (2022), inadequate sleep results in poor cognitive function, low mood and increased stress levels. In the current study, participants reported not only fatigue, low mood and

agitation, but also poor motor skills, leading to incidents like spilling breast milk on their neonates or almost dropping neonates because of lack of sleep.

The findings relating to sleep and mandatory maternal participation were consistent with Nyaloko et al. (2024). Mothers in that study reported emotional and physical strains as a result of being in the NICU. Inadequate sleep and the prescribed care-by-parent interventions contributed to these strains.

As most of the participants reported little to no collaboration, nurse support or negotiation on maternal visitations for care-by-parent interventions and father visitation restrictions, it can be concluded that the integration of families in the NICU is not fully compliant with the philosophies associated with FCC.

4.4.4 Theme 4: Implications of hospital stay on maternal wellbeing

The findings showed that participants appreciated the opportunity to care for their neonates and engage in the parenting process. However, the consequences of inadequate sleep due to the parental routine in the unit were particularly emphasised. Participants reported physical, mental and emotional implications for maternal wellbeing such as stress, exhaustion, depression and, in one case, increased blood pressure. Being regularly exposed to other sick neonates also negatively altered the mental state of the participants.

Socially, the participants identified that the primary consequence of mothers staying in the hospital was the neglect of other children at home. Participants were concerned about the physical and financial security of their other children. The current dynamics of FCC implementation in the unit do not appear centred on the family system in its entirety. Caring for one neonate, results in the care of other children being neglected, leading to maternal stress, frustration and depression.

The negative implications of the hospital stays can be equated to the level of negotiation parents hold in the unit. This phenomenon was also observed by Sir Roy Meadow (1969) who coined the phrase *the captive mother.* Captive mothers are those whose children have been admitted to hospital, and parental participation is imposed by the health institution. These mothers receive little to no negotiation in parental presence and participation; this is the adverse result of poorly implemented family inclusion in paediatric units. In the current findings, one can observe how imposed

parental presence and participation in neonatal care adversely affects the physical, mental, emotional, financial and social wellbeing of mothers.

Janvier et al. (2022), in a study involving ethics around family integrated care, found a similar trend: parents wished to have more autonomy in being present and participating in FCC. Janvier et al. (2022) recommended negotiation and viewing families as individual and unique systems. Parents also expressed the desire to have less guilt about not participating in FCC, as other responsibilities, such as work, must be considered. This recommendation is fundamentally part of the FCC philosophy, as it considers families in neonatal care as a whole, rather than just focusing on patient care.

4.5 CONCLUSION

This chapter represented the research findings from the Phase 1 data collection process. The research findings were categorised into appropriate themes and subthemes, with participant quotes from the FGDs representing raw data. The following chapter represents the research findings from the Phase Two data collection process. The Phase Two data collection involves the experiences of professional nurses in care-by-parent interventions at a regional NICU. The chapter is divided into themes and their corresponding sub-themes.

CHAPTER FIVE: PRESENTATION AND DISCUSSION OF FINDINGS (PHASE TWO)

5.1 INTRODUCTION

This chapter presents and describes the findings from Phase Two of the data collection, with the purpose of answering the following research question:

What are the experiences of nurses regarding the mothers' involvement in the care of their neonates admitted in a public regional NICU?

The chapter provides the findings of the individual interviews with the professional nurses. A detailed description of three themes along with corresponding sub-themes identified during thematic data analysis is provided. Each theme is explained, followed by an explanation of its respective sub themes and supporting evidence through raw data quotations from the transcripts. The quotes are presented verbatim, in italics, with quotation marks. Moreover, participant pseudonyms are provided at the end of each quote, e.g., (Participant 1, Interview 1). The demographic data of the participants in Phase Two is also presented in this chapter followed by a discussion of the demographic data. The chapter ends with the discussion of identified themes and chapter conclusion.

5.2 FINDINGS FROM PHASE TWO DATA COLLECTION

5.2.1 DEMOGRAPHICS OF THE PARTICIPANTS

Seventeen (n=17) participants participated in Phase Two of the data collection process. The participants represented professional nurses working in a regional Neonatal Intensive Care Unit (NICU) where mothers are involved in care-by-parent interventions. The data collection was individual semi-structured interviews and were collected over a period of two months at the research setting. The semi-structured interviews ranged from 20 to 40 minutes in duration. Distress protocol (Annexure K) was not initiated nor needed in the Phase Two of data collection.

Table 5.1 illustrates the demographic data collected from seventeen (n=17) participants according to the categories provided. The frequency refers to the number

of participants whose demographic data falls into the respective category. The percentage represents the frequency as a fraction of 100.

Table 5. 1 : Phase Two demographic data

Demographic variable	Category	Frequency	Percentage
Age (In years)	20-29	7	41%
	30-39	2	12%
	40-49	3	18%
	50-59	5	29%
Gender	Female	17	100%
	Male	0	0%
	Non-binary	0	0%
Highest qualification	Undergraduate diploma/degree	16	94%
	Postgraduate diploma	1	6%
	Other	0	0%
Years of nursing experience	6 months to 1 year	0	0%
	1-5 years	6	35%
	5-10 years	5	29%
	10-20 years	6	35%
	20 + years	0	0%
Neonatal Intensive Care Unit experience	6 months to 1 year	2	12%
	1-5 years	7	41%
	5-10 years	8	47%

	Over ten years	0	0%
Which best describes your current role in the unit?	General professional nurse	16	94%
	Child nursing trained	1	6%
	nurse		
	Other	0	0%
Nurse: Patient ratios in the unit	1:2	0	0%
	1:3	1	6%
	1:4	4	23%
	1:5	1	6%
	1:6	4	23%
	1:7	7	41%

5.2.2 DISCUSSION OF DEMOGRAPHIC DATA

The demographic data revealed that all the participants in the study identified themselves as female, which correlates with the recent statistics provided by the World Health Organisation (WHO, 2025c), indicating that 90.1% of South African nursing personnel are women. This trend may be favourable as female nursing personnel are associated with increased health service delivery and decreased infant mortality (WHO, 2025a).

The participants in the study ranged from 20 to 59 years old, with the majority falling into two distinct age groups: 20-29 (41%) and 50-59 (29%). These two groups represent the youngest and oldest segments of the neonatal ICU (NICU) nursing workforce, each with unique implications for the unit.

Nurses aged 50-59 bring extensive experience, advanced knowledge, and critical skills to neonatal care (Mohamed & Shaban, 2024). However, they are also at risk of ageism, which can limit their access to professional and educational development opportunities compared to younger colleagues. This lack of career advancement prospects may discourage older nurses from remaining in the profession beyond the age of 60, exacerbating the global nursing shortage (Mohamed & Shaban, 2024). Conversely, nurses in the 20-29 age group face challenges associated with limited experience, making them more vulnerable to burnout syndrome. A study on COVID-19 identified age as a predictor for burnout, with younger nurses being at the highest risk (Moya-Salazar et al., 2023). Similarly, research on competency and work experience found that lower experience levels correlated with decreased competency, increased work-related stress, and higher burnout rates. This is particularly relevant as 53% of participants in the current study had five years or less of NICU experience, highlighting the potential impact of inexperience on workforce stability and patient care.

Moreover, a significant number of participants (94%) in the current study were classified as general professional nurses, meaning that they did not have a postgraduate qualification in a nursing speciality, even though NICU is considered a speciality unit. As shown in the demographic data, only one participant held a speciality qualification, classifying them as a child nurse specialist. This could be the result of the two-year gap prescribed by the South African Nursing Council (SANC), during which entry to post-basic nursing qualifications was limited to persons with a minimum NQF 7 qualification and a midwifery qualification (Crowley & Daniels, 2023).

Another study conducted by Havenga and Sengane (2018), described challenges to postgraduate study for nurses. Challenges included finances, family and employment. Participants described challenges in accessing funds for tuition, travel, printing and research-related fees. The responsibilities of caring for a family was also described as a challenge to postgraduate study. However, the most prevalent challenges discussed by participants were employment barriers to postgraduate study – participants stated difficulties in accessing study grants and also high workload experiences.

Furthermore, SANC experienced challenges in accrediting the programme reform for post-basic qualifications and other nursing programmes, limiting the number of schools

(universities and colleges) offering undergraduate and postgraduate qualifications. The gap can also be linked to COVID-19, which affected the feasibility of some postgraduate programmes (Crowley & Daniels, 2023). The practical guidelines for intensive care in South Africa indicate that at least 25% of nursing personnel in regional hospitals should be intensive care unit (ICU) trained (Critical Care Society of Southern Africa, 2022), however in the data collected only one participant held a postgraduate qualification in the relevant unit speciality.

According to the Critical Care Society of Southern Africa (2022), the recommended nurse-to-patient ratio is 1:1 for ICU patients and 1:2 for High Care patients. However, the findings of this study indicate significantly higher nurse-to-patient ratios within the neonatal intensive care unit (NICU). Notably, no participant reported a ratio below 1:3. It is important to acknowledge that the reported ratios encompass both the ICU and High Care sections of the unit.

The majority of participants indicated an average nurse-to-patient ratio of 1:7. These elevated ratios contribute to an increased nursing workload, which has been directly linked to compromised patient care, higher rates of infection, and increased mortality. Research has shown that excessive workload in the ICU negatively impacts the quality of care and heightens the risk of adverse patient outcomes (Azadi et al., 2020). Furthermore, the heavy demands placed on ICU nurses, particularly within the NICU, contribute to heightened stress levels and burnout. On an institutional level, inadequate staffing has been associated with increased morbidity and mortality rates (Amiri et al., 2020). These findings underscore the critical need for improved staffing policies to ensure optimal patient care and nurse wellbeing within the NICU setting.

5.3 THEMES AND SUBTHEMES

The data analysis revealed three emerging themes: 1) Barriers to effective nursing care, 2) professional nurses' perceptions of family integrated care, and 3) The impact of working challenges on professional nurses' physical and mental health. Table 5.2 shows the themes and subthemes for Phase Two of the study:

Table 5.2: Phase Two themes and subthemes

Themes	Subthemes
5.3.1 Barriers to effective nursing care	5.3.1.1 High workload due to staff shortages 5.2.1.2 Strained nurse-mother relationship dynamics
5.3.2 Professional nurses' perceptions of family integrated care	5.3.2.1 Benefits in involving mothers in the care of their neonates 5.2.2.2 Challenges of involving mothers in the care of their neonates
5.3.3 Impact of working challenges on Professional nurses' physical and mental health	5.3.3.1 Effects on physical health 5.3.3.2 Effects on psychosocial health

5.3.1 Theme 1: Barriers to effective nursing care

This theme describes the barriers related to effective neonatal and maternal nursing care in the NICU. The main perceived barriers to FCC were identified as, 1) high workload due to staff shortages, and 2) strained nurse-mother relationship dynamics, which are discussed below.

Nursing care in the NICU involves the holistic care of neonates, inclusive of the respective family systems. Nurses act as facilitators in integrating families into neonatal care and, therefore, are instrumental in the implementation and maintenance of family-centred care (FCC) (Phiri et al., 2020). However, barriers exist on the personal, family and institutional level that prevent proper FCC practice in the NICU and essentially nursing care (Xiang et al., 2020).

5.3.1.1 High workload due to staff shortages

The subtheme explores the high workload experienced by professional nurses due to staff shortages. The subtheme also describes the overcrowding in the unit resulting in high nurse-to-patient ratios and introduces the over-reliance of mothers in rendering care-by-parent tasks. All participants interviewed in Phase Two described a high workload in the unit, this was largely attributed to overcrowding and high nurse to patient ratios. It is reported that the NICU has a prescribed bed capacity of 45 beds;

however, due to patient demands, the unit often does not adhere to the prescribed capacity. The participants explained that the Standard Operating Procedure (SOP) of the unit outlined that the unit is to cater for 45 patients and that the unit is limited to have five invasively ventilated patients at a time:

"... There is one SOP [Standard Operating Procedure] that came out, I think in 2022, that mentioned that we need to have 45 babies in total in the ICU, in the unit, in the total unit. And it was said that the moment we have five ventilators, regardless of the number of babies, or 45 babies regardless of the ventilators…So that practice is not being done" (Participant 5, Interview 5).

Another participant emphasised that the unit can sometimes be found with up to 60 patients. This was regarded as overcrowding as it is over the prescribed bed capacity:

"No, it's a 45 bed for the unit. 45 beds but because of this overcrowding… we're [NICU] taking until 60 babies admitting until to 60 babies" (Participant 7, Interview 7).

Many participants described the NICU as having an unlimited bed capacity, which subsequently led to high nurse-to-patient ratios. One participant stated that institutions disregard the number of professional nurses in the unit when admissions occur:

*"... The neonatal ICU doesn't have bed capacity. Doesn't have that… No matter what, you just have to admit and move. You admit and move. They [the hospital] don't even count how many staff are. You admit and move" (*Participant 10, Interview 10).

The participants did not appear to have an established nurse-to-patient ratio in their experiences in the NICU; however, all of them stated ratios that could be considered high according to the Critical Care Society of Southern Africa (2022). In ICU 1 (most critical section of the NICU), the ratio was described as 1:3, while in ICU 2 (second most critical section of the NICU), the ratio was 1:6. High care was reported to have a ratio of 1:7 or 1:8.

"... So, ICU-1, we can have nine babies with three sisters there. Ehh… We can have less, we can have more. ICU-2, we can have 12 with two sisters. Yah. So, it depends on that number and that specific day" (Participant 16, Interview 16).

"We [professional nurses] are overwhelmed. Even now, they [nurses allocated at High Care] are going to have 7 - 7 [seven seven], yesterday they [nurses allocated at High Care] had to have 8 - 8 [eight eight]" (Participant 4, Interview 4).

In addition to the high nurse-patient ratios, participants were assigned additional duties, which they believed worsened the workload:

"I feel like that's overwhelming. Remember, you still have, um, extra routines with, like, you have to do, um, order drugs. You check emergency trolley, matrons' report. You are still going to admit baby number four, which you are going to continue nursing. Number five, if the ward is busy" (Participant 3, Interview 3).

Moreover, one participant revealed that many of the nurses in the NICU are general professional nurses without post-basic nursing qualifications. The participant explained that they often practise outside their scope of practice to address the unit's shortage of speciality nurses:

"Many of us [professional nurses] don't have speciality in this unit. So, yeah… Some of the things you are doing, they are above your scope of practice" (Participant 15, Interview 15).

All these factors are perceived as contributing to the high nursing workload. Participants also reported that the high nursing workload has negatively impacted the quality of care provided to neonates and their families, particularly mothers. This is evident in the following statements that illustrate how time and human resource constraints can cause neonatal and maternal neglect:

"... I think because of- also the ratio… that we [professional nurses] are having- we don't have time to attend emotionally - emotionally wellbeing [of the mothers] … we don't have time to take care of their baby" (Participant 11, Interview 11).

"Because now you'll be thinking of umm writing your files, carrying out the doctor's files. At the end of the day, we [professional nurses] are neglecting the mothers. Umm. And

some babies are not getting the care they're supposed to be getting. And there's just loopholes" (Participant 9, Interview 9).

Additionally, participants conveyed that the high nursing workload experienced in the NICU hinders the professional nurses' ability to assist mothers in care-by-parent interventions. This created difficulties for professional nurses to relieve mothers in the care of their neonates, as participants could not feed neonates properly because of high nurse patient ratios:

"... Because we [professional nurses] can't feed the baby, like I can't feed six babies at the same time… I can't, like I won't be able to, even if I try to, some babies will aspirate because I won't, like I have to have time in between, like each patient" (Participant 12, Interview 12).

The participants also expressed strong reliance on maternal involvement in the care of their neonates. Some even reported that without the mothers' participation, neonatal care would either be compromised or absent altogether:

"... Because if ever we [professional nurses] do it alone, as we have such a huge amount of babies, we are not going to do correct things" (Participant 6, Interview 6).
"... I think it would be, um, actually, I, I, I don't think we [professional nurses] would be doing patient care, just focus on writing- writing… Just to, you know, how nursing is, if it's written then it's done" (Participant 3, Interview 3).

The subtheme outlined the high nursing workload experienced by professional nurses in the NICU and its implications on neonatal and maternal care, the subtheme also outlined the reliance professional nurses have on mothers performing care-by-parent interventions. Interestingly, this is observed in a study conducted in Iran, in which nurses were not able to provide emotional support to mothers as a result of high nursing workloads in the NICU. Moreover, the high nursing workload caused nurses to be reliant on mothers caring for neonates (Negarandeh et al., 2021).

5.3.1.2 Strained nurse-mother relationship dynamics

The subtheme describes the nurse-mother relationship dynamics in the NICU: the perceived role of the mothers in the NICU; the communication practices and perceived attitudes and respect from mothers and professional nurses to one another.

The findings from the study showed conflicting perceptions regarding the nurse-mother relationship, with the majority of participants perceiving it as strained. This perception was linked to instances of mistreatment observed from both professional nurses and mothers towards one another; communication practices in the unit; and unclear role definitions for mothers and professional nurses in neonatal care.

Some participants viewed the nurse-mother relationship positively, while others described it as poor:

"It's good. It's good. Umm… I think I think… Umm… we have open channels and there's- there's- a there's an open channel between the mothers and the nurses, so the relationship is good" (Participant 9, Interview 9).

"Very poor, very poor, that's the only thing that I can say. I won't elaborate on anything but it's [relationship] very poor" (Participant 11, Interview 11).

Part of the reason that there are inconsistencies in the nurse-mother relationship are the unclear roles and responsibilities in the unit. One participant described an incident in which a mother refused to change the linen savers of their neonate's bed, believing it was the nurse's responsibility. In the same incident, the participant also describes the same mother reporting that an unspecified oxygen delivery item had fallen off; the participant asked the mother to place the apparatus back, but the mother refused, stating that it was the nurse's job. The mothers' refusal to cooperate with instructions was perceived as an example of disrespect in the unit:

"... I treat the mothers with dignity and respect… but they [mothers] don't treat us [professional nurses] with respect and dignity. They'll give you attitude as if you're - you're shouting at them and it's something that they need to do [participate in neonatal

care] … Then they'll say 'why don't you [professional nurse] do it? It's your job'" (Participant 12, Interview 12).

Perceived disrespect from the mothers towards the professional nurses was recurrent theme during the data collection. Many participants felt that professional nurses treated mothers with respect and dignity; however, they perceived that mothers did not show the same level of respect towards them:

"With nurses towards the mothers, definitely we treat them [mothers] with respect and dignity. But with mothers towards the nurses- Ay, Ay [no, no] I don't think they [mothers] give us the same treatment that we give them" (Participant 16, Interview 16).

Interactions with mothers were also viewed as difficult, as some mothers did not communicate with professional nurses in a respectful manner, even though this was at times understood as a manifestation of maternal stress:

"Yoh we have a difficult time with these mothers. Sometimes the mothers have the stress. They [mothers] don't communicate with you nicely. And they [mothers] provoke you as a professional nurse to change not communicating with that mother nicely" (Participant 8, Interview 8).

In contrast to the above statements, other participants perceived the mothers as being afraid of professional nurses due to the communication practices in the unit, including instances where some professional nurses scolded the mothers:

"They [mothers] fear others [other professional nurses] because they [professional nurses] don't talk to the mothers the way they have to… at times you're [professional nurse] busy with your phone and the mother is asking you something, then you are shouting at the mother" (Participant 14, Interview 14).

The same participant also stated that professional nurses do not assist mothers. For example, mothers are expected to find their own chairs and medical stock, such as linen savers. The participant perceived these tasks as the professional nurses' responsibilities:

“And when I can see that I can assist this mother, like maybe the mother is looking for a linen saver, you can stand up, go in the stock room, bring linen savers, put them there… And if there's a chair, there's no chair and the mother is looking for a chair in the unit, just stand up [referring to other professional nurses] and look for a chair” (Participant 14, Interview 14).

As per participant statements, the maternal role in the NICU was viewed as performing feedings and diaper changes:

“The mother's role is to feed the baby, change the nappy and assist us [professional nurses]” (Participant 7, Interview 7).

This also meant that others were not regarded as part of the care team in decisions related to neonatal care and treatment. Participants explain that the lack of maternal involvement in neonatal decisions was attributed to potential conflicts arising from individual cultural and religious beliefs. One participant explained that conflicts may arise when procedures such as intravenous cannulation on the neonate’s head are performed, as these procedures may not align with the mothers’ cultural beliefs:

“We [NICU] admit most black Africans and they [mothers] have their beliefs in religion, culture and stuff. So certain things are not allowed to be done, but medically you [professional nurse] need to do it in a sense of helping the baby… Cutting the baby's hair to get a vein? And the mom says “culturally you cannot cut my baby's first hair”. So somehow, somehow it [decisions] will have a clash” (Participant 1, Interview 1).

However, this was not the perception of all participants as some participants regarded mothers as part of the care team and the decisions relating to neonatal care and treatment. Some participants explained that certain procedures and medications require mothers’ consent. Additionally, mothers are reported to be involved in decisions regarding formula or breast milk feeding:

“... They [mothers] are part of the team because there are certain procedures. You cannot do them without them consenting. Blood transfusion…when we [professional

nurses] give medication bo di [those] colistin, they [mothers] still have to consent…" (Participant 2, Interview 2).

This is to highlight the perceptions professional nurses have pertaining the maternal roles in the NICU as inadequate communication practices can stem from these perceptions. The findings revealed inconsistent communication practices. While some participants asserted that there was adequate communication and information sharing with the mothers:

"... We tell them [mothers] about the progress. Whether the vitals [vital signs] are alright. Whether they [neonates] are coping, they [neonates] are placed out of oxygen. You see… why they [neonates] are still admitted" (Participant 4, Interview 4).

Many participants expressed that communication was limited to the care-by-parent interventions, such as feedings and nappy changing :

"We do communicate with the mothers, but not all the time. Because it's possible kgore [that] neh [right] - that the mother can come the whole day. The only time when you communicate with the mother, ke re hore ukakile? [did they [the neonate] pass stools?] - o mfile bo kayi? [how much did you [mother] give [the neonate?]] and that's it" (Participant 2, Interview 2).

The limited communication practices between professional nurses and mothers illustrates the level of intentionality in the nurse-mother relationship. Coupled with the perceived disrespect experienced by professional nurses and unclear role placement for mothers and professional nurses; the relationship appears strained.

5.3.2 Theme 2: Professional nurses' perceptions of family integrated care

The theme focuses on the perceptions professional nurses have on the involvement of families, particularly mothers, in the care of their neonates. The theme highlights the benefits and challenges perceived and experienced by professional nurses while facilitating care-by-parent interventions in the NICU.

5.3.2.1 Benefits in involving mothers in the care of their neonates

The subtheme outlines the positive perceptions nurses in the study held on involving mothers in the care of their neonates. These positive perceptions were largely based on the benefits mothers brought to their involvement. The findings showed that involving mothers facilitated bonding and attachment to their neonates:

"... I feel it's a good thing to involve the mothers because of the bonding. Yes, they [mothers] are bonding with their babies" (Participant 7, Interview 7).

Participants also believed that the involvement of mothers allowed mothers to parent even though their neonates were admitted in the NICU:

"I think they [mothers] enjoy feeding their babies. It gives them [mothers], I don't know, some… I don't know, but I think they enjoy… 'At least I'm [mother] doing something for my baby, and I [mother] get to hold my baby'" (Participant 13, Interview 13).

Additionally, involving mothers in neonatal care and adherence to the NICU's parental routine was perceived as helping to establish a routine in preparation for discharge. One participant explained that the routine could be viewed as the wake-sleep cycle neonates, with mothers receiving practice in this process:

"It's [routine] more like at home, whereby every time the baby sleeps, you have [mother has] to make sure that you sleep. When the baby wakes up, you [mother] wake up. So it's the- like the routine is more or less the same way that will assist them [mothers] in case- when they [mothers] get discharged to adapt at home" (Participant 3, Interview 3).

Another major benefit described by participants was the increased competency and confidence in parental skills compared to mothers who have not had a neonate admitted to the NICU. This was attributed to the increased nurse teaching those mothers receive during neonate's admission:

“Most mothers are doing well. With the caring of their babies, after the teaching we give them, so that even when they [mothers] are no longer at the hospital, at home they [mothers] could manage to take care of their babies” (Participant 10, Interview 10).

“... Especially first-time moms or others they do not even know… They've [mothers] never cared for small- for small babies [premature babies]. So we give them [mothers] that confidence, we educate them, we assist them, we support them in taking care of the baby” (Participant 1, Interview 1).

Participants expressed that mothers reportedly gained increased knowledge in neonatal care and became more adept at identifying changes in neonatal wellbeing due to their involvement in their neonates' care:

“They [mothers] get knowledgeable about if their baby changes, they are able to see even if they are discharged. Even if they [mothers] are discharged, they can notice if their baby changes at home” (Participant 6, Interview 6).

Participants perceived maternal exposure to neonatal progress and deterioration as a positive effect of involving mothers in their neonates’ care. Participants believed that it is better for mothers to physically and visually experience the progression of neonates rather than only being informed by the NICU staff:

“Yes, it’s beneficial. Cause at least you [referring to the mother] can see the child’s progress… There’s no need for someone to inform them [mothers]” (Participant 2, Interview 2).

“... It's beneficial for them [mothers] because they [mothers] see their babies growing” (Participant 6, Interview 6).

On the other hand, participants also outlined that professional nurses benefited by involving mothers in the care of their neonates. The primary benefit experienced by the participants was a lessened workload. Participants explained that mothers performing

care-by-parent intervention such as feedings and nappy changing allowed them to meet other demands of the unit:

"... They [Mothers] lessen our workload. For the mother to come here and feed, for the mother to come here and change dia - nappies, make sure the baby is in a clean environment, that's something for us" (Participant 16, Interview 16).

"So when they[mothers] come at least they [mothers] change nappies, feed. It is a benefit for me" (Participant 4, Interview 4).

Secondary to the reduced workload, it was reported that mothers also provide resources such as nappies and cotton wool. One participant acknowledged how this assisted the unit when there is insufficient stock:

"... Uh where there is no stock- the moms provides for themselves. So in that instant [instance], uh uh staff members don't need to worry about providing - like looking - what's the word - like providing - so the mom do [does] provide for the babies" (Participant 1, Interview 1).

In the findings, the professional nurses described the benefits experienced by both mothers and nurses. The mothers are given the opportunity to bond and grow with their neonates as opposed to being separated. The nurses are reported as experiencing reduced work in neonatal care. These findings are similar to a study conducted in New Dehli, India in which nurses held positive percetpions towards FCC as parental involvement in care reduced the workload of nurses (Maria et al., 2021).

5.3.2.2 Challenges of involving mothers in the care of their neonates

The subtheme outlines the challenges professional nurses experienced in involving mothers in the care of their neonates. Participants held negative perceptions on the manner in which families, particularly mothers, were integrated into the NICU. The most recurrent challenge mentioned by participants was the exposure to the parental routine and its implications on maternal wellbeing. This challenge was exacerbated by

the participants' inability to relieve mothers from the prescribed routine. Participants described the mothers in the NICU as experiencing exhaustion and impaired wellbeing:

"Yoh! I always think about that. Cause they're [mothers] always tired. I don't want to lie. They're always tired." (Participant 16, Interview 16).

"The cycles... every day, every day, every day, you could see the fatigue in them [mothers]. But like they [mothers are] just pushing because it's for their babies" (Participant 1, Interview 1).

Participants also shared that the parental routine not only had a negative impact of the mothers' quality of sleep, but also affected them emotionally, to the point where some mothers could not cope or required admission themselves:

"They're [mothers are] not getting enough sleep. And then some are being affected, and then some are being admitted… and then some are not coping" (Participant 8, Interview 8).

"It's not fair, especially at night, like you say… They [mothers] don't get enough sleep. Hence, most of them [mothers] umm, they [mothers] end up - umm not being okay emotionally" (Participant 9, Interview 9).

Participants also indicated that mothers complained about their experiences regarding the prescribed parental routine to the professional nurses. Mothers expressed a desire to be home rather than remain in the hospital:

"... Sometimes they [mothers] complain about like the long hours here, like having to wake up three hourly, having to wake up at night. Some would say 'I'd rather be at home. If I was home, I would be sleeping by now. I'll be with my other kids and stuff..'" (Participant 12, Interview 12).

Even though participants empathised with mothers and their desire to be home, the NICU has a history of mothers absconding and abandoning their neonates when allowed to go home which creates a problem for the NICU:

“It [staying at the hospital] works because the mothers must come. We [professional nurses] don't have a choice. The mothers must be here so that we can get the expressed breast milk. Because if the mothers go home, they [mothers] don't come back” (Participant 7, Interview 7).

Historically, mothers have been seen giving up their neonates for adoption because of premature delivery and the inability to stay at the hospital:

“The mom would be like, ‘Yoh I was supposed to deliver this time but this baby came this time, so I have to go to work, I’m losing my job’, some they [mothers] even abscond… And some would give their [mothers] baby for adoption… And I [referring to mothers] can't stay in hospital for the required time” (Participant 3, Interview 3).

This highlights the implications of little to no negotiation on parental involvement during NICU admission.

Participants also recognised the implications of the prescribed parental routine on maternal health, but also believed that change would not be implemented:

“… I don't know. I just kind of feel like also it's hard to change these things. It has been happening for a long time. I just recently joined and it's [current parental routine] not going to change” (Participant 13, Interview 13).

A minority of participants viewed mothers as a hindrance in the delivery of nursing care. One participant believed that procedures are paused or delayed in attempts to accommodate mothers and their parental routine:

“... If the mothers weren't here [NICU], we would have- we’ll-we’ll have more to do… But also when they [mothers] are here, sometimes you can't perform umm procedures when they're here and then sometimes they'll be wanting your [professional nurses’] attention and wena [you]- you want to chart or something…” (Participant 12, Interview 12).

The same participant described the involvement of mothers in the NICU as additional work, because mothers involved in neonate care require close supervision to prevent medico-legal events:

"... Especially at night, it [having mothers at the hospital] gives us extra duty because sometimes the mom will be holding the baby, also sleeping on the other side" (Participant 6, Interview 6).

The environment was identified as a challenge to involving mothers in the care of their neonates. Participants perceived the NICU environment as not accommodative for the patients, staff and family. It was described as small and packed, largely due to the overcrowding in the unit:

"It's [the environment] packed. They [mothers] can't even move in between. We have to now squeeze and it's not nice. You can't even breathe. There's no fresh air. It gets too hot. Yeah, it's too much. And we try and squeeze the babies" (Participant 13, Interview 13).

Additionally, participants also reported that language barriers between the professional nurses and mothers hindered the level of care and support provided to mothers. Moreover, interactions with mothers who faced language barriers were perceived as adding to the nursing workload. Professional nurses also viewed the language barrier hindered some mothers' teaching in parental skills as professional nurses would rather perform care-by-parent interventions than to interact with mothers who have a language barrier:

"... I can say it's adding more work when you find the mother having a barrier [language] communication. It's too bad because you have to use even non-verbal communication... And then you see you- you're not going anywhere because you're standing in the same place. It's better for yourself to do it [care-by-parent interventions]" (Participant 8, Interview 8).

Lastly, the sub theme focused on the challenges of involving mothers in the care of their neonates. However, the involvement of fathers was also identified as a challenge

in the NICU. Fathers are allowed only one parental visitation during the entire neonatal admission period and many participants expressed discontent over the matter. Participants believe that the current level of involvement and integration of fathers into the unit deprives and disrupts the relationship between the father and their neonate:

“Like I said, it's just how it is. It's the rules, Bra [friend] So… I feel like we [NICU] are depriving the baby” (Participant 13, Interview 13).
Other participants agreed with the current level of involvement of fathers in the NICU. One participant stated that bonding between the father and neonate would occur after discharge:

“We [NICU] don't include the father that much. We don't. They'll [father and the neonate] bond at home. They'll bond at home, hey? When the baby is no longer sick. Remember the first person to take care of the baby is a mother when they're [the baby is] sick” (Participant 16, Interview 16).

Space constraints were also identified as a challenge in involving fathers in the NICU:

“We don't [NICU does not] have space for that [involving fathers] due to overcrowding of patients. We don't have space for that. We don’t-yeah” (Participant 1, Interview 1).

The restriction on father visitations and other family members is said to be an infection control measure in the NICU:

“The reason being is that we [NICU] are minimising the outside people coming in. In a sense of infection control. They [father and other family members] are not screened so in a sense of infection control, they [NICU] are limiting their visiting” (Participant 1, Interview 1).

And one participant did not agree with the infection control measure of limiting father visitations:

"...They [fathers] are not allowed sometimes to hold the baby. They'll [other professional nurses] be telling you [fathers] they are afraid of infection blah blah, and they [fathers] are not allowed to stay long…" (Participant 6, Interview 6).

As shown in the findings, even when professional nurses have positive perceptions on maternal involvement in the NICU, organisation barriers prevent effective FCC implementation in the NICU. This can be illustrated in an Australian study in which the high nursing workload resulted in internal emotional conflict and tension between nurses and mothers. The nurses acknowledged that mothers can opt to not fully participate in care-by-parent interventions but the high nursing workload would cause mothers to participate even when they do not want to participate (Simpson-Collins et al., 2024).

5.3.3 Theme 3: The impact of working challenges on professional nurses' physical and psychosocial health

The theme explores the implications of working challenges on professional nurses' health. According to the WHO (2025) health involves not only the absence of disease, but also complete physical and psychosocial wellbeing. The primary working challenge experienced by the participants was the increased workload caused by an unlimited bed capacity, resulting in high nurse-patient ratios and prevalent staff shortages. Increased nurse workload is associated with physical and emotional strains to wellbeing.

5.3.3.1 Effects on physical health

The subtheme describes the implications of working challenges of physical health. In the findings, the impact of working challenges on professional nurses' physical health was attributed to the heavy workload experienced in the unit. This has affected the nurse-patient ratios resulting in an increased workload for the professional nurses. Participants complained that the increased workload has led to fatigue, making it difficult for them to feel motivated or willing to return to work:

“Yoh… It [workload] affects a lot because when you [participant] arrive at home, you are very, very tired. You are very, very tired. You are exhausted” (Participant 7, Interview 7).

“Yoh! Mina [me]- I [participant] feel tired. I feel drained. I don't want to lie. If it's like overcrowding and we [NICU] don't have staff and there's just lot of babies… And then thinking of coming back to work to the same load, Yoh its so it's draining” (Participant 16, Interview 16).

In addition to the fatigue experienced in the unit, some participants reported health problems such as backaches and swollen feet, because of the heavy nursing workload in the NICU:

“I'm always fatigued. I'm experiencing backaches sometimes. And also my feet swell. Because when you stand, especially when you're working in ICU one, the very ill baby- [the participant] will be running around the whole day” (Participant 13, Interview 13).

“... We end up getting back pain due to sitting down and writing instead of taking care, long time of taking- of patient care… We spend most of the time writing...” (Participant 14, Interview 14).

One participant even stated that they are seeking treatment from a physiotherapist to address some of the ailments caused by the nursing workload in the NICU:

“... Even now I'm attending physio because I'm always running around and working around so it [workload] has taken a toll on my health” (Participant 12, Interview 12).

The subtheme illustrated implication on the professional nurses’ physical health and the findings described the professional nurses’ experiencing fatigue and ailments such backaches. It is also reflected that nurses feel drained when working, this could be a sign of burnout which has a high occurrence among neonatal nurses (Carton, Steinhardt & Cordwell, 2022).

5.3.3.2 Effects on psychosocial health

The subtheme describes the implications of working challenges on psychosocial health. Majority of the participants identified that the lack of institutional support for professional nurses had significant implications for their psychosocial health. Participants felt that the hospital itself did not care about the nurses' wellbeing. One participant explained that they work 12-hour shifts caring for six neonates whilst also attending to other duties, like maternal supervision and performing medical procedures. The participant added during the shifts, they often faced resuscitations or sick mothers, adding to the overwhelming workload. The participant stated that at times the professional nurses are relied upon by others, but no support is provided for the professional nurses:

"So I feel it is overwhelming when everything as a professional nurse looks upon you or is dependent on you, and you have nowhere else - off loading, yeah" (Participant 5, Interview 5).

The same participant added that their emotional health had deteriorated due to continuous exposure to traumatic events, such as morbidity and death. Institutional support for these traumatic events was not made available for participants:

"I've never personally encountered having a session or rather a debriefing session, especially with umm nursing babies that are premature or big babies that demise… and I feel as a young person as well, I don't have a baby myself, but seeing young women at my age losing their babies, it takes a toll on you emotionally…" (Participant 5, Interview 5).

Similar concerns on the lack of psychological support from the institution were raised by another participant:

"I'm always stressed after work… They don't [hospital does not] support us... They don't even offer psychologists for us. Even after a death of a baby, they [hospital] don't ask you, how are you or how are you feeling? Do you need a psychologist?" (Participant 12, Interview 12).

One participant stated that psychological support was offered in the form of a referral, however, the high workload in the NICU was a barrier to accessing the support:

"... The institution doesn't support me in any way. They [hospital] will tell you, they [hospital] will refer you to a psychologist or a therapist or whatever. And then you [participant] never really get to go because it's [NICU] busy and it's short staffed" (Participant 13, Interview 13).

Other participants equated institutional support to the provision of adequate human resources. Since the unit was experiencing staff shortages and overcrowding, the participant did not believe they were supported by the institution:

"... I don't think umm they're [hospital] supporting us on that. We just work with what we have. If we are 8 or 10 and we have 60 50 babies on that day, on that shift, then we just split the babies amongst us" (Participant 9, Interview 9).

The theme illustrated the implications of working challenges on the physical and psychosocial health of profession nurses working in the NICU. Due to the physical and psychological demands of the work, nurses working in the NICU are at high risk of burnout syndrome (Carton, Steinhardt & Cordwell, 2022).

5.4 DISCUSSION OF FINDINGS (PHASE TWO)

The study aimed to describe the experiences of nurses regarding the implementation of care-by-parent interventions at a regional Neonatal Intensive Care Unit (NICU) in Gauteng. The findings presented above describe the experiences and perceptions of professional nurses facilitating care-by-parent interventions at a regional NICU. The major themes were outlined under Table 5.2 following thematic analysis and will also be discussed below:

5.4.1 Theme 1: Barriers to effective nursing care

In the study, high nursing workload and the relationship dynamics between the professional nurse and the mother were identified as barriers to effective nursing care

and the adequate integration of mothers into the principles of FCC. The findings showed that high nursing workload, exacerbated by non-adherence to the bed capacity outlined in the units' policies, led to adverse effects not only on the quality and/or existence of maternal care but also on neonatal care. The high nursing workload also negatively affected the professional nurses' ability to assist mothers with care-by-parent interventions, such as feedings and nappy changing. Ultimately, this reliance on mothers to render care-by-parent interventions meant that neonatal care would suffer in the absence of maternal involvement.

The NICU has created a system where the mothers' participation in neonatal care alleviates the high workload caused by the unlimited bed capacity. With the mothers' involvement in care-by parent interventions, participants can complete their daily nursing duties. Without maternal involvement, the high nurse-patient ratios could lead to adverse outcomes for both the neonates and professional nurses. Azadi et al. (2020) identified the NICU as an ICU with a high workload due to the dependence of its patients on nurses to render activities of daily living, such as feedings and maintaining hygiene. Increased workloads in the NICU were also linked to a decline in quality of care, increased risk of medical errors, hospital acquired infections and patient death. Nurses are also vulnerable to stress, anxiety and burnout because of the high workload.

The high nursing workload in the NICU of the current study has led to an increased reliance on mothers to render care-by-parent interventions. This finding correlates with the Simpson-Collins et al. (2024) study conducted in Australia, which described parental reliance in rendering patient care. This led to an environment in which nurses and mothers experienced internal conflicts and tension with one another. This affected the level of negotiation mothers had on participating in care-by-parent interventions. Nurses in the study expressed guilt over the reliance they had on mothers participating in care. Mothers in the study also reported feelings of guilt when leaving their children in the NICU seeing that the nurses were experiencing high workload. Like the Australian study, the current study does not allow mothers to negotiate their level of involvement in neonatal care. Such negotiation could lead to higher workloads, leading to insufficient basic nursing care for neonates.

The relationship dynamics and communication practices in the unit were also identified as barriers to nursing care, particularly the integration and support of mothers in the NICU. Some participants perceived the mothers' role as limited to assisting with feedings and nappy changing, while there were opposing opinions regarding the mothers' involvement in neonatal decisions. Some participants acknowledged that a mother's involvement was necessary in decisions regarding blood transfusions and colistin administration, as both treatments require consent due to their potential for adverse side effects (Murphy et al., 2021; Chibabhai et al., 2023).

The participants who disagreed that mothers were argued that mothers had little influence on the decisions regarding neonatal care. In these cases, mothers were described as doing what they are told by professional nurses, rather than contributing to the treatment plan. Similarly, this was observed in a South African study on barriers to family-centred care in a paediatric setting. Participants shared that the primary caregivers (e.g. mothers) had little influence on the decisions regarding neonatal care. Participants who were primary caregivers explained that their involvement was limited to signing consent forms for operations even with little understanding of what was being signed (Malepe, Havenga & Mabusela., 2020).

Another study in Malawi revealed similar findings, where mothers were not involved in the decisions related to paediatric care. Mothers' religious and cultural beliefs were perceived as barriers that led to conflicts about certain procedures and decisions of care (Wong et al., 2023). The current findings from Phase Two showed that participants also viewed mothers' religious and cultural views as a barrier to involvement in decision making.

Disrespect and mistreatment from both professional nurses and mothers were major occurrences in the study. Many participants held negative perceptions towards the mothers due to previous negative experiences involving disrespect and mistreatment. Some participants also acknowledged witnessing professional nurses mistreating mothers, even though many of the participants stated that the professional nurses respected mothers.

The mistreatment by both parties towards each other aligns with the current literature outlining barriers to FCC. A Malawian study on the perceptions, practices and factors influencing FCC implementation found similar results. Nurses and mothers are reported to shout and interact negatively towards each other (Wong et al., 2023). Malepe, Havenga and Mabusela. (2022) also noted that negative attitudes and mistreatment between nurses and mothers persist. These interactions are also associated with negative perceptions of professional nurses towards mothers and negative perceptions of professional mothers towards nurses. This adds to the strained relationship in the unit and makes FCC implementation challenging, as the primary players in FCC do not respect one another.

5.4.2 Theme 2: Professional nurses' perceptions of family integrated care

The study findings outlined the perceptions professional nurses held on family integration in neonatal care, particularly mothers' involvement in care-by-parent interventions. The mothers were described as adhering to a parental routine in which care-by-parent interventions such as feeding and diaper changes were performed every three hours for one hour in a 24-hour cycle. The benefits outlined by the participants corresponded with the advantages of FCC found in the literature.

Most of the participants agreed with the involvement of mothers in neonatal care as this facilitated bonding and attachment between the mother and neonate (Shetty et al., 2024; Mariano et al., 2022). Participants also found it beneficial for mothers to be involved in the NICU, as it equipped them with increased parental skills and competency. Furthermore, mothers were described as confident and able to identify changes in their neonate's condition. The participants believed that these mothers were set apart, because mothers who were discharged after birth were not equipped with the same knowledge and skills (Reid, Bredemeyer & Chiarella, 2021; Mariano et al., 2022). Participants also believed that involving mothers in neonatal care allowed mothers to parent during neonatal hospitalisation and helped child rearing to continue uninterrupted (Reid, Bredemeyer & Chiarella, 2021). Participants in the current study, also indicated professional nurses benefit in the involvement of mothers in neonatal care as mothers participating in interventions such as feedings and diaper changes lessened the nursing workload.

Even though participants perceived positive outcomes for mothers integrated into neonatal care and for themselves, they also held negative perceptions about the manner in which mothers were integrated, specifically the prescribed parental routine. The parental routine was viewed as detrimental to maternal physical and emotional wellbeing. The routine required mothers to practice intermittent sleep, which resulted in poor sleep quality and fatigue. Mothers were described as tired, exhausted, and with impaired coping skills and emotional wellbeing as a result. Moreover, participants found the continuous exposure to impaired maternal wellbeing to be a disheartening experience. This was identified as a major challenge in involving mothers in the NICU, especially since mothers complained about the hospital stay and desired to be home.

Findings from this study corresponded with Nyaloko's (2024) study on exploring the cultural determinant of parents caring for preterm infants in the NICU. Participants, who were mothers caring for preterm infants in the NICU, reported inadequate rest and fatigue due to the infant's care routine. The inadequate rest and fatigue were attributed to the time spent caring for infants during the routine and time spent travelling from lodging facilities to the NICU. The findings were also similar to the parental routine described in Mahwasane et al's (2023) study, in which parents participated in infant care. According to the study, the parental routine led to sleep deprivation, exhaustion and fatigue for parents caring for their neonates. Both these studies were conducted in South Africa and illustrate a recurring pattern regarding the implications of parental involvement and participation in these settings.

Notably, some participants perceived mothers as worsening the existing high workload experienced by professional nurses. This was also attributed to the lack of sleep experienced by mothers in the NICU. Participants indicated that mothers required close supervision as mothers would fall asleep while holding their neonates. This increased nursing duties and the risk of medico-legal events which the participants believed they would be accountable for. Mahwasane et al.'s (2023) study had similar findings in which nurses had to closely monitor mothers during neonatal care. Mothers were found obstructing the nasal passages of the neonates. Additionally, Vittner et al's (2022) nurse participants confirmed that neonatal care was already a difficult task to complete, and that involving families increased the nursing workload.

Participants also outlined other challenges in involving mothers in neonatal care, particularly related to the NICU environment. According to participants, the NICU faces space constraints caused by overcrowding of patients, mothers and healthcare professionals. Mothers and neonates are reportedly “squeezed” in to accommodate them. According to Kokorelias et al. (2019), the development of FCC facilities should be created with consideration of both patients and families. The limited space does not adequately support families’ involvement.

Lastly, fathers are reported to have limited involvement in the care of the neonate because of the unit restrictions on family visitations. Fathers are reportedly allowed to visit the neonate once during the neonatal period. While some participants viewed this restriction as deprivation of the father-neonate bond and attachment, others viewed it as necessary to minimise hospital acquired infections and mitigate pre-existing space constraints. Regardless, to implement FCC in the NICU, father involvement is required.

Lack of father involvement in NICU is a common theme even in current literature. Additionally, even when involved, fathers are not as supported by nurses as mothers (Konukbay, Vural & Yildiz, 2024). This can also be observed in Participant 16's statement that fathers will bond with their neonates after discharge. The mother was regarded as more important than the father.

The current study findings conveyed positive perceptions regarding mothers’ involvement in the care of their neonates. However, perceived challenges, such as the exposure and supervision of sleep-deprived, and emotionally unwell mothers, created a negative perception among participants. Environmental constraints and father visitation limitations also led to negative perceptions about involving families in the NICU.

5.4.3 Theme 3: Impact of working challenges on professional nurses’ physical and mental health

The unit is described as overcrowded and understaffed, which is linked to the high nursing workload. NICU is known to have a higher workload compared to other ICUs as neonates have a higher dependency on nurses to perform activities of daily living

(Azadi et al., 2020). Even though participants did not describe their experiences as burnout, long-term physical and psychological affliction can lead to burnout. Moreover, burnout has a high occurrence among neonatal nurses due to the physical and emotional demands of the work (Carton, Steinhardt & Cordwell, 2022).

Participants verbalised experiencing physical ailments such as back pain and swollen feet because of high nursing workload. Back pain is a prevalent occupational musculoskeletal clinical manifestation in nurses, largely due to physically demanding hours and patient handling (Tariq et al., 2023). Swollen feet are also associated with nurses due to prolonged standing (Bernardes et al., 2023). The participants also verbalised fatigue and exhaustion due to the work demands in the unit.

The ailments along with fatigue correspond with the findings of Banda, Simbata and Mula (2022) in their study of the effects of high nursing workload in ICUs in Malawi. The high workload experienced by the nursing participants led to physical illness. Participants in the Malawian study reported continuous exhaustion and body pains inclusive of aching leg, which correlates with the experiences of participants in the current study. Similarly, participants in the Malawian study also felt that the quality of care rendered was negatively affected by the increased workload in the units.

In terms of psychosocial health, the findings showed that participants equated psychosocial health to the psychological and staffing support provided by the health care institution. The findings revealed a perceived lack of institutional support for the professional nurses. Also, more than not, participants reported that the hospital does not offer psychological support for the professional nurses. In cases where psychological support was offered and conveyed by participants, the high nursing workload in the NICU acted as a barrier to receiving support.

According to Zhou et al. (2022), psychological support for nurses was positively linked to alleviating stress and pressure caused by heavy workloads. The absence of such support may exacerbate stress and increase pressure in the NICU. Additionally, Flaubert et al. (2021) adds that a lack of psychological support heightens the

established risk of ICU nurses developing Post Traumatic Stress Disorder (PTSD), anxiety, depression, and burnout due to repeated exposure to traumatic events.

Contrary to the assumption that nurses are at risk of compassion fatigue as they are exposed to critically ill patients, participants still appeared to be emotionally impacted by traumatic events, such as severe illness and death, experienced in the NICU. Even so, long-term exposure to such events can lead to compassion fatigue (Kutahyalioglu et al., 2022).

In FCC and nursing care, nurses are often the mediators and facilitators of care models and the delivery of care. Nurse involvement in these care models is positively associated with increased FCC practices and parental support and satisfaction in the NICU (Loutfy et al., 2024). However, in this study, the mediators and facilitators experienced emotional and physical strains because of the high nurse-patient ratios and unlimited bed capacity. Participants reported being overwhelmed, with no institutional support. Effective implementation of FCC will not occur when the mediators and facilitators of FCC are not well enough to render care.

The findings expand the body of knowledge, as FCC often focuses on the wellbeing of the mothers and the rest of the family system. However, the wellbeing of nurses rendering family integrated care in low resourced settings has not been studied.
Therefore, this study provides valuable insight into professional nurse wellbeing in a South African NICU with prevalent nurse-patient ratios and staff shortages.

5.5 CONCLUSION

This chapter presented the research findings from the Phase Two data collection process, which involved individual semi-structured interviews with professional nurses working at a regional NICU. The findings were categorised into appropriate themes, with raw data being represented through participant quotes from the individual interviews. Chapter Six is the concluding chapter encompassing an overview of the study, evaluation of the study findings as per comparative analysis of Phase One and Phase Two data collection. Chapter Six also describes the implications to practice, recommendations from findings and limitations related to the study.

CHAPTER SIX: STUDY OVERVIEW, EVALUATION OF THE FINDINGS, IMPLICATIONS TO PRACTICE, RECOMMENDATIONS AND LIMITATIONS OF THE STUDY

6.1 INTRODUCTION

The experiences of mothers and professional nurses in the NICU profoundly shape neonatal care, yet a persistent gap exists in understanding their differing perspectives. This chapter bridges that gap by comparatively analysing these viewpoints, revealing critical insights for improving family-centred care. This chapter will first present a comparative analysis of mothers' and nurses' experiences, then discuss implications for practice, make recommendations and conclude with the limitations observed during the study.

6.2 OVERVIEW OF STUDY

The study aimed to describe the experiences of mothers and nurses regarding the implementation of care-by-parent interventions at a regional NICU in Gauteng. This was achieved through a qualitative descriptive research design. Additionally, an inductive and interpretivist approach was employed to gather new knowledge regarding the phenomenon, particularly the experiences, meanings, beliefs, values and ideas associated with mothers' involvement in the care of their neonates in the NICU.

A qualitative descriptive study design was implemented in two phases, with each phase employing a distinct method of data collection. Phase One focused on the experiences of mothers involved in the care of their neonates admitted to a regional NICU. Thirty-three (n = 33) participants were purposively sampled according to the inclusion criteria and focus group discussions (FGD) were conducted. Data saturation was reached after six (6) FGDs.

Phase Two explored the experiences of professional nurses regarding mothers' involvement in the care of their neonates admitted to a regional NICU. Seventeen (n = 17) participants were sampled using total sampling. Seventeen (17) semistructured

individual interviews were conducted by the researcher until data saturation was achieved.

The data collected from Phases One and Two were analysed using thematic analysis. Specifically, the researcher employed Creswell's method of data analysis. Major themes were identified and presented separately for each phase.

Phase one and two elicited varying responses regarding the experiences of mothers and nurses regarding the implementation of care-by-parent interventions at a regional NICU in Gauteng, however both mothers and professional nurses shared similar experiences.

6.3 EVALUATION OF STUDY FINDINGS: COMPARATIVE ANALYSIS

6.3.1 Perceived maternal roles in the NICU

The findings revealed that mothers in the NICU were primarily limited to basic caregiving tasks, such as feeding and diaper changes, with little decision-making power. They felt secondary to the care team and perceived a lack of partnership with professional nurses, reinforced by inadequate information sharing. Care team refers to the healthcare professionals caring for neonates in the NICU.

Professional nurses confirmed this perception, similarly, viewing mothers as assistants rather than active participants in neonatal care. Some professional nurses attributed mothers' limited involvement to cultural and religious biases that conflicted with medical practices, seeing their inclusion in decision-making as potentially contentious. While a few professional nurses acknowledged mothers as part of the care team, their influence remained restricted to feeding choices and procedural consent. Professional nurses also cited high workloads as a barrier to information sharing. This disconnect contradicts Family- Centred Care (FCC) principles, which emphasise parental collaboration in neonatal care, including participation in rounds and decision-making (Harrison, 1993).

The shared view of mothers and professional nurses that maternal roles in the NICU are limited to basic caregiving highlights a systemic undervaluation of mothers as active partners in neonatal care. Despite Family-Centred Care principles, the NICU

environment may reinforce a hierarchy where medical expertise overshadows parental input, undermining maternal confidence and the mother-infant bond. Professional nurses' attribution of limited maternal involvement to cultural or religious biases risks devaluing diverse parenting approaches and neglecting opportunities for culturally sensitive care. Addressing this requires re-evaluating NICU practices to ensure mothers are genuinely involved and valued in their child's care.

6.3.2 Perceptions related to paternal involvement in the NICU

Findings from both mothers and professional nurses highlighted a stark disparity in paternal involvement in neonatal care. Fathers were allowed only one five-minute visit to the NICU and were sometimes not permitted to hold their neonates. Mothers saw this restriction as a barrier to paternal bonding and a missed opportunity to share caregiving responsibilities, leading some to attempt additional visits, only to be reprimanded.

Most professional nurses also viewed these restrictions as detrimental to paternal bonding, though a few justified them by citing infection risks and space constraints, despite evidence showing no significant increase in infections with parental involvement (Lv et al., 2019; Reiter et al., 2022).

Both mothers and most professional nurses advocated for increased paternal involvement, citing benefits for the father, mother, and neonate. Greater father participation in neonatal care is linked to lower rates of paternal and maternal postpartum depression, stronger paternal attachment, and improved neonatal outcomes, including better weight gain, cardiac stability, and thermoregulation (CajiaoNieto et al., 2021; Mancini, 2023).

6.3.3 Perceived communication barriers in the NICU

The findings revealed inadequate and inconsistent communication practices between professional nurses and mothers in the NICU. Mothers reported receiving little to no information regarding the progression of their neonates' wellbeing, as well as the procedures and equipment used in their care. Mothers also reported little to no active and timely updates from professional nurses regarding neonatal changes and procedures. Some mothers stated that they were scolded when approaching

professional nurses for information, which exacerbated their communication challenges and caused them to fear approaching professional nurses for updates.

The lack of information sharing was identified as the primary contributor to a discomforting experience in the NICU and often led to emotional distress, including feelings of depression. This lack of communication also reinforced mothers' perception of their roles in the NICU as insignificant. Moreover, the lack of timely updates to mothers resulted in other family members, including the father, uninformed about the neonates' progress.

Professional nurses had mixed opinions on the communication practices in the NICU. Some contradicted the statements from mothers, indicating that there were open communication channels and that mothers were regularly informed about their neonates' health status. However, other professional nurses acknowledged that improvements were needed. They admitted that they largely focused on neonatal wellbeing, with communication with mothers being secondary. Some professional nurses viewed communication with mothers as limited to conversations regarding neonatal feedings and diaper changes. Other professional nurses recognised that the lack of communication was indicative of a lack of support for mothers, aligning with the mothers' perceptions that if professional nurses were supportive, greater efforts to share information would occur.

Language barriers were also identified by professional nurses as a hindrance to effective communication. Mothers with language barriers were perceived as requiring extra effort and were often excluded from care skills training. Instead, professional nurses performed care-by-parent interventions on their behalf to avoid potential misunderstandings.

Both mothers and professional nurses agreed that communication in the NICU was inconsistent. Mothers felt that the inconsistencies stemmed from the lack of active information sharing, whereas professional nurses believed that mothers were well informed but acknowledged that communication could be improved. Professional nurses also acknowledged that discussions about mothers' emotional and social wellbeing were often overlooked, with the focus largely on neonatal care. This lack of communication regarding maternal wellbeing was perceived by professional nurses as neglect of the mothers' emotional and social needs in the NICU. This suggests that the

largest contributor to a discomforting maternal experience was not always recognised by the professional nurses.

Furthermore, professional nurses attributed the limited communication exchange experienced in the NICU to the high nursing workload. This aligns with the findings from Negarandeh et al. (2021) where the nursing workload was described as a barrier to providing maternal support in the NICU, including providing information to mothers.

Effective communication between HCPs and parents in the NICU is linked to reduced parental stress, increased NICU adaptability, high perceived parent-provider partnership and empowerment in parental roles and skills. Conversely, negative communication experiences are associated with feelings of anger, guilt, self-blame and hopelessness among parents (Labrie et al., 2021). As seen in the current findings, lack of communication negatively significantly impacts maternal wellbeing.

6.3.4 Perception of nurse-mother relationships in the NICU

Findings revealed inconsistent and inadequate communication between professional nurses and mothers in the NICU. Mothers reported receiving little to no updates on their neonates' progress, procedures, or equipment used, often fearing reprimand when seeking information. This lack of communication caused emotional distress, reinforced their feelings of insignificance, and left other family members uninformed.

Professional nurses had mixed views, some believed communication was sufficient, while others admitted it was secondary to neonatal care. Many saw discussions with mothers as limited to feeding and diaper changes, with little focus on maternal emotional wellbeing. Language barriers further excluded some mothers from care training, as professional nurses preferred to perform tasks themselves to avoid misunderstandings.

Both groups agreed communication was inconsistent. While mothers saw it as a lack of active information sharing, professional nurses attributed it to high workloads, aligning with findings by Negarandeh et al. (2021). Poor communication in the NICU is linked to parental distress, reduced adaptability, and weakened parent-provider partnerships (Labrie et al., 2021), highlighting its critical impact on maternal wellbeing.

6.3.5 Emotional and psychological stress experienced by mothers and professional nurses in the NICU

Findings revealed that both mothers and professional nurses in the regional hospital NICU experienced significant emotional and psychological stress. Mothers reported anxiety, depression, and distress linked to the unit's routine, their child's illness, and their limited involvement in care. Similarly, professional nurses found their work overwhelming, with childless professional nurses particularly affected by exposure to critically ill neonates. The NICU environment, daily routine, and overall atmosphere negatively impacted both groups.

Mothers with other children at home faced additional stress due to rigid hospital lodging policies, leaving them unable to provide care for their families. Some worried about their children's wellbeing while they remained in the NICU, exacerbating their emotional strain. Professional nurses empathised but cited past maternal abscondment as a barrier to flexible policies.

While some mothers initially expected a supportive NICU environment, many felt a lack of nurse support, which they equated with information sharing, emotional reassurance, and assistance with care. This contrasts with professional nurses' belief that increased communication alone constituted adequate support. Some professional nurses acknowledged that maternal wellbeing was often overlooked due to the priority placed on neonatal care and the demands of a high workload.

Professional nurses also reported insufficient institutional support, particularly a lack of psychosocial resources and heavy workloads that limited access to available assistance. Overall, the study highlighted the need for enhanced support systems: nurse support for mothers and institutional support for professional nurses, to mitigate the emotional strain experienced by both groups.

6.3.6 High workload experienced by mothers and professional nurses in their duties in the NICU

Both mothers and professional nurses in the NICU faced overwhelming workloads, negatively impacting their wellbeing and the quality of neonatal care. Professional nurses described mothers as fatigued and struggling with care-by-parent tasks, a

sentiment mothers echoed, citing exhaustion and physical ailments like headaches and high blood pressure.

Professional nurses also reported excessive workloads, largely due to overcrowding, often operating beyond capacity. Likewise the high workload also impacted the professional nurses' physical wellbeing with ailments such as fatigue, back aches and swollen feet. The high workload led to prioritising paperwork and medical tasks over maternal and neonatal care. To compensate, professional nurses relied heavily on mothers for feeding and diaper changes, with some admitting that without mothers, these tasks would be omitted.

Mothers, in turn, feared their infants would be neglected if they weren't present — not just due to the high nursing workload but also a lack of trust in professional nurses' commitment to care. The perceived absence of support reinforced maternal concerns about both their own wellbeing and their neonates' care.

The findings reveal a shared experience of overwhelming workloads and inadequate support for both mothers and professional nurses in the NICU, negatively affecting wellbeing and care quality. Mothers struggled with the physical and emotional demands of care-by-parent tasks, while professional nurses faced high workloads due to overcrowding and time constraints, leading to a reliance on mothers to perform essential caregiving duties. This created a cycle of mistrust, where mothers feared their infants would be neglected in the absence of their involvement, while professional nurses struggled to balance administrative duties with patient care. Ultimately, the lack of support for both groups highlighted the need for better resource allocation and a more balanced approach to caregiving in the NICU.

6.4 IMPLICATIONS FOR NURSING PRACTICE

In resource-limited settings, parental involvement in neonatal care can place significant physical and emotional strain on mothers due to an over-reliance on their participation in routine neonatal care. Studies conducted in similar settings highlight that mothers and primary caregivers often experience fatigue and distress due to prescribed caregiving responsibilities (Mahwasane et al., 2023; Nyaloko et al., 2024). To mitigate this, healthcare providers should offer mothers the choice to lodge at the hospital or

stay at home, reducing dependency on maternal involvement and creating a stronger case for increased professional nurses to maintain optimal nurse-patient ratios.

While parental involvement in neonatal care can alleviate certain aspects of the nursing workload, such as feeding, diaper changes, and administering basic medication also inadvertently contributes to higher nurse-patient ratios in the regional NICU. Although this practice allows for task-sharing, the high nurse-patient ratios are associated with compromised quality of care, increased risk of medical errors, hospital-acquired infections, and higher patient mortality rates. Additionally, nurses working under such conditions often experience heightened stress, anxiety, and burnout (Azadi et al., 2020).

The high workload in NICUs also impacts the level of support provided to mothers during neonatal admission. The findings indicate that mothers often feel unsupported, citing inadequate information sharing, limited emotional support, and insufficient guidance in care-by-parent interventions. Given that effective nurse support is a cornerstone of family-centred care (FCC) and maternal wellbeing, reducing the nursing workload could enhance the quality of support provided to mothers, thereby improving their overall experience and confidence in neonatal care.

Furthermore, the study highlights that inadequate institutional support negatively affects professional nurses' physical and emotional wellbeing. Providing active and timely psychological support for professional nurses, particularly those in critical care areas like NICUs, is essential for sustaining nurse mental health and job performance. Institutions must acknowledge and address the impact of high nursing workloads on nurse wellbeing, ensuring that professional nurses receive the necessary resources and support to maintain both patient care standards and their own professional sustainability. This includes maintaining manageable nurse-to-patient ratios by providing additional human resources.

The study also illustrates inadequate institutional support and consideration for mothers in terms of creating a therapeutic and supportive environment. As outlined under the FCC principles, a supportive environment is one that accommodates parents in terms of space, time, needs and presence (Harrison, 1993; Soni & Tscherning, 2020). Therefore, institutions should be actively involved in the creation and maintenance of such spaces.

6.5 RECOMMENDATIONS

6.5.1 Recommendations for nursing education

- Establish structured FCC training programs for NICU professional nurses to enhance family involvement in care. This training should emphasise effective information sharing, parental participation, collaboration, and emotional support for families.

- Provide ongoing professional development in patient- and family-centred communication to improve interactions between professional nurses and mothers in the NICU. This will ensure consistent, compassionate, and effective communication, fostering trust and collaboration.

- Integrate cultural competency training into nursing education to equip NICU professional nurses with the skills needed to understand, respect, and address the diverse cultural needs of families. This will help minimise disparities in care and enhance patient-centred approaches.

- Provide education and training on identifying, screening, and addressing maternal stress and mental health challenges. Early detection of postpartum psychological conditions, such as anxiety, depression, and trauma will enable timely interventions. Additionally, this training should include social service screening for mothers facing challenges due to neonatal hospitalisation, such as unattended children at home.

6.5.2 Recommendations for nursing policy development

- Establish policies to reduce nurse-to-patient ratios in the NICU by ensuring alignment with the guidelines for the provision of critical care services in South Africa; the Critical Care Society of Southern Africa (2022) recommends a 1:1 nurse to patient ratios for ventilated patients and 1:2 for non-ventilated patients.

- Develop standardised communication guidelines for communication between the NICU and families. These guidelines should ensure consistent information sharing and regular updates on neonatal wellbeing are provided to families.

- Establish policies on the role of families in the NICU outlining the mothers' role and responsibilities in the NICU, including the expected level of participation. These policies should align with the principles of FCC for safe and ethical implementation of parental involvement: communication and information sharing; respect and dignity; collaboration; participation/involvement and a supportive environment (Harrison, 1993).

- Revise and extend visitation policies to provide fathers and family members access to neonates. Additionally, offer an opportunity for fathers and other family members to engage with HCPs and ask questions.

6.5.3 Recommendations for nursing research

- Research strategies to better integrate mothers into the NICU, focusing on their involvement in decision-making and information sharing. Studies should explore how this integration impacts maternal satisfaction and neonatal outcomes.

- Investigate the effects of more frequent and longer paternal visits in the NICU, focusing on neonatal bonding, maternal stress, and family dynamics. Research should also address potential barriers such as infection control and space limitations.

- Identify best practices for communication between professional nurses and mothers in the NICU, including protocols for regular updates on neonatal health and emotional support. Studies should examine the impact on maternal mental health and trust in healthcare providers.

- Explore interventions to reduce emotional and psychological stress for both mothers and professional nurses, such as psychological support services and stress management programmes. Research should assess the effectiveness of these interventions on wellbeing and stress reduction.

- Investigate how institutions can better support both professional nurses and mothers by improving nurse-to-patient ratios, providing psychosocial support for professional nurses, and creating a therapeutic environment for mothers. Studies should evaluate the impact of these measures on nurse burnout, care quality, and maternal satisfaction.

6.6 LIMITATIONS OF THE STUDY

- Due to participants' high workloads and time constraints, the researcher was unable to conduct focus group discussions (FGDs) in Phase Two. Instead, semi-structured individual interviews were conducted, offering flexibility and detailed personal accounts. However, FGDs could have provided a more dynamic platform for discussion, encouraging participants to build on each other's insights, challenge differing viewpoints, and reflect on shared challenges. This collaborative approach would likely have led to a richer, more comprehensive exploration of care-by-parent interventions.

- Total population sampling was employed in Phase Two due to the small number of professional nurses who met the inclusion criteria. The population consisted of twenty-six (N = 26) professional nurses, including the operational unit manager and two community service professional nurses. Seventeen professional nurses were interviewed based on the inclusion criteria and willingness to participate in the study. Even though total population sampling was employed, some potential participants were not able to participate, which may have excluded diverse perspectives and experiences that could have further enriched the study.

- For phase two, the study sampled and collected data solely from professional nurses working in the NICU. The professional nurses are the vast majority of nurses in the unit and the only ones nursing neonates requiring intensive care. This meant that other populations such as enrolled nurses in the unit were not eligible to participate in the study as they did not nurse neonates requiring intensive care and their mothers. Involving enrolled nurses could have added a richer and comprehensive perspective on care-by-parent interventions in less critical areas of neonatal care.

- The study was conducted at a single regional NICU in Gauteng, limiting the generalisability of findings to other NICU settings within the province.

- Additionally, the researcher was employed as a professional nurse at the study site during data collection. This dual role may have introduced potential bias,

particularly selection bias. In addition, the familiarity between the researcher and participants may have influenced participants' responses as they may have been more or less willing to share certain experiences or opinions.

- Moreover, the researcher being employed as a professional nurse at the study site could have imposed power balances, particularly for the phase one data collection involving mothers whose neonates have been admitted at the study site. However, the researcher did receive consent from relevant stakeholders including the unit manager of the NICU. Additionally, a research assistant non-affiliated with the study site was present in all focus group discussions. These actions were done to limit potential power imbalance. Participants were also provided with information sheets outlining the ethical considerations such as informed consent and confidentiality and should participants believe the researcher was operating unethically participants could contact the Human Ethics Department at the University of Witwatersrand.

6.7 CONCLUSION

Even though FCC is widely applied and advocated worldwide, its application in resource-limited neonatal intensive care units (NICUs) remains underexplored. Moreover, its application in these settings has been observed to cause unfavourable effects on the emotional, psycho-social and physical wellbeing of the parents, primarily mothers, and the nurses caring for the neonates. Therefore, the study offered insights on the experiences of mothers and professional nurses at a regional hospital NICU, furthermore these experiences may assist in informing new polices related to family-centred care in South Africa.

REFERENCE LIST

Abukari, A.S. and Schmollgruber, S. (2024). Perceived barriers of family-centred care in neonatal intensive care units: A qualitative study, Nursing in Critical Care, 29(5), 905–915. Available at: https://doi.org/10.1111/nicc.13031

Akyildiz, S.T. and Ahmed, K.H. (2021). An Overview of Qualitative Research and Focus Group Discussion. *International Journal of Academic Research in Education*. 7(1), p.1–15.

Altimier, L.B. and White, R.D. (2019). The Neonatal Intensive Care Unit (NICU) environment, In: Kenner, C. and Lott, J.W. eds. Comprehensive Neonatal Nursing Care, New York: Springer Publishing, pp. 722-738. Retrieved from: https://doi.org/10.1891/9780826139146.0032.

Altobelli, E., Angeletti, P.M., Verrotti, A., et al. (2020). The Impact of Human Milk on Necrotizing Enterocolitis: A Systematic Review and Meta-Analysis. *Nutrients*. 12(5), p.1322.

Alsadaan, N., Ramadan, O.M.E., Alqahtani, M., et al. (2023). Impacts of Integrating Family-Centered Care and Developmental Care Principles on Neonatal Neurodevelopmental Outcomes among High-Risk Neonates. *Children*. 10(11), p.1751. Available at: https://doi.org/10.3390/children10111751.

Amiri, E., Ebrahimi, H., Areshtanab, H.N., et al. (2020). The Relationship between Nurses' Moral Sensitivity and Patients' Satisfaction with the Care Received in the Medical Wards. *Journal of Caring Sciences*. 9(2), p.98–103. Available at: https://doi.org/10.34172/jcs.2020.015.

Armond, A.C.V., Cobey, K.D. and Moher, D. (2024). Key concepts in clinical epidemiology: Research Integrity definitions and challenges. *Journal of clinical epidemiology*. 171, p.111367–111367. Available at: https://doi.org/10.1016/j.jclinepi.2024.111367.

Azadi, M., Azimian, J., Mafi, M., et al. (2020). Evaluation of Nurses' Workload in the Intensive Care Unit, Neonatal Intensive Care Unit and Coronary Care Unit: An

Analytical Study. *Journal of Clinical and Diagnostic Research*. 14(11), p. 5-7. Available at: https://doi.org/10.7860/jcdr/2020/44824.14181.

Bamm, E.L. and Rosenbaum, P. (2008). Family-centered theory: Origins, development, barriers, and supports to implementation in rehabilitation medicine. *Archives of Physical Medicine and Rehabilitation.* 89(8), p. 1618–1624. Available at: https://doi.org/10.1016/j.apmr.2007.12.034.

Banda, Z., Simbota, M. and Mula, C. (2022). Nurses' perceptions on the effects of high nursing workload on patient care in an intensive care unit of a referral hospital in malawi: A qualitative study. *BMC Nursing.* 21(1). Available at: https://doi.org/10.1186/s12912-022-00918-x.

Bernardes, R.A., Caldeira, S., Parreira, P., et al. (2023). Foot and Ankle Disorders in Nurses Exposed to Prolonged Standing Environments: A Scoping Review. *Workplace Health & Safety.* 71(3), p. 101-116. Available at: https://doi.org/10.1177/21650799221137646.

Bowlby, J., Robertson, J. and Rosenbluth, D. (1952). A Two-Year-Old Goes to Hospital. *The Psychoanalytic Study of the Child.* 7(1), p. 82–94. Available at: https://doi.org/10.1080/00797308.1952.11823154.

Bowlby, J. (1953). Some pathological processes set in train by early mother-child separation, Journal of Mental Science, 99(415), 265–272.

Botma, Y., Greeff, M., Mulaudzi, F.M., et al. (2022). *Research in Health Sciences* 2nd edition. Cape Town: Pearson Holdings Southern Africa.

Brodsgaard, A., Thise, J., Larsen, P., et al. (2019). Parents' and Nurses' Experiences of Partnership in Neonatal Intensive Care Units: A Qualitative Review and MetaSynthesis. *Journal of Clinical Nursing.* 28, p. 3117-3139.

Cacciattolo, M. (2015) Ethical considerations in Research. In: eds. *The Praxis of English Language Teaching and Learning (PELT).* Location: Publisher, pp. 61–79. doi:10.1007/978-94-6300-112-0_4.

Cajiao-Nieto, J., Torres-Giménez, A., Merelles-Tormo, A., et al. (2021). Paternal symptoms of anxiety and depression in the first month after childbirth: A comparison between fathers of full term and preterm infants. *Journal of Affective Disorders*. 282, p. 517–526. Available at: https://doi.org/10.1016/j.jad.2020.12.175

Carton, A.M., Steinhardt, K. and Cordwell, J. (2022). Exploring factors which contribute to the resilience of nurses working in the neonatal care unit: A grounded theory study. *Intensive and Critical Care Nursing. 68,* p.103137.

Chappell, M.T., Kelly, C. and Rosenthal, K.S. (2021). Why Is a Child Not a Mini adult for Infections?. *Infectious Diseases in Clinical Practice*. 29(3), p. e169–e173. Available at :https://doi.org/10.1097/ipc.0000000000001012.

Chibabhai, V., Bekker, A., Black, M., et al. (2023). Appropriate use of colistin in neonates, infants and children: Interim guidance. *Southern African Journal of Infectious Diseases.* 38(1), p. 555. Available at: https://doi.org/10.4102/sajid.v38i1.555

Chapko, H., et al. (2022). Implementation of a nurse-led family centered engagement intervention for caregivers of extremely premature infants in the neonatal intensive care unit. *Journal of Neonatal Nursing*. 28(5), p. 365–367.

Collins, C.S. and Stockton, C. (2022) The theater of qualitative research: The role of the researcher/actor, International Journal of Qualitative Methods. 21, 1-9. doi:10.1177/16094069221103109.

Coyne, I., Murphy, M., Costello, T., et al. (2013). A Survey of Nurses' Practices and Perceptions of Family-Centered Care in Ireland. *Journal of Family Nursing*. 19(4), p. 469–488. Available at :https://doi.org/10.1177/1074840713508224.

Coyne, I. (2015). Families and health-care professionals' perspectives and expectations of family-centred care: hidden expectations and unclear roles. *Health Expectations.* 8(5), p. 796–808. Available at: https://doi.org/10.1111/hex.12104

Creswell. J.W. and Creswell, J.D. (2017) *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches* 4th Edition. Newbury Park: Sage.

Creswell, J.W. and Creswell, J.D. (2022). *Research design: Qualitative, quantitative, and Mixed Methods Approaches* 6th Edition. SAGE Publications.

Critical Care Society of Southern Africa. (2022). Critical Care Society of Southern Africa Guidelines for the Provision of critical care services in South Africa. *Critical Care Society of Southern Africa.* Available at: https://criticalcare.org.za/wpcontent/uploads/2022/07/CCSSA-guidelines-final.pdf [Accessed 21 Mar. 2025].

Crowley, T. and Daniels, F. (2023). Nursing education reform in South Africa: Implications for postgraduate nursing programmes. *International Journal of Africa Nursing Sciences.* 18, p. 100528. Available at: https://doi.org/10.1016/j.ijans.2023.100528.

Davies, R. (2010). Marking the 50th anniversary of The Platt Report: From exclusion, to toleration and parental participation in the care of the hospitalized child. *Journal of Child Health Care.* 14(1), p. 6–23. Available at: https://doi.org/10.1177/1367493509347058.

Dickinson, C., Vangaveti, V. and Browne, A. (2022). Psychological impact of Neonatal Intensive Care Unit admissions on parents: A regional perspective. *Australian Journal of Rural Health.* 30(3), p. 373–384. Available at: https://doi.org/10.1111/ajr.12841.

Doyle, L., McCabe, C., Keogh, B., et al. (2020). An Overview of the Qualitative Descriptive Design within Nursing Research. *Journal of Research in Nursing*. 25(5), p.443–455. Available at: https://doi.org/10.1177/1744987119880234.

Dressler, C. (2024). The psychological implications of having an infant in the NICU for mothers and fathers. *Journal of Neonatal Nursing*. 30(5), p. 467-469. Available at: https://doi.org/10.1016/j.jnn.2024.01.005.

Fernandez, S.B., Ahmad, A., Beach, M.C., et al. (2024). How patients experience respect in healthcare: findings from a qualitative study among multicultural women living with HIV: BMC medical ethics. *BMC medical ethics.* 25(1), p. 39. Available at: https://doi.org/10.1186/s12910-024-01015-1.

Flaubert, J.L., Menestrel, S.L., Williams, D.R., et al. (2021). Supporting the Health and Professional wellbeing of Nurses. *National Academies Press*. Available at: https://www.ncbi.nlm.nih.gov/books/NBK573902/.

Franck, L.S. and O'Brien, K. (2019). The evolution of family-centered care: From supporting parent-delivered interventions to a model of family Integrated Care. *Birth Defects Research.* 111(15), p. 1044–1059. Available at: https://doi.org/10.1002/bdr2.1521.

Ghorbani, F. and Jabraeili, M. (2022). Beliefs and attitudes of nurses towards open visiting policy in neonatal intensive care units: A descriptive cross-sectional study in northwest of Iran. *Journal of Neonatal Nursing.* 28(2), p. 123-129.

Gibbs, D.P., Boshoff, K. and Stanley, M.J. (2016). The acquisition of parenting occupations in neonatal intensive care: A preliminary perspective. *Canadian journal of occupational therapy.* 83(2), p. 91–102. Available at: https://doi.org/10.1177/0008417415625421

Goga, A., Feucht, U., Pillay, S., et al. (2021). Parental access to hospitalised children during infectious disease pandemics such as COVID-19. *South African Medical Journal.* 111, p. 100-105.

Govindaswamy, P., Laing, S., Spence, K., et al. (2023). Do neonatal nurses' perceptions agree with parents' self-reported needs and stressors in a surgical neonatal intensive care unit? *Journal of Neonatal Nursing.* 29(1), p. 149–157. Available at: https://doi.org/10.1016/j.jnn.2022.04.006.

Gul, P. and Hulya, E. (2020). Experiences of New Mothers with Premature Babies in Neonatal Care Units: A Qualitative Study. *Journal of Nursing and Practice.* 3(1). Available at: https://doi.org/10.36959/545/381.

Hall, S. and Liebenberg, L. (2024). Qualitative description as an introductory method to qualitative research for master's-level students and research trainees. *International Journal of Qualitative Methods*. 23(1), p. 1–5. Available at: https://doi.org/10.1177/16094069241242264

Harrison, H. (1993). The principles of family-centered neonatal care. *Pediatrics*. 92(5), p. 643-650. Available at: https://doi.org/10.1542/peds.92.5.643

Harrison, T.M. (2010). Family-centered pediatric nursing care: State of the science. *Journal of Pediatric Nursing*. 25(5), p. 335–343. Available at: https://doi.org/10.1016/j.pedn.2009.01.006.

Havenga, Y. and Sengane, M.L. (2018). Challenges experienced by postgraduate nursing students at a South African university. *Health SA Gesondheid*, 23, p. 1107 doi:https://doi.org/10.4102/hsag.v23i0.1107.

Institute for Patient and Family-Centered Care. (2024). *What is PFCC?* [online] Institute for Patient and Family Centered Care. Available at: https://www.ipfcc.org/about/pfcc.html. [Accessed 12 Jan. 2025].

Janvier, A., Asaad, M.-A., Reichherzer, M., et al. (2022). The ethics of family integrate[d care in the NICU: Improving care for families without causing harm. *Seminars in Perinatology.* 46(3), p. 151528. Available at: https://doi.org/10.1016/j.semperi.2021.151528

Kokorelias, K.M., Gignac, M.A.M., Naglie, G., et al. (2019). Towards a universal model of family centered care: A scoping review. *BMC Health Services Research*. 19(1), p. 1–11. Available at: https://doi.org/10.1186/s12913-019-4394-5

Konukbay, D., Vural, M. and Yildiz, D. (2024). Parental stress and nurse-parent support in the neonatal intensive care unit: a cross-sectional study. *BMC Nursing*. 23(1). Available at: https://doi.org/10.1186/s12912-024-02458-y.

Kraft, S.A., Rothwell, E., Shah, S.K., et al. (2020). Demonstrating 'respect for persons' in clinical research: findings from qualitative interviews with diverse genomics research participants. *Journal of Medical Ethics.* 47(12). Available at: https://doi.org/10.1136/medethics-2020-106440.

Kutahyalioglu, N.S., Scafide, K.N., Mallinson, K.R., et al. (2022). Implementation and Practice Barriers of Family-Centered Care Encountered by Neonatal Nurses. 22(5), p. 432-443. *Advances in Neonatal Care.* Available at: https://doi.org/10.1097/anc.0000000000000948.

Labrie, N.H.M., van Veenendaal, N.R., Ludolph, R.A., et al. (2021). Effects of parentprovider communication during infant hospitalization in the NICU on parents: A systematic review with meta-synthesis and narrative synthesis. *Patient Education and Counseling*. 104(7), p. 1526–1552. Available at: https://doi.org/10.1016/j.pec.2021.04.023.

Larocque, C., Peterson, W., Squires, J., et al. (2021). Family-centred care in the neonatal intensive care unit: a concept analysis and literature review. *Journal of Neonatal Nursing.* 27, p. 402-411.

Leavy, P. (2022). *Research Design: Quantitative, Qualitative, Mixed Methods, ArtsBased, and Community-Based Participatory Research Approaches* 2nd Edition. New York, NY: The Guilford Press.

Lee, J. (2023). Neonatal family-centered care: evidences and practice models. *Clinical and Experimental Pediatrics.* 67(4), p. 171-177 Available at: https://doi.org/10.3345/cep.2023.00367.

Lee, S.Y. and Hsu, H.C. (2012). Stress and health-related wellbeing among mothers with a low birth weight infant: The role of sleep. *Social Science & Medicine.* 74(7), p. 958–965. Available at: https://doi.org/10.1016/j.socscimed.2011.12.030

Lincoln, Y.S. and Guba, E.G. (1989). *Fourth generation evaluation*. Newbury Park: Sage.

Lorie, E.S., Wreesmann, W.W., van Veenendaal, N.R., et al. (2021). Parents' needs and perceived gaps in communication with healthcare professionals in the neonatal (intensive) care unit: A qualitative interview study. *Patient Education and Counseling.* 104(7), p.1518–1525. Available at: https://doi.org/10.1016/j.pec.2020.12.007.

Loutfy, A., Mohamed Ali Zoromba, Mai Adel Mohamed, et al. (2024). Family-centred care as a mediator in the relationship between parental nurse support and parental stress in neonatal intensive care units. *BMC Nursing*. 23(1). Available at: https://doi.org/10.1186/s12912-024-02258-4.

Lowe, N.K. (2019). What is a pilot study?. *Journal of Obstetric, Gynecologic & Neonatal Nursing*. 48(2), p. 117–118.

Lyndon, A., Jacobson, C.H., Fagan, K.M, et al. (2017). Parents' perspectives on safety in neonatal intensive care: a mixed-methods study. *BMJ Quality & Safety.* 23(11).

Lv, B., Gao, X., Sun, J., et al. (2019). Family-Centered Care Improves Clinical Outcomes of Very-Low-Birth-Weight Infants: A Quasi-Experimental Study. *Frontiers in Pediatrics*. 7. Available at: https://doi.org/10.3389/fped.2019.00138

Mahwasane, T., Netshisaulu, K.G., Malwela, T.N., et al. (2023). Support needs of parents with preterm infants at resource-limited neonatal units in Limpopo province: A qualitative study. *Curationis*. 46(1), p. 2409. Available at: https://doi. org/10.4102/curationis. v46i1.2409

Malepe, T.C., Havenga, Y. and Mabusela, P.D. (2022). Barriers to family-centred care of hospitalised children at a hospital in Gauteng. *Health SA Gesondheid.* 27.

Moloisane, M. (2018). Tshwane Metropolitan Municipality's responses to informal settlements : a case study of Mamelodi. Master's dissertation. *University of South Africa.* Available at: https://uir.unisa.ac.za/items/59f52982-8af9-44af-88348e60581a6137

Mancini, V.O. (2023). The role of fathers in supporting the development of their NICU infant. *Journal of Neonatal Nursing.* 29(5), p. 714-719. Available at: https://doi.org/10.1016/j.jnn.2023.02.008

Maria, A., Litch, J.A., Stepanchak, M., et al. (2021). Assessment of feasibility and acceptability of family-centered care implemented at a neonatal intensive care unit in India. *BMC Pediatrics.* 21(1), p. 171. Available at: https://doi.org/10.1186/s12887-02102644-w.

Mariano, K., Silang, J., Cui-RaMos, R., et al. (2022). Maternal stress and perceived nurse support among mothers of premature infants in the neonatal intensive care unit of a tertiary hospital in Qatar. *Journal of Neonatal Nursing*. 28, p. 98-102.

Meadow, S.R. (1969). The captive mother*. Archives of Disease in Childhood*. 44(235), p. 362–367. Available at: https://doi.org/10.1136/adc.44.235.362

Mehrpisheh, S., Doorandish, Z., Farhadi, R., et al. (2023). The effectiveness of Kangaroo Mother Care (KMC) on depression, anxiety, and stress of mothers with premature infants. *Journal of Neonatal Nursing.* 29(5), p. 786-790. Available at: https://doi.org/10.1016/j.jnn.2023.03.002

Miller, J.J., Serwint, J.R. and Boss, R.D. (2021). Clinician–family relationships may impact Neonatal Intensive Care: Clinicians' perspectives. *Journal of Perinatology.* 41(9), p. 2208–2216. Available at: https://doi.org/10.1038/s41372-021-01120-8.

Mohamed, S.A.A.K. and Shaban, M. (2024). Age and expertise: The effects of ageism on professional recognition for senior nurses, Geriatric Nursing, 60, 70–78. Available at: https://doi.org/10.1016/j.gerinurse.2024.08.045.

Moya-Salazar, J., Buitrón, L.A., Goicochea, E.A., et al. (2023). The Age of Young Nurses Is a Predictor of Burnout Syndrome during the Care of Patients with COVID-19. *Nursing Reports.* 13(2), p. 721–730.

Murphy, M.F., Harris, A. and Neuberger, J. (2021). Consent for blood transfusion: summary of recommendations from the Advisory Committee for the Safety of Blood, Tissues and Organs (SaBTO). *Clinical Medicine.* 21(3), p. 201–203. Available at: https://doi.org/10.7861/clinmed.2020-1035

Naeem, M., Ozuem, W., Howell, K., et al. (2024). Demystification and Actualisation of Data Saturation in Qualitative Research Through Thematic Analysis. *International Journal of Qualitative Methods.* 23(23). Available at: https://doi.org/10.1177/16094069241229777. Negarandeh, R., Hassankhani, H., Jabraeili, M., et al. (2021). Health care staff support for mothers in NICU: a focused ethnography study. *BMC Pregnancy and Childbirth*. 21(1), p. 520. Available at: https://doi.org/10.1186/s12884-021-03991-3.

Nyaloko, M.J., Lubbe, W., Moloko-Phiri, S.S., et al. (2024). Parental experiences of caring for preterm infants in the neonatal intensive care unit, Limpopo Province: a descriptive qualitative study exploring the cultural determinants. *BMC health services research*. 24(1), p. 669. Available at: https://doi.org/10.1186/s12913-024-11117-6.

Nyumba, T.O., Wilson, K., Derrick, C.J., et al. (2017). The use of focus group discussion methodology: Insights from two decades of application in conversation. *Methods in Ecology and Evolution*. 9, p. 20-32.

Oude Maatman, S.M., Bowlin, K., Lillieskold, S., et al. (2020). Factors influencing implementation of family-centered care in a neonatal intensive care unit. *Frontiers in pediatrics.* 8, p. 222. Available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7219204/ [Accessed: 7 Feb. 2023].

Phiri, P.G.M.C., Chan, C.W.H. and Wong, C.L. (2020). The scope of family-centred care practices, and the facilitators and barriers to implementation of family-centred care

for hospitalised children and their families in developing countries: An integrative review. *Journal of Pediatric Nursing.* 55(1), p. 10–28. Available at:

Prugh, D.G., Straub, E.M., Sands, H.H., et al. (1953). A study of the emotional reactions of children and families to hospitalization and illness. *American Journal of Orthopsychiatry*. 23(1), p. 70–106.

Rajabzadeh, Z., Moudi, Z., Abbasi, A., et al. (2021). The Effect of Family-Centered Educational Supportive Intervention on Parental Stress of Premature Infants Hospitalized in the NICU. *Medical - Surgical Nursing Journal.* 9(3). Available at: https://doi.org/10.5812/msnj.111847.

Razeq, N.M.A., Arabiat, D.H. and Shields, L. (2021). Nurses' perceptions and attitudes toward family-centered care in acute pediatric care settings in Jordan. *Journal of Pediatric Nursing.* 61, p. 207–212. Available at: https://doi.org/10.1016/j.pedn.2021.05.018

Reid, S., Bredemeyer, S. and Chiarella, M. (2021). The evolution of neonatal family-centred care. *Journal of Neonatal Nursing*. 27, p. 327-333.

Reiter, A., De Meulemeester, J., Kenya-Mugisha, N., et al. (2022). Parental participation in the care of hospitalized neonates in low- and middle-income countries: A systematic review and meta-analysis. *Frontiers in Pediatrics.* 10. Available at: https://doi.org/10.3389/fped.2022.987228

Robertson, J. (1952). A Two-Year-Old Goes to Hospital. [Film]. London: Tavistock Child Development Research Unit.

Rogers, A. and Nurse, S. (2019). Child Protection in the neonatal unit. *Journal of Neonatal Nursing.* 25(2), p. 99–101. Available at: https://doi.org/10.1016/j.jnn.2018.09.007

Sahni, M. and Mowes, A.K. (2023). Bronchopulmonary Dysplasia. [online] *PubMed*. Available at: https://www.ncbi.nlm.nih.gov/books/NBK539879/.

Sarin, E. and Maria, A. (2019). Acceptability of a family-centered newborn care model among providers and receivers of care in a Public Health Setting: a qualitative study

from India. *BMC Health Services Research.* 9(1). Available at: https://doi.org/10.1186/s12913-019-4017-1.

Saunders, M., Lewis, P. and Thornhill, A. (2019). Research Methods for Business Students. 8th ed. United Kingdom: Pearson.

Shetty, A.P., Halemani, K., Issac, A., et al. (2024). Prevalence of anxiety, depression, and stress among parents of neonates admitted to neonatal intensive care unit: a systematic review and meta-analysis. *Clinical and Experimental Pediatrics.* 67(2), p. 104–115. Available at: https://doi.org/10.3345/cep.2023.00486.

Shields, L. (2015). Family-centred care: the 'captive mother' revisited. *Journal of the Royal Society of Medicine.* 109(4), p. 137–140. Available at :https://doi.org/10.1177/0141076815620080.

Shokoane, M.A., Mogale, R.S. and Maree, C. (2023). Preparing for implementation of family-integrated neonatal care by healthcare providers in a district hospital of Limpopo Province. *International Journal of Africa Nursing Sciences*. 19, p. 100575. Available at: https://doi.org/10.1016/j.ijans.2023.100575.

Simpson-Collins, M., Fry, M., Sheppard-Law, S., et al. (2023). Parents' and nurses' perceptions and behaviours of family-centred care during periods of busyness. *Journal of Clinical Nursing*. 33 (2).

Smith, W. (2018). Concept analysis of family-centered care of hospitalized pediatric patients. *Journal of Pediatric Nursing*. 42, p. 57–64.

Soni, R. and Tscherning, C. (2020). Family-centred and developmental care on the neonatal unit. *Paediatrics and Child Health*. 31(1), p. 18-23 Available at: https://doi.org/10.1016/j.paed.2020.10.003.

Sousa, F. and Curado, M.A. (2022). Parental stress - the influence of hospital stay length and neonatal unit differentiation. *Journal of Nursing.* 26. Available at: https://doi.org/10.56732/pensarenf.v26isup.226.

South Africa. (2005). Nursing Act 33 of 2005. Pretoria: Government Printer.

South African Government (2024) Press statement on the release of the Final White Paper on Citizenship, Immigration and Refugee Protection: Towards a complete overhaul of the migration system in South Africa. [online] Available at: https://www.gov.za/news/media-statements/minister-aaron-motsoaledi-release-final-white-paper-citizenship-immigration [Accessed 17 July 2025].

South African Legal Information Institute. (2019). Regulations relating to categories of hospitals. South African Legal Information Institute. Available at: https://www.saflii.org/za/legis/consol_reg/rrtcoh462/ [Accessed 18 Jan. 2023].

South African Nursing Council. (2022). South African Nursing Council Provincial Distribution of Nursing Manpower Versus The Population of the Republic of South Africa. [online]. Available at: https://www.sanc.co.za/wp-content/uploads/2022/01/Stats-2021-1-Provincial-Distribution.pdf [Accessed 9 Oct. 2023].

Stahl, N. and King, J. (2020). Expanding Approaches for Research: Understanding and Using Trustworthiness in Qualitative Research. *Journal of Developmental Education*. 44, p. 26-28.

Stats SA. (2017). Public healthcare: How much per person? Statistics South Africa. [online]. Available at: https://www.statssa.gov.za/?p=10548

Suni, E. (2022). *Interrupted Sleep.* Sleep Foundation. Available from: https://www.sleepfoundation.org/sleep-deprivation/interrupted-sleep [accessed 17 Sep. 2022].

Tariq, R.A., George, J.S., Ampat, G., et al. (2023). Back Safety. *StatPearls*. StatPearls Publishing.

Taylor, K.D., McLaughlin, L., Kuehn, D., et al. (2020). The impact of parental presence in the NICU on hospital alienation and other distress measures. *Patient Experience Journal*. 7(3), p. 44-48.

The Welfare of Children in Hospital. (1959). British Medical Journal, 1(5115), 166–169.

Van Dokkum, N.H., de Kroon, M.L.A., Reijneveld, S.A., et al. (2021). Neonatal Stress,

Health, and Development in Preterms: A Systematic Review. *Pediatrics*. 148(4). Available at: https://doi.org/10.1542/peds.2021-050414

Varma, J., Nimbalkar, S., Patel, D., et al. (2019). The level and sources of stress in mothers of infants admitted in neonatal intensive care unit. *Indian Journal of Psychological Medicine.* 41(4), p. 338. Available at: https://doi.org/10.4103/ijpsym.ijpsym_415_18.

Vittner, D., DeMeo, S., Vallely, J., et al. (2022). Factors That Influence NICU Health Care Professionals' Decision Making to Implement Family-Centered Care. *Advances in Neonatal Care*. 22(1), p. 87-94. Available at: https://doi.org/10.1097/anc.0000000000000846.

Whitney, C. and Evered, J.A. (2022) The qualitative research distress protocol: A participant-centered tool for navigating distress during data collection. *International Journal of Qualitative Methods*. 21. Doi:10.1177/16094069221110317.

Wong, C.L., Phiri, P., Chan, C.W.H., et al. (2023). Nurses' and Families' perceptions and practices and factors influencing the implementation of family-centred care for hospitalised children and their families. *Journal of clinical nursing*. 32(17-18), p. 6662–6676. Available at: https://doi.org/10.1111/jocn.16740

World Health Organisation. (2023a). Newborn Health. World Health Organisation. [online] Available at: https://www.who.int/westernpacific/health-topics/newbornhealth#:~:text=A%20newborn%20infant%2C%20or%20neonate,to%20health%20car e%20is%20low. [18 January 2023].

World Health Organisation (2023b). Kangaroo mother care: a transformative innovation in health care. Global position paper. World Health Organisation.

World Health Organisation. (2023c). Preterm birth. World Health Organisation. [online]. Available at: https://www.who.int/news-room/fact-sheets/detail/preterm-birth/.

World Health Organisation. (2025a). Constitution of the World Health Organisation. World Health Organisation. [online]. Available at: https://www.who.int/about/governance/constitution.

World Health Organisation. (2025b). Preterm and low birth weight. World Health Organisation. [online]. Available at: https://www.who.int/teams/maternal-newbornchild-adolescent-health-and-ageing/newborn-health/preterm-and-low-birth-weight/

World Health Organisation. (2025c). Nurses by sex (%). World Health Organisation. [online]. Available at: https://www.who.int/data/gho/data/indicators/indicatordetails/GHO/nurses-by-sex-(-).

Xiang, X., Xia, S., Zhu, X., et al. (2020). Attitudes and concerns of neonatologists and nurses to family- integrated-care in Neonatal Intensive Care Units in China. *Translational Pediatrics.* 9(5), p. 603–609. Available at: https://doi.org/10.21037/tp-20-60.

Zhou, Y., Wang, Y., Huang, M., et al. (2022). Psychological stress and psychological support of Chinese nurses during severe public health events. *BMC Psychiatry.* 22(1), p. 800. Available at: https://doi.org/10.1186/s12888-022-04451-8

Zietlow, A., Nonnenmacher, N., Reck, D., et al. (2019). Emotional Stress During Pregnancy – Associations With Maternal Anxiety Disorders, Infant Cortisol Reactivity, and Mother–Child Interaction at Preschool Age. *Frontiers in Psychology. 10.* Available at: https://www.frontiersin.org/articles/10.3389/fpsyg.2019.02179.

ANNEXURES

ANNEXURE A: POSTGRADUATE COMMITTEE APPROVAL

UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

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

Reference: Mrs Sandra Benn
E-mail: sandra.benn@wits.ac.za

26 June 2023
Person No: 1417852
PAG

Miss NG Kgosana
2700 Ngoma Street
Mamelodi West
Mamelodi
0122
South Africa

Dear Miss Ntombikayise Kgosana

Master of Science in Nursing: Approval of Title

We have pleasure in advising that your proposal entitled *The experiences of mothers and nurses in care-by-parent interventions in a neonatal intensive care unit of a regional hospital in Gauteng* has been approved. Please note that any amendments to this title have to be endorsed by the Faculty's higher degrees committee and formally approved.

Yours sincerely

Mrs Sandra Benn
Faculty Registrar
Faculty of Health Sciences

ANNEXURE B: HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL) CLEARANCE CERTIFICATE

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

R14/49 Ntombikayise Kgosana M230738 MED23-07-002

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M230738 MED23-07-002

NAME: (Principal Investigator)	Ntombikayise Kgosana
STUDENT/STAFF NO:	1417852
DEGREE:	MSc Nursing
DEPARTMENT:	Nursing Education Mamelodi Regional Hospital
PROJECT TITLE:	The experiences of mothers and nurses in care-by-parent intervensions in a neonatal intensice care unit of a regional hospital in Gauteng
DATE CONSIDERED:	11/08/2023
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Miss Kerry-Ann Singaram
APPROVED BY:	Prof P Ruff, Chair, HREC (Medical)
DATE OF APPROVAL:	17/01/2024 **EXPIRY DATE:** 17/01/2029

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

DECLARATION OF INVESTIGATORS

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report** in July each year until study is closed. Failure to submit annual report will result in ethics clearance certificate suspension. The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. In this case, the study was initially reviewed in July and will therefore be due in the month of July each year. Unreported changes to the application invalidate the clearance given by the HREC (Medical). Email signed copy of this ethics clearance certificate prior to commencing with the study hrec-medical.researchoffice@wits.ac.za

Principal Investigator Signature Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

ANNEXURE C: PERMISSION FROM STUDY SITE

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

[redacted]

DECLERATION OF INTENT FROM THE CLINICAL MANAGER

I do give permission to : Miss Ntombikayise Kgosana GP_202311_037

to do research on: The experiences of mothers and nurses in care by parent interventions in neonatal intensive care of a regional hospital in Gauteng.

Other Comments or Conditions prescribed by the Clinical Manager:

1.The research outcome to be reported to the institution.

DR EB Mankge

Signature:
Clinical Manager

Date: 12 / 12 / 2023

ANNEXURE D: NATIONAL HEALTH RESEARCH ETHICS COUNCIL

Title of Research Project

THE EXPERIENCES OF MOTHERS AND NURSES IN CARE-BY-PARENT INTERVENTIONS IN A NEONATAL INTENSIVE CARE UNIT OF A REGIONAL HOSPITAL IN GAUTENG

Status of Application

Pending (New Application)

Status of Project

On-Going

Research Staff assigned to Project/Proposal

Title	Name	Surname	Role	CV/Resume
Mrs	KERRY-ANN	SINGARAM	Supervisor	Download CV

Aim and Objectives

THE AIM OF THE STUDY IS TO DESCRIBE THE EXPERIENCES OF MOTHERS AND NURSES IN THE INVOLVEMENT OF MOTHERS IN THE CARE OF THEIR NEONATES IN A REGIONAL NICU

Academic Study

Yes

Study Area(s)/Field(s)

Description

Study Design(s)

Description

Data Collection Method(s)

Method Category	Method Description
Qualitative	Focus group discussions

Interview Request(s)

Position
Hospital CEO

Sample

Two groups will be sampled from Mamelodi Regional Hospital. 1. Mothers of newborn infants admitted in the respective neonatal intensive care unit- Purposive sampling will be used to sample mothers till saturation is reached. there is no definite sample size, it is all dependent on saturation being reached. furthermore, to randomise the focus group discussions, the others who meet the inclusion criteria will be randomised into groups using a Random choice generator app. 2. Group 2 are registered nurses d total sampling will be used. this means that the recruitment process aims to have participation from every registered nurse meeting the inclusion criteria in the unit.

Data Analysis Tool(s)

Tool Description

Information / Data Request ?

No

Information / Data request details.

No Data Requested

Locations(s) where study will be conducted

Facility
Mamelodi Hospital

Anticipated Start Date

2023/12/01

Anticipated Completion Date

2024/06/30

Institution(s) which gave ethical approval

nstitution
Nits - Human Research Ethics Committee(Medical), University of the Witwatersrand

Ethics Approval Number

M230738 MED23-07-002

Date of Ethical Approval

11/3/2023 12:00:00 AM

Date Ethical Approval Expires

11/10/2027 12:00:00 AM

If Clinical Trial, MCC Approved

No

National Clinical Trials Registry Number

No Clinical Trial

Funding source

Organisation

Budget (in ZAR)

1 001 - 10 000

ANNEXURE E: STUDY INFORMATION DOCUMENT FOR AN INTERVIEW

THE EXPERIENCES OF MOTHERS AND NURSES IN CARE-BY- PARENT INTERVENTIONS IN A NEONATAL INTENSIVE CARE UNIT OF A REGIONAL HOSPITAL IN GAUTENG

Hello,

Introduction: I am Ntombikayse Kgosana and I am student at the University of Witwatersrand doing my Masters in nursing science (dissertation). As part of the course requirements, a research project ought to be conducted and submitted in a written document to the University in order to successfully complete the course. In this research project I intend to identify the implementation gaps in family-centred care at a regional hospital setting. This will be achieved through the perceptions and experiences of professional nurses and mothers whose neonates are currently admitted in the neonatal intensive care unit. Knowing this information will bring new insights into family care in the neonatal intensive care unit and hopefully improve the experiences of both nurses and mothers.

Invitation to participate: as mothers whose neonates have been admitted in the NICU and as professional nurses caring for the mothers' infants, you are invited to partake in the study.

What is involved in the study: participation in a focus group discussion, discussions will be 40 minutes to 60 minutes. Family-centred care will be discussed through your individual perceptions and experiences.

Please note:

Participation is entirely voluntary and participants may withdraw from the study at any time.

You may refrain from certain questions.

Privacy and confidentiality will be maintained through the use of pseudonyms in the study.

No personal information will be released in any report and/or publication of the study.

No foreseen risk will be associated with the study.

An audiotape will be used to assist with the transcribing of interview information and analysis, please refer to the consent form for audiotape recording.

Should you require additional information regarding the study, feel free to email me at: 1417852@students.wits.ac.za

Thank you for reading this information document

Yours Sincerely,

Ms N Kgosana (Msc Nursing student)

Supervisor: Ms K. Singaram

ANNEXURE F: CONSENT FORM OF THE INTERVIEW (Mothers of neonates)

I, _____ hereby consent to participate in the research study.

I am consenting that:

I have been given an information sheet that explains the aim of the study and the procedures involved in the study.

I have been given time to read the information sheet and have been given time to ask any questions regarding the information sheet and the study. Furthermore, I was given satisfactory answers to the questions asked.

I understand the purpose of the study and the data collection.

I understand that the study conducted will hold no immediate benefit to participants and that participation is voluntary with no monetary gains.

I understand that even though I volunteered as a participant in the study, I may withdraw at any given moment during the interview and will not be required to justify withdrawal.

I have been given the contact details of the researcher, and the researcher's supervisors should I require more information and have questions about the study.

Contact details:

Ntombikayise Kgosana (researcher): 1417852@students.wits.ac.za

Supervisor Kerry-ann Singaram (Msc): kerry-ann.singaram@wits.ac.za

011 4884270

For the Human Research Ethics Committee (Medical)

Email: HREC-Medical.researchoffice@wits.ac.za, alternatively, call Dr Clam Penny at 011488382

ANNEXURE G: AUDIOTAPE RECORDING CONSENT FORM

I, _____

, consent to the use of audiotape recording during the interview process.

I understand that:

The recording will be active during the interview process.

That participants will be regarded with pseudonyms to preserve confidentiality. That the tape recordings will be placed in a secure location, under password lock in a computer, with restricted access to the researcher and the researcher's supervisors.

The recordings will be transcribed and information that reveals identity will be removed.

The recordings will be erased within 2 or 6 years respectively, depending on whether publications arise from this research.

Approval from the Human Research Ethics Committee at the University of Witwatersrand, Johannesburg will be required to access recordings.

Date:

Place:

ANNEXURE H: DEMOGRAPHIC DATA SHEET (Mothers of neonates)

THE EXPERIENCES OF MOTHERS AND NURSES IN CARE-BY- PARENT INTERVENTIONS IN A NEONATAL INTENSIVE CARE UNIT OF A REGIONAL HOSPITAL IN GAUTENG

Pseudonym:

Please ✖ on the applicable response.

Age

Under 15 years old	
15-17	
18-29	
30-40	
40-50	
50 +	

Marital Status

Single	Co-habitation	Married	Separated/Divorced	Rather not say

Employment

Full-time Employment	Part-time Employment	Unemployed	Student	Other
				Please Specify:

Nationality

South African (RSA)	Non-South African
	Please specify:

Gravida and Parity

Gravida (How many times have you been pregnant, please include miscarriages, termination of pregnancies and children who have passed o). Twins count as one pregnancy).

1 pregnancy	2 pregnancies	3 pregnancies	4 pregnancies	5 pregnancies	6 or more pregnancies

Parity (How many children do you have at home, delivered by you, and alive)

1 child	2 children	3 children	4 children	5 or more children

Have any of your children been admitted to the neonatal intensive care unit?
Do not count the current admission.

0 previously admitted children	1 child	2 children	3+ children

Human Immunodeficiency Virus status:

Negative	
Positive prior to pregnancy	

Positive, diagnosed during pregnancy/labour	

Do you have supporting structures at home? (Where you currently reside)

I do have a support system at home	
I do NOT have a support system at home	

What is the weight range of your baby/ies?

0-799 grams	
800-1199 grams	
1200-1799 grams	
1800-2499 grams	
2500+	

ANNEXURE I: INTERVIEW GUIDE FOR FOCUS GROUPS (NICU MOTHERS)

- **Central question**

Based on your experience as a mother, what is your experience with your involvement in the care of your baby admitted in the neonatal intensive care unit.

Guiding questions

Communication: How would you describe the communication between families and staff? How do you feel about the current information sharing in the unit? 1. **Respect and dignity**: do you feel you are treated with respect and dignity? 2. **Collaboration**: how would you describe your role in the decision-making process?

3. **Participation**: do you feel that you are an active participant in the care of your child?
4. **Environment**: How would you describe the environment in the unit?
5. **Emotional and social suppor**t: are your emotional and social support needs being met?

ANNEXURE J: SAMPLE FOR FIELD NOTES DURING FOCUS GROUP DISCUSSIONS

Date:

Time:

Interview number and location:

Participant 1 **Pseudoname:** **Comments:**	**Participant 2** **Pseudoname:** **Comments:**
Participant 3 **Pseudoname:** **Comments:**	**Participant 4** **Pseudoname:** **Comments:**
Participant 5 **Pseuonames:** **Comments:**	**Participant 6** **Pseudonames:** **Comments:**

Participant 7 **Pseudonames:** **Comments:**	**Participant 8** **Pseudonames:** **Comments:**

ANNEXURE K: DISTRESS PROTOCOL

The following distress protocol was followed:

4. Stopping/pausing the focus group discussions and removing the participant from the group to receive immediate support from the research assistant.
5. Assessing the participant's psychological and emotional status, with the option to continue or leave the discussion.
6. If the participant preferred to be excused from the focus group discussion; they were permitted to leave, and were offered a psychological referral.

ANNEXURE L: INTERVIEW GUIDE FOR FOCUS GROUPS (NURSES)

Central question

Based on your experience as a professional nurse in the unit, what is your experience on the involvement of mothers in the care of their babies admitted in the NICU?

Secondary questions:

- Would you describe the integration and involvement of families in the unit beneficial to the health institution? Justify response.
- Would you describe the integration and involvement of families in the unit beneficial to mothers and families? Justify response.

Questions based on the FCC principles:

Communication: How would you describe the communication between families and staff?

Respect and dignity: how would you describe the current relationship between nurses and mothers?

Collaboration: how would you describe the role of mothers in the decision making process?

Participation: how would you describe family participation in the unit?

Environment: would you describe the environment conducive for family-centred care?

Emotional and social support: do you believe that the families' emotional and social support needs are met?

ANNEXURE M: CONSENT FORM OF THE INTERVIEW (NURSES)
CONSENT FORM OF THE INTERVIEW (Nurses)

I, _____ hereby consent to participate in the research study.

I am consenting that:

I have been given an information sheet that explains the aim of the study and the procedures involved in the study.
i have been time to read the information sheet and have been given time to ask any questions regarding the information sheet and the study. Furthermore, that I was given satisfactory answers to the questions asked.
I understand the purpose of the study and the data collection.
i understand that the study conducted will hold no immediate benefit to participates and that participation is voluntary with no monetary gains.

I understand, that even though I volunteered as a participant in the study, I may withdraw at any given moment during the interview and will not be required to justify withdrawal.
I have been given the contact details of the researcher and the researcher's supervisors should I require more information and have questions about the study.

Contact details:
Ntombikayise Kgosana (researcher): 1417852@students.wits.ac.za
Supervisor Kerry-ann Singaram (Msc): kerry-ann.singaram@wits.ac.za
011 4884270

For the Human Research Ethics Committee (Medical)
Email: HREC-Medical.researchoffice@wits.ac.za, alternatively, call Dr Clam Penny at 0114883820

ANNEXURE N: INFORMATION SHEET (NURSES)

THE EXPERIENCES OF MOTHERS AND NURSES IN CARE-BY- PARENT INTERVENTIONS IN A NEONATAL INTENSIVE CARE UNIT OF A REGIONAL HOSPITAL IN GAUTENG

Hello,

Introduction: I am Ntombikayse Kgosana and I am student at the University of Witwatersrand doing my Masters in nursing science (dissertation). As part of the course requirements, a research project ought to be conducted and submitted in a written document to the University in order to successfully complete the course. In this research project I intend to identify the implementation gaps in family-centred care at a regional hospital setting. This will be achieved through the perceptions and experiences of professional nurses and mothers whose neonates are currently admitted in the neonatal intensive care unit. Knowing this information will bring new insights into family care in the neonatal intensive care unit and hopefully improve the experiences of both nurses and mothers.

Invitation to participate: as mothers whose neonates have been admitted in the NICU and as professional nurses caring for the mothers' infants, you are invited to partake in the study.

What is involved in the study: participation in a focus group discussion, discussions will be 40 minutes to 60 minutes. Family-centred care will be discussed through your individual perceptions and experiences.

Please note:

Participation is entirely voluntary and participants may withdraw from the study at any time.

You may refrain from certain questions.

Privacy and confidentiality will be maintained through the use of pseudonyms in the study.

No personal information will be released in any report and/or publication of the study.

No foreseen risk will be associated with the study.

An audiotape will be used to assist with the transcribing of interview information and analysis, please refer to the consent form for audiotape recording.

Should you require additional information regarding the study, feel free to email me at: 1417852@students.wits.ac.za

Thank you for reading this information document

Yours Sincerely,

Ms N Kgosana (Msc Nursing student)

Supervisor: Ms K. Singaram

ANNEXURE O: DEMOGRAPHIC DATA FOR NURSES

Please ✖ on the applicable response.

Pseudonym:

Age (in years)

20-29	
30-39	
40-49	
50-59	
60+	

Gender

Female	**Male**	**Non-Binary**	**Other**

Highest Qualification

Undergraduate diploma/degree	
Postgraduate diploma	
Masters degree	
Doctoral degree	
Other:	**Please specify:**

Years of nursing experience

6 months to 1 year	1-5 years	5-10 years	10-20 years	20+ years

Neonatal Intensive Care Unit Experience

6 months to 1 year	1-5 years	5-10 years	10-20 years	20+ years

Which best describes your current role in the unit?

General professional nurse	
Child nursing trained nurse	
ICU(Paeds/Adult) trained nurse	
Operational Manager	

Patient: Nurse Ratio

2:1	3:1	4:1	5:1	6:1	7:1

ANNEXURE P: NON-DISCLOSURE AGREEMENT (TRANSCRIBER)

Confidentiality Agreement for Transcription Services

Research Study Title: The experiences of mothers and nurses in care-by-parent interventions in a neonatal intensive care unit of a regional hospital in Gauteng

As a transcriber of this project, I understand that I will be listening to audio/video recordings of private and confidential interviews. The information relayed in these audio/video recordings has been willingly revealed by participants, who requested strict confidentiality. I understand that I have an important responsibility of honoring this non-disclosure agreement.

I agree not to discuss or share any information found in the audio/video recordings with any third parties except the research team providing the audio/video recordings. Violating this agreement or any of the terms set below will be considered breach of contract and can lead to legal action being taken against me. I am confirming that I will strictly adhere to the agreement in full.

I, Welshman Dube transcriptionist, agree to maintain full confidentiality of all research data received from the research team related to this research study.

1. I will hold in strictest confidence the identity of any individual that may be revealed during the transcription of interviews or in any associated documents.
2. I will hold in strictest confidence the contents of the recordings and any associated documents.
3. I will not make copies of any audio-recordings, video-recordings, or other research data, unless specifically requested to do so by the researcher.
4. I will not discuss the research data with any third parties without the researcher team's consent.
5. I will not provide the research data to any third parties without the researcher team's consent.
6. I will transcribe the audio/video recordings in private, and I will store all study-related data in a safe, secure location as long as they are in my possession. All video and audio recordings will be stored in an encrypted format.
7. All data provided or created for purposes of this agreement, including any back-up records, will be returned to the research team and/or permanently deleted. When I have received confirmation that the transcription work I performed has been satisfactorily completed, any of the research data that remains with me will be returned to the research team or destroyed, pursuant to the instructions of the research team.

Transcriber's name (printed) Welshman Dube

Transcriber's signature WD Date 30 March 2024

ANNEXURE Q: PHASE ONE TRANSCRIPT Focus group discussion 02

Interviewer: okay, so as we start, igama uNtombikayise and this is [redacted], research assistant today. So please everyone introduce yourselves, ka di fake names tsa lona. Asiqale la.

M1: i am mother 1

M2: i'm mother 2 M3: i'm mother

3 M4: i'm mother 4 M5: i'm mother

5

M6: i'm mother 6

Interviewer: Okay… so you guys are at neonatal, could you please describe your routine at neonatal? Anyone can answer. What happens, what do you do, when do you do it. Routine yenu ihamba kanjani? M1: mother 1, every three hours we go for the feedings and changing the naps. Yah.

Interviewer: is that all?

M1: sometimes if you have questions, you can ask the sisters and if they are not sure, they ask the doctors to come so that they can explain more, so that you can understand what is going on with the baby. Interviewer: so she said something about i-routine, it's every three hours. How does the three hours look, is it in a 24 hour cycle or is it 12

hour cycle, like during the day or how is it?

M1: it is a 24 hour cycle.

Interviewer: okay, and when do you guys sleep?

M1: when do you?

Interviewer: like when do you guys sleep… anyone but mother 1 please, (laughs), its an open discussion neh.

M5: we just sleep for 30 minutes…

Interviewer: uzi identif-iye qala

M5: oh okay… i am mother 5, for sleeping, you just sleep for 30 minutes because because you have to express first. And then the time you take to express is too long than the time you sleep.

Interviewer: so the two hours that you have in between, it becomes 30 minutes M5: yes

Background: no

M5: for sleeping it's only 30 minutes.

Interviewer: 30 minutes every three hours, how many hours is that in a day? (mumbling)

Interviewer: no im saying how many hours is the 30 minutes during the day?

Background: ohh

M5: then it means its 30 minutes times 8.

UI: it's 4 hours, yes.

Interviewer: how are you guys still walking then? (chuckles) M5: cause we are exhausted.

Interviewer: ni exhausted now?

M5: hmm

Interviewer: i think before we go deeper, let's just do the main question that i have. Based on your time as a neonatal mother, what is your experience or your view about being the ones taking care of umntwana and this arrangement that you have? Mother 3, how do you feel?

M3: nna ke feel-a sharp cause ke kgona kgo bona ngoana, kgore o recover beang. Like be kea, be ke kreya di changes. (i feel okay because i get to see the child, to see the recovery , like when i go there, i can see changes)

Interviewer: okay, so mother 3 uvoice ukuthi yena, o sharp because she gets to see ngoana wa hae and ngoana wa hae a progressa and be there for those things. Does anyone else feel the same way? Mother 6?

M6: ya i feel the same way…

Interviewer: so is there anything else anyone wants to add about their experiences? Mother 4

M4: mina sometimes, cause si si… si expressa ubusi senza njani si, cause sometimes isikhathi lesi, i 30 minutes, ngilala i 10 minutes cause ubisi bawunga phumi, masengibuya lapha, nginobuthongo, ngisaba nokubamba umntwana, ngobangizamuwisa. Eh. (i sometimes, because we express milk and other things, sometimes its not 30 minutes, i sleep 10 minutes because milk does not want to

come out, and when i come back, i am sleepy i am even afraid to hold the baby because i might make them fall)

Interviewer: umwisa usually what time… let's just say bowukhathele the most. When is it?

M4: sometimes ngabo 3. 3.

Interviewer: ebusuku or ekuseni?

M4: ekuseni, A.M.

Interviewer: lapho ku most difficult?

M4: yah yah lapho ku difficult. Ngisaba nokum'bamba… ubuthongo. Interviewer: okay, so mother 3 6 and 4 have expressed ukuthi umm they like to see the progress but also umm the sleeping is not enough and uku expressa takes a long time… mother 1, what are your experiences here on involvement ngomntwana wakho?

M1: like rea taba bere bona bana ba rena ba progressa, but on the other hand le rona, we are draining ourselves, because we need to rest, a re khotse enough, so that we can be strong for our kids, because sometimes o kgona kgo-check-a ngoana and they are changes. Eh. moshini a sharp then all of a sudden, he is critical or she is critical and then that thing yao stressa and you cant sleep. You want to sleep but you cant sleep. Yah. because you are stressed, then ngoana a lwale. Ngoana waka swanetse a be strong, but you cant be strong for yena if you are not strong yourself, kgo need-deka kgore o be strong first, so that ngoana oa hae a be lematla, ngoana can feel hore mamaka a sharp, mamaka is losing hope so into eo e kgona kgo affecta ngoana.

Yah.

Interviewer: the stress you are talking about, is it more physical or emotional?

M1: it's both because physically my body is tired! But also mentally my brain, its not working also, because from the stress- i'm stressed and i'm physically tired.

Interviewer: does anyone have anything to add on what she said? M2: mother 2, ya ukhuluma iqiniso neh, mina i will talk based on my experience… cause it's my first time- umm my baby is premature- 7 months- oh this is my third kid… so it's very very very difficult on my side… cause firstly, he is small, he is premature, udla nge-tube, uyangi-understanda? Like okay, like she said, days are not the same. Sometimes you go there and you find your baby is okay, then the next day you find your baby is critical. That is very very emotionally draining, like emotional. Mina i will talk on my side, emotionally, yah, it is not working out, cause sometimes you will go there check your baby an

um'thola bamu chang-ile. But then you dont have any explanations, they dont come to you and tell you, you have to go them, which is wrong! Cause i feel like whenever they are changes on my baby, you have to come to me and tell me ukuthi okay um we have discovered this and that and we want to change the baby to this and that, but instead of doing that, they just do. So i find that very wrong. I believe we should be told each and every step when it comes to abantwana bethu.

Interviewer: i just want to write down what you said…cause i have two follow up questions… given ukuthi wena- the stress that you have, umntwana bamu chang-ile and all that… how do you feel ukuthi faneke uqubeke- let's just say carrying for umntwana during that hour. Cause amatubes and ama-what what ayenzeka, do you feel like uready to go back and take care of umntwana for that one hour? M2: sometimes not.. Cause when you get there- let's just say for instance, i came at twelve, ngathola umntwana akekho-right… in the morning he was fine, when i go back there at twelve seka angekho right ashintshile you understand? So many changes, so when i go back to sleep, i cannot sleep. Cause i have to think- manje ingqondo yami sebuhlungu- cause okay mina im there resting but yena usele a-right na? Cause abanye aboSister, they are- what can i say- they are not that friendly. They are not that caring towards the kids. Cause umntwana vele anytime, angashintsha, ek'seni singavuka umntwana a-right, and along the day umntwana ashintshe, it's something that happens. Ive experienced it, nginabantwana aba-three ngaloya…

Interviewer: yah

M2: so loko siyakwazi, but then if you have to take care of your kid uyi-1, hhayi, it's something else. More especially bosesibhedlela, nawe akazewa-experienca ukuhlala esibhedlela. It's very hard. Interviewer: so you feel also alone in this? Awuna support from the nursing staff?

M2: sometimes, it's different. Yah. abantu aba- nurses are not the same, i dont want to lie. Sometimes uzothola nurse o-right wazi ukuthi atleast for that day, less stress, i'll rest… cause i know ukuthi lomuntu will take care of my child, i know very well ukuthi u-very observant. So for that day or for that few hours, you'll be stressless until the next shift ..

Interviewer: okay

M4: ngifuna ukungeza, ngifuna ukungeza ngendaba ye-staff. Sometimes uyasaba ukubuza, ukubuza something, ukuthi lapha ngenze njani? Ngoba uba um'bona uthi hhayi (sigh) umuntu akekho corporative ukuthi ungam'buza, akutshele. So kuzahlala enhlizweni, mawusuka uyacabanga ukuthi hey maybe umntwana wami izayenza njani ngoba angibuzanga. But ukuthi um'buze uyasaba futhi, cause ungamutshela like me, ngathi intambo ye-oxygen, wathi- ungamuphendula uyambona ukuthi ufeela

pain … ngamubuza ngathi “sister intambo le ayikho buhlungu emntwaneni? Athi “umntwana wakho ukhaya kakhulu uyahlupha.” that was the reply from the sister. So ebangifika phale, ngiyahlala ngoba ubisi awuphumi, ngiyam’buzisa ukuthi umntwana wami uzasala ayenza njani?

Interviewer: okay… does anyone have anything to add- izi-story? Number 3?... okay so one of the things that mother 2 mentioned ukuthiand mother 4, ukuthi we are not well-informed ngomntwana, how would you describe information sharing between abonurse nabo doctors. M1: mother one, as mother 4 said, when the sister- like batho aba tshwane, sometimes o kreya Sister o friendly, sometimes they even update you hore ngoana wa hao kgo dira hala so so so. Mara some of them- aba ho botse, it goes with staff pela pela esi tseneng. Hore o tlo este problem ya ngoana wa hao or not. Abangwe they just keep quiet, and a kgona hore o kamomotsesa. Mara omonwe o safetla o kgona kgobotsa hore doctor ba fetlele a re ngoana wa hao o so so so, just like nna today ba mpoditse kgore like ngoana waka o tsa doctor wa mahlo, ba mo tshela di eye drops, and i was very happy, o re ka etse nou hore ho dira kgelang ka ngoana waka. So staff sa depend-a.

Interviewer: okay… umm. Before we go further, i just want to go hereon their views as well of being a mother ko neonatal. Your experiencesangisho besihamba one by one. Wena i-experience yakho in terms of taking care of umntwana wakho esibhedlela, how is it? Is it good? Is it bad?

M3: mina i experience yami eish, sometimes- njenga manje i-bad. Interviewer: hmm

M3: ya… ngoba eish, njengo mother 1, ukhulumile ukuthi sometimes uhlala three days ungazi ukuthi umntwana uya-recover or yini. Ngoba you can’t. Kuya ngokuthi istaff sinjani, ukuthi ukutshelile or akutshelanga. Asithi sokhe sazi ukuthi amamachine nezinto zihamba njani. Bomele ufeed-e, uyafeed-a ubuyela back, awazi nokuthi kune-change or akuna-change. Yabona- for three days! Bawungathola udoctor akhona, uzakutshela, manje abodoctor abekho isikhathi sonke. Ungahlala naye uyabuza “doctor umntwana wami uyenza njani?” uzakutshela, but istaff hhayi.

(sighs) Interviewer: okay… mother 5?

M5: mother 5, okay, the sense you get there, i think it’s highly professional. The reason I am saying that is that our kids came here critical. And then step by step-healing healing until they got better. I saw- i just see maybe one of ten from the critical kids who are passing away, so…

Interviewer: so ubona abantwana passing away?

M5: yes, maybe one out of ten, out of those who are critical so that is increasing. The only problem we have is the sisters. The sisters they need to know… (background noise) … they need to understand that we are emotionally broken. So they have to find a way with communicating with us- to to to lift our spirits, not to break our spirits. Cause sometimes they just take you- they just talk to you like they are talking to each other, when you are the parent. So the way they are treating us is very bad, but the same treat they give to our kids, its fine. The only problem is that for us as the mothers- they need to talk to us like the mothers. Interviewer: okay, so i got lack of information sharing and also lack of respect also? From the nursing staff

M5: yes lack of respect

Interviewer: Okay umm, just to dive in to you caring for umntwana wakho, you being the one here. Yah. how is it?

M5: taking care of my child?

Interviewer: yes you being the one taking care of umntwana, you being here, every three hours ula until idiscarge. How do you feel? M5: (cough) no- i think it is a must for me to be here, no one can care for my child other than me, so i think i have to be strong. Interviewer: why do you feel like no one can care for your child other than you?

M5: are you talking about the nurses or- they are also there for our child, but they- they are not compared to us.

Interviewer: hmm… mother number 6?

M6: nna a ke happy. Cause today your baby has one thing, then tomorrow has another thing. And when you ask, the nurses shout. Yah. Interviewer: so what i got from the group is umm- not the word being joy- but you prefer being here because you get to see umntwana wakho akhula aprogressa. You also get to be umama cause no one can take care of umntwana more than umama. But the attitude, the not being well informed is a major problem.

Background: hmm

Interviewer: okay. So there is something that mother 2 also said, she mentioned that she has three kids, laba abesekhaya ba-take cara ubani?

M2: umama wami.

Interviewer: umama wakho… okay… does anyone have kids at home? Background: yes we do have.

Interviewer: you do have, how does it feel being here and not with your kids.

Background: depressing.

Interviewer: identify yourself (chuckles)

M5: mother- mother 5, it's so depressing like we do miss them, cause they are still young, seven years, imagine leaving a child of seven years, not knowing how is it, not knowing whether they go to school. Yoh its very depressing.

M1: eh mother one, i dont have another child at home, that's my first child, eh, so eh it's not something i expected, that my first child would stay long in the hospital, yah, and then not having to hold my child for the first few days, that is not what i expected. I expected that my first child i would have them then go home and be able to be free with them. Hugging him, kissing him because we are not allowed to kiss them because of infections and so on, i feel like my first child is not getting that enough love. Yah. if i was home, i would be able to give them all the love, i feel like here i can give the love but not 100%, i have to hold back some of my feelings.

Interviewer: okay… um mother two, your other kids how old are they?

M2: my firstborn is ten, then the other one is almost two years.

Interviewer: and how are you coping?

M2: i'm not

Interviewer: you're not?

M2: i'm not coping unfortunately, cause sometimes they will update you and say "your child will come into your bed and he didn't find you there so he started crying" so those kind of things, they are very heartbreaking.

Interviewer: do they come visit?

M2: yah they do.

Interviewer: okay, so it helps?

M2: yeh it helps a lot, but it's not right.

Interviewer: who else has a kid um at home?

M4: mother 4, eish kimi kunzima ngoba sometimes baya-fona and bathi naye usegula. Eish, so for ukuthi ubaba wakhona asuke emsebenzini, ukuthi ayekele- asoze sithole ukudla. So faneke udinge omunye umuntu

ayenaye eclinic. Yabona, nako kubuhlungu kakhulu. Umntwana futhi agule nawe umubona, so eishinhliziyo yami ibuhlungu. (eish for me it's hard cause sometimes they call and they say they are sick. Eish and for the father to leave work would mean no food. So you have to now search for a person to take them to the clinic. You see, that also hurts a lot. You can see the child is sick. So my heart hurts.)

Interviewer: ekhaya at the moment ubani omu-take carayo ?

M4: sorry?

Interviewer: ekhaya at the moment ubani omu-take carayo?

umm, sometimes bahamba baya esikoleni, babayenzela amatiye,

M4:

1st born, mele ahambe ngesikhiya, akhiye umnyango. ukudla - then bayadla. Ubaba wabo ufika late ngabo six.

Interviewer: so it's a safety issue also.

M4: ayikho

Interviewer: and finances, faneke anga stoppi ukusebenza cause wena awukho?

M4: ey, (background noise)

Interviewer: so i care by parent intervention neh, its part of this other thing called family-centred care neh, family-centred care is integrating abomama into the care of their children neh, so we are just going to be going through the principles. The principles are five and each principle has a question to see ukuthi you are not just here for… (background noise) (cough) so the first one, i under communication- how would you describe the communication between the mothers and the nurses or the staff? Ngikhuluma ngabo doctor, abo dietitian and all that, and how do you feel about the current information sharing in the unit? I think we've already discussed some of these, does anyone have anything to add in terms of communication between mothers and the staff before siyivala. M1: mina i do, the communication between the mothers and the nurses, for me i'd say its not good, it's not. Because i'd say out of 100%, 70% of the time there is no communication. Only 30%.

Interviewer: hmm… okay… anyone else.

M2: mother two, okay mina, we cannot all say izinto ezibi, cause they do nabo- um okay- im saying ukuthi they should be human, just because banakelela bantwana bethu neh. But then siyacela, we are pleading to atleast- they must also think that nathi we are in a situation which is also hard… emotionally, cause firstly it's not easy waking up after every three hours. Coming to see your child. It's much better when

you are having your child with you, knowing that it's everyday. I think it's much much better than the three hours, cause you have to walk up and down, and some of us are staying far. Stepdown is very far, especially you would feel it's very far, especially ngabo 3, 12, 3. That's when it is the hardest. But we are very grateful for the things that they do, but then we are just pleading- may they sympathise with us, especially when it comes to the emotional part. Yah, cause that one is very hard, sometimes you would- a person would come onto you, not knowing that day ukuthi uvuke kanjani, maybe you are frustrated, you understand? And they will come with that attitude yokuthi "i'm a sister and you won't tell me anything". Then akhulume the way afuna ngakhona, then nawe you snap then and there, cause you are human also. U-frustrated and ngapha umntwana wakho akakhali, ubona ngathi akakhali, but there's improvement, uyangi- understand. But just because of icommunication, it's very bad. Ubona ngathi akuna improvement. You're not a nurse, you're not a doctor, but then we seriously plead ukuthi mele- maybe kungaba sort of iworkshop nyana ukuthi bafundise or uyangi-understanda, like i-one on one, so that they can know ukuthi sifeel-a kanjani. Yah.

Interviewer: before i go back to the rest of the group, umm… the arrangement you have right now, in terms of the ward, like now and what you do as a mother and your role now. Umm… what would you improve on that arrangement? To make it better for abomama.

M2: firstly, ama hours neh cause i believe we need more rest. Regardless ukuthi we have to take care of our kids, we do need rest. Cause remember, uthola umntwana then bakutshele after two hours faneke uyochecka umntwana so, awu phumulanga cause what we know is bawuqeda ukuthola umntwana bayaku- discharge uya ekhaya. Bawufika ekhaya, they give you time ukuthi okay phumula sizomunakelela umntwana up until uya-right physically. Cause it's not easy uku-phusha out umuntu then umnakelele on the spot. Yah. it's hhayi. So i would improve the hours especially around 12 and 3. Yah those hours are really really hard, i think if it was possible- at least u3 they were supposed to cancel it. 12 is much better. U3 i think they should have just said "okay just drop the milk or whatever it is and then go back and rest"

Interviewer: okay, umm… does anyone else have-... okay mother 4? M4: mina ngikhuluma nge explanation ukuthi umntwana ubanjani ubanjani. Cause basicele ukuthi basitshele ngoba ngale ekhaya bafuna ukuzwa ukuthi umntwana uyenza njani.

For three days- ba-fona ngithi angazi. Bafone futhi ngithi angazi! Bathi umama onjani? Uhlaleleni?

Ngapha ngisaba nokubuza …

Interviewer: so you feel a conflict between-

M4: ungang'- explainela noma kungana improvement, but ngiyathaba ukuthi namhla bangitshele ukuthi umntwana wami uyenza so so so. So i-explaination.

Interviewer: so wena improve the hours, and more emotionalness- and ngapha it's more information sharing. Umm… does anyone have anything to add? Mother six do you have something to add? Okay. do you agree with someone that said something?

M6: mother 6, i agree with mother 2, amahours, siyakhathala. Ngapha faneke uexpresse. Ey. siyakhathala.

Interviewer: hmm okay… number 2, is on collaboration, so the whole point of i-family-centred care, it started a while back in the 60s, where abomama they were complaining ukuthi bona they don't see their children for weeks upon weeks, they just delivered and abonurse they won't allow to visit their child as much as they want. So bayenze this thing yokuthi bangenise abomama instead. Le enikuyo neh. But the whole thing it's supposed to be a partnership neh between ama- istaff and between the mothers as well..

Background: yes

Interviewer: umm… ukuthi bani integrate part of the team neh, do you feel that at this moment you are a partner in this, and side question- do you take part in the decision making about your child?

M1: hmm… mother one, the decision making no, not always.

Interviewer: there are sometimes?

M1: yah i'd say like sometimes, but mostly we don't. Because nna my child ba mo ke rele hlogo. I had no idea hore ngoana waka o kerewa hlogo, abampotsa hore ho dire halang. Nou ngoana waka o nale lebadi kohlogong. I'm not even sure hore le tlo tsamaya and the time ba mo kera hlogo, ke kreyile moriri was all over, ba o sheyile mo. but they are telling us about infection, how about ngoana a heme that hair, what is going to happen, ngoana aka tlahatlahana, will they take me hore ko moriri oa, or are they just going to blame you ba pontsha hore ea ngoana wa hao o paletse ho

hema due to infection. Not looking that they were careless on their part, ho shiya moriri mola! Ngoana oa- he is still small, moriri e la can just inhale akere? Ya. (because they cut my child's head, i had no idea that my child's hair will be cut off. They did not tell me what was the reason, and now my child has a scar on his head. I am not even sure if it will go away and the time they had cut the hair, i found the hair all over. They just left it there. But they are telling us about infection, what if my child inhaled that hair, what is going to happen, my child could complicate, will they tell me it's because of the hair or are they just going to blame you telling you your baby is having difficulty breathing due to infection, not looking that they were careless on their part, to leave the hair there. The child is small, they could inhale the hair. ya.)

Interviewer: okay… does anyone have a comment on the partnership as well?

M2: mother 2, obviously i think the partnership is- is, i think it's 20%. Cause like mother one said, most of the time you go back to your resting place and when you come back you find your child- it's either bamukerile or bamufake i drip, but then they don't explain ukuthi yidrip yani, uyangi-understanda? Sometimes bafake umntwana amadrip ayitwo but then you don't know ukuthi wani, so i think it's just 20%, cause when you go and ask, it's like umuntu uyamhlupha. Ufuna ukwazi, cause as long as umntwana wakho aphefumula it's okay, which is wrong cause umzele lomntwana, bowusem'thola anadrip enhlokeni, and you don't even know ukuthi is it good or not for idrip ukuthi ibe enhloko, wena as a mother. Umzwele lomuntu, you feel that pain, like what if iyam'affecta in a long period or short period, anyeke uwazi. So i think it's just 20%

Interviewer: hmm… does anyone have anything to add about decision making and partnership, mother 5?

M5: mother five, partnership, a ke bone partnership mo la cause nna the time ke tlo attenda theatre, the doctor told me hore ngoana waka o na le foetal distress. That's the only thing that i know ka ngoana waka until today. So if i go there, just change the nappy, and then breastfeed, go back.

Interviewer: you don't feel part of the-

M5: i just know hore before i go to theatre that is what they said, foetal distress. From there, hhayi, i'm just feeding the baby, changing the nappy, life goes on. I don't know anything- i don't know progress- i don't know if there progress or- they don't tell us anything!

Interviewer: okay…

M5: you just breastfeed, change the nappy, go back to the room, come back, change the nappy. so I think for us- we are just waiting for the baby- we are going. I don't know when cause i don't know if he is progressing or not.

Interviewer: hmm… if you put that in an emotion, how would you describe your emotions towards day in and day out wena you are not part of the partnership, you are not part of the decision making and you are not being told things. But you are going there every three hours, how does it make you feel?

M5: it's very bad, very bad. You just feed the baby, change the nappy not knowing what is going on! So it is very bad. At least, they can tell me ukuthi today i spoke, he's going from this room to that room because of 1234. Now he is dropping because of 123. Then you get to understand, you gain experience. Mina i don't experience anything, you just feed, change the nappy, no experience no nothing.

Interviewer: (sighs) mother three?

M3: i agree with mother five, i think there is no partnership. Nna ke ele ko checka after three hours, doctor a tla a tlo tseya madi, then madi a spraya ko linen sheet and moroto bao tletse ko containeng- then- then doctor a re sister o tlomo checka- otlo change linen e la, o tlo tseya moroto, then after three hours, ke boa gape, ke kreya ngoana gape a robetse modimo ga madi, le moroto o tletse mo, then like amo attendi, and tshwanege nna ke direng. Ke mokoke nna, and a ketse ke dire jwang, cause ke yo monyane, ke mo tswara ka tsogo ele 1 and ke tsaba gore ke tlomo wesa. And le sister yena, a botsese selo, amo checki. And partnership ayi teng. M5: mother 5, one other thing hore, eish i feel like re refe chance go tseya ngoana picture, for the sake of the memory. Like ngoana ba rona, a rena memory le bona, we've been there and there and there, you know? So like… you started kamo and o tse dinto tse so and then wa changa waya komo shineng o so, so if they can give us the chance to take the pictures as for the memory to show that the child is growing, we've been here and now we are here.

Interviewer: okay… umm.. Participation we already spoke about, right now i just get the emotional and social support. Do you guys have support system ko hae, that supports you through this time?

Background: yeh i do have

Interviewer: o nale support system? Ke mang?

M6: Mother 6, ke koko lemama, bayang' supporta.

Interviewer: okay… am i ask how old?

M6: 18

Interviewer: 18? Are you still in school?

M6: no

Interviewer: okay, bangizothi how does it affect you, i-schooling sako, if you are here also.

M6: askies?

Interviewer: Bangizothi if you were still in school, how does it affect you being here, knowing ukuthi bakufaneke ube' eskoleni? M6: mother 6 angazi ukuthi ngingayibeka kanjani, angazi ukuthi ngingayibeka kanjani

Interviewer: no, it's fine… mother 4, support system ko hae?

M4: eish, ikhona, yindoda yami.

Interviewer: okay, bayeza for amavisits?

M1: mother 1, mother 1, mina my support system is my mother, the father of the baby, my brother, and yah they do come a lot and they are always calling me "be strong" and so on, on my side, it's fine.

Interviewer: okay, mother 2?

M2: yah, mother 2, ikhona i-support system on my side, it's my mother and my sisters. So yah… ubaba womntwana usebenza ekudeni so unfortunately not, but he came once. But we always speaking on the phone, we okay.

Interviewer: okay, mother 3?

M3: mother 3, nna ke nale support system ko hae, mama waka o tla for visiting hours, and papa wa ngoana waka ba pela ba fona. So yah. M5: mother 5, ke nale yona support system, but the problem is ma security ba botsa gore there's no visit. You just come and drop something.

Interviewer: i think there are visiting hours, during the day? M5: neonatal, it's neonatal, they say there is no visit at all. You just come and drop something and go back.

M1: mother 1, based on what mother 5 is saying, when it's ward 9 and 7, they tell you there's no visitors, they have written on the door when you go in that visiting hour is from 1 till 2, but no. they don't. Yah. they don't.

Interviewer: Thank you, umm… how would you describe the environment in the unit, in the ward? How would you describe i-environment.

M2: mother 2, umm.. I think it depends on the mothers. Cause some are open, some are not. Umm… i think the most support we get is from each other, cause that's when we see each other, all the time, sometimes you come back, they are the only people you have at that time. So you will just express your feelings amongst them.

So i think the most support we get is amongst each other.

Interviewer: anyone else?

M5: mother 5, nna ke bona e sharp, bosego rea tsosana, i think some of us become exhausted and re robale and you are suppose to be somewhere then rea tsosana re sharp. Re expressa di-feelings tsa rona mola, "ke thuse abang tsara sharp", the discussions we have, is very good, unlike re bolela le bonna ya bona, maybe… hayi no hare ke a di hang-a M1:

mother 1, it's very true, we are there for each other. And sometimes o kreya hore you start crying but batho ba ona le bona, your roommates, ba gona kgo console-a " os'ka wara kgotloba sharp." like us as mothers, like we are the best we have, ka bo rena. Yah. Interviewer: umm… on the line ya support. Umm, i want to talk about mental health and since being here, since admission, how would you describe mental health ya lona, cause somebody said "emotionally draining" someone mentioned stress, umm she just mentioned crying, how is the mental health- emotional and mental health ya lona. E re keye one by one.

M1: nna pela pela it's up and down, sometimes ke kotla sharp ke be happy, kore ke amogele hore ke ko' spetlela then ke bonne batho bawa discharge and then ke ba low. Hore they are going home and nna ka sala and so on, ke di up and downs on my side, mother 1.

Interviewer: have the hours and sleep affected your mental health at all?

M1: ah… like eish… keya try-a, i just make the best of it, like yang' affecta. just trying, hore ke be strong for the sake of my baby.

Interviewer: But let's focus on you right now.

M1: a ke sharp, i'm tired, ke lapele yoh, yoh ke lapele, ke kolota borogo big time.yeh mother 1 (laughs) Interviewer: mother 2?

M2: eish, on the mental health issue, i think we are not okay. Cause i remember there was this one lady, that was admitted with- umm she had the same condition ya ngoana wamo bedi so she thought she had dealt with the issue, but until one day, she came back to the ward and then er, im not sure what they told her but that's when she realised she hasn't dealth with the first one, and it's happening for the second time. And that's when she confessed that she seriously needs help. So on the mental health issue, hayi i think we need a serious intervention- like a one on one where you can express your feelings, express like how weak you are, cause sometimes some days are better are better than others. But we are not okay. We might act okay, but we are not okay. Sometimes it's a faith issue, you pray to God like really do i have to walk this path alone, cause when you are here, you are alone, if you are not with the mothers. You are alone. So you just have to accept and be strong for my baby, otherwise we are not. Cause you will start- the moment you feel like you are exhausted that's when you have to know mentally you are okay, and when you start crying that's when you know hore i haven't dealt with anything i'm just brushing things off. Interviewer: so you are just-

M2: you are just doing it for the sake of that person lying there who doesn't know anything, you are just doing it for him.

Interviewer: okay…

M3: mother 3, emotionally like a ke sharp cause ba kefetsa kgo bona ngoana 1 hour ela, ba ke fetla ko roomong, maybe ke tshwe ke re keya ko toilet, then ba ke thoma go nagana, ke thoma go lla, a ketse kgore kgodira halang, abang' putse and then ke nagana hore a sharp, hore maybe- ke nagana hore tsanege ke be le peace hore ke sa nagana into eo.

Interviewer: how's your mental wellbeing?

M4: mother 4, eish, jengamanje angikho right ngoba bengiqala ukucabanga kakhulu umzimba uyakhathala. Ngiyazizwa besengigula, sometimes ngiyakhala, so eish,

kubuhlungu. Kubuhlungu, angifuni ukuqamba amanga. Kubuhlungu, so ah asazi. But mina angikho right.

Interviewer: mentally ukugula or physically?

M4: sorry?

Interviewer: physically or phezulu?

M4: sometimes uyakhohla ukuthi mele udle. Uthole ubisi ufeed-e futhi, yabona. Awucabangi kakhulu yah. Usuka le ucabanga indlala. Sfika bakutshela enye into- uza! Nokubamba umntwana, uzazihlalela ubambe umntwana eish. I stress. Bangazi ukuthi ngale unjani, o ufika ngapha so thola okunye. Abantu laba bayangihlolela, umntwana wami uzaphila. Yabona. So kubuhlungu angifuni ukuqamba amanga. M5: mother 5, emotionally ke nagana re tloga counselling because the reason we are here ke some of the problems… and we thought we are strong until re land-a mo. cause nna ba ke nagana ke strong ka- cause ke re "it's fine, it's fine" kanti into e yang' affecta be ke fetla mo. i think if ba keyele counseling, i wouldn't be here. I think if ba ke fetlele mo, sister le doctor. I think counselling yao phumula, go erase-a into tsa morao and then o start-e afresh. Bao bontse dinto ba re tshwanege o bereke so, so ke nagana hore mentally ke yona.

M6: mother 6, nna a ke sharp, cause sometimes ke feel-a hare ke lla. Kgore why nna, ke diputsese if ase nna, e be mang? Yah, ke firstborn yaka- why kgo diregala so?

Interviewer: so already before the hours and sleep play- like put into the job of being here, you guys are already not okay because ngoana o ko ICU? Background: hmm

Interviewer: Umm okay… in terms of staff support mother 6, in terms of your emotional wellbeing?

M6: askies?

Interviewer: staff support, like o kreya support from staff, in terms of your emotional wellbeing ?

M6: hmm

Interviewer: okay, o ya kreya support from staff in terms of your emotional wellbeing?

M5: which staff?

Interviewer: neonatal staff (chuckles)

M5: are you talking about the sisters or the mothers or..

Interviewer: no, staff, batho aba bereka mo.

M5: ohh… the sisters and doctors. Interviewer:

batho aba bereka mo

M1: eh mother 1, mina from my side no, i don't. From the staff i don't get support.

M5: mina- for some of them yes, but for some of them, let's say 50/50, you already know that this one- i will not- even if- i will not.

M1: mother 1, like nna for my side, i'd say 90- not, but 10 percent yeh there are those, i know, when i see them i just become happy, even when i was down, hore for that day ke tloba happy- at least staff sesi tsene today, ngoana waka o tloba sharp. Ke tlo etse kgore kgo direhalang, even when i'm that side, i don't have to worry kgore ngoana waka a ka sala ajika basimmoni, cause ka etse kgore staff sesi tsene sela, ba tlomo support-a.

Interviewer: wena, support for wena?

M1: (chuckles) i'd say 90/10.

M5: mother 5, problem hore-

Interviewer: le re a le-sharp, leya ekreya support for lo nna? M5: they will talk about you like you are not here. So wena o feel-a hare a kgona into okababotsa yona cause kedi sister.

M6: 10% i-right, but 90% i- bangenza istress kithi. Yah. basingeza istress. The way wakhuluma ngawe, ngathi bakhuluma nomntwana omuncane. Yah. so bowubona something iyenzakala, awazi- awusoze ukhulume nabo, ufuna ukuthula ukuthi, is'khathi masihambe, ngizihambele ngiyohlala, hhayi ukuthi ngoyenza ini… ngiyohlala. Ukulala awusoze ulale. Uyocabanga ukuthi umntwana wami unjani, ne staff sinjani. And sibayazi, abaright siyabazi, abangekho right… nami ungathola umuntu oright, uya smile-a, besengibuyela ngithi "bye bye" ngiwazi- ngizowazi ukuthi uyosala right umntwana wami. Abanye, hhayi, uyobeka isikhathi ukuthi isikhathi asikahambi, ngihambe, umntwana uzasala asibonela naye. Akunanto engayenza but mina ngiyamuthanda umntwana wami.

Interviewer: okay, mother 3?

M3: nna support a keye kreyi. Like nako enwe ba ke botsesa doctor hore, ankere bang tlalosetsa hore ngoana o dirang, so ba ke botsesa doctor hore yena o tloba sharp na? Doctor ompotsa hore yena a etse, ja neh, maybe a mpotse hore "ya e ba le faith, ngoana o tloba sharp".

Yena a boleli ditaba, yena a re a etse.

Interviewer: hmm… i think because of time, i just want to ask two questions to mother 5, and 1 question to all the moms and then we can close. Neh. umm. Mother 5, you mentioned something about ke do sister, and um is there a power dynamic, bow'sothi like do you feel like aba sister baphezulu kuwe, in terms of how you treat them?

M5: in terms of?

Interviewer: like how you treat them and how they treat you, do you feel like- baku- do you treat them like baphezulu kuwe? In that sense… asithi mina ngikusister neh… uyangisaba, uyenza izinto cause ngikusister or ayikho lento leyo ewardini? M5: no it started, it starts well until they turn you down, so nna once i see motho o otla thuso, until they turn me down. So that's the problem. Cause obvious sister ke motho o tlhokometse ngoana… so the minute kemo botsesa question a turn-a down somara communication broken. A ke samo botsesa anything- awu feel-i sharp hore o ka botsesa yena.

Interviewer: okay… the other thing you mentioned is seeing death, does it affect you and your wellbeing in being there in the ward and seeing that? Mother- um M5: too much, too much, cause o robetse ko wardini ya hao, o shiyile ngoana, a wetse hore bo boa, they will call you aside, bao botse eng.

So yona yao affecta.

Interviewer: so you have that thing in the back of your head hore wenaM5: anytime, anytime. ba o betsa that means- so seeing a dead babyhhayi i cant.

Interviewer: any contributions before the last question… okay last question is umm how is family visitation in the ward. M5: as i've said nna a ba domele batho. A kgona letsatsi, a kgona sense. O ya ko ward-eng, o ya ko ngoaneng, o tsoga ko ngoaneng, you are not allowed to leave and buy a drink or something, you drink water and go.

Background: (chuckles)

Interviewer: in terms of family visitation for umntwana, let's talk about that. M5: i just told you hore only the father, mother, maybe your dad neh?

So they came once and that is it

Interviewer: and how long have you been here?

M5: 3 weeks.

Interviewer: is there someone longer than 3 weeks? M1:

2 months.

Interviewer: 2 months and only seen once?

M5: and since-

Interviewer: is that fair?

Numerous background responses: not fair

Interviewer:in 2 months a lot can happen.

Background: yes.

Interviewer: how does it make you feel ukuthi the family only comes once ukubona umntwana?

M1: mother 1, a kena choice, yah. I just have to accept hore kgojoalo, mara nna ayi tshware sharp.

Interviewer: Okay.

M5: Let's say the child came like the week after birth, then i spend maybe 4 or 5 weeks, then the child passed away. Since - since he saw the child when she was 3 days, 2 days or something, so you see.. Atleast if he see maybe once a week, maybe twice a week, and then they say hhayi the child is passed away, maybe he can be fine. Interviewer: mother 6?

M6: i have nothing to say Interviewer: okay… anyone else?

M2: mother 2, ngibona ngathi akukho right cause umm…more especially when they have to tell you something new ngomntwana, i think it's much better bakutshele ukuthi "call someone cause we want to tell you a certain thing ngomntwana and we don't think you can take it bawu 1. So i think ukuthi on that note, akukho right, like everything you have to take it alone. And that is very straining, alone.

Interviewer: okay… mother 3 and 4, ni sharp?... okay thank you guys, that is the end of the recording, before i close it- comments- ni sharp? Okay.

ANNEXURE R: PHASE TWO TRANSCRIPT

Interview six

Interviewer: Okay, hi, it's 17.04.2024 at 27 past 1. I am with Sister E, that's how you call yourself, or Nurse E, regardless your letter is E neh. So the study is on care by parent interventions and we'll be exploring the experiences of nurses in this particular… experiences of nurses and care by parent interventions in a NICU. Umm… to begin, could you please describe the routine for the mothers in the unit?

Interviewee: Okay, the mothers come three hourly to visit their babies. Umm… They're usually asked to bring along cotton wools, um, nappies, and surgical spirit. And then they come into the ward, take the chairs that are provided by the hospital, wash their hands, change their baby's nappies, wash their hands again, and then they're encouraged to breastfeed or to cup feed, whichever method is safe for their baby. Yeah, that's basically the routine that they do. They sometimes get health education, depending on the days or how hectic the ward is, yeah.

Interviewer: Okay, and the resources that you provide, are there any provisions for those who cannot afford?

Interviewee: Sometimes we do have, well, most of the times we are able to provide them with nappies, but unfortunately we can't provide with surgical spirit and cotton wool.

Interviewer: What happens in those situations?

Interviewee: Uhhhh… when the mother doesn't have nappies, we provide, or when the mother doesn't have surgical spirit and cotton, we usually let them use the hand sanitizer that we have in the ward.

Interviewer: Okay. And in terms of the mother's participation, is it only limited to the feeding and the nappy changing, or do they have other duties?

Interviewer: Well, most of the time, they are- it is limited to just feeding the nappies and onlycounselling sessions, where there will be a shared decision-making process that will be for very ill babies, or babies that are on vent but are not coping, or have to be extubated, but yeah, basically the activities that they do on their babies, and if needed, counselling sessions with the doctors.

Interviewer: What do you mean by the decision-making process? Shared decisionmaking?

Interviewee: I mean when, for example, you have a baby that is NNE, or is not coping, let's say on a ventilator, and the patient's condition is not improving, therefore the parents will be called in, and then the doctor, the consultant, and the parents will be there, they will be informed about the current conditions of their babies, and there is that option or decision to say they need to take off the baby on vent, put the baby on nasal prongs, because the- some indications medically that the baby is not going to make it, or the baby, we are not doing any good keeping the baby on vent, that's what I mean.

Interviewer: And in those decisions, is there a decision respected in terms of, if they say no, keep the baby on vent, do you continue with the vent, or what happens?

Interviewee: I've only seen it once, where the mother's, or rather the family's decisions was respected to say, okay, we're going to keep the baby on vent until the baby, the outcomes are there, and then, umm… (loud background noise) and then, in most of

the cases, we, not to say we do not respect their decisions, but because of their medical (someone who needed the participant was speaking) because of the medical, uh what can I say, indications that would say there is no uh that reflecting the baby's eyes are not responding to light, those are the things that would push, or rather be an indicator to, let's say, extubate the baby, but then in terms of where the parents do not understand, that's where we refer to the psychologist for further counselling.

Interviewer: Are there any other decision makings that you involve the mothers in, besides the critically ill babies?

Interviewee: I think that would be maybe on the feeding, but not, yeah, especially for mothers who are struggling for quite some time with er expressing milk, that's when they would have a sit down with the doctors and nurses to decide on a feeding plan for the baby, and obviously, what we call an FS score would be done to see if the mother would be able to afford the uh milk and has the resources like your electricity, and clean water too, yeah, that's one of the shared decisions that we involve the mothers in, yeah.

Interviewer: Okay. And what are your duties outside? Angisho the mothers, their duties you've stated, what are your duties?

Interviewee: Okay, ooh, a long list, but then, usually, umm my duties as a nurse every day, obviously, I'm obligated to do nursing care on their babies and uh when it comes to the mothers, I think most of the time is health educating them, reassuring, and referring to necessary, umm what can I say, multidisciplinary team members, that would be your psychologist, your social worker, sometimes we even have to refer to our art clinic, sometimes we have to go as far as rehab, because there is another place where they assist mothers who are on drugs and all that with, yeah, rehabilitation, so yeah. Yeah, then the long list is with the babies, obviously.

Interviewer: I want the neonatal list.

Interviewee: Okay, the neonatal one. Okay, let's just say at 7 a.m., we're in the ward, we're taking report, we're delegating duties according to the delegation principles. We then work in our allocated units. First thing of the day, obviously, is checking readiness for emergency in the room and in the ward as a whole. We're checking your emergency points, your oxygen points, your- your neopuff that we use to resuscitate, and then we have babies allocated to you, and obviously, personally, the first thing I do first is ensure

to delegate—ehh- the baby is identified- the baby that I'm nursing, the drip site, which can be a challenge. We also suction the babies, especially babies on the machines, on the ventilators, do the three hourly vital signs on babies that are on O2, on room air, and on CPAP. Then with babies on ventilators, we do the- uhh the vital signs two hourly, and then during the day, there will be those orders of doing the doctor's orders. There's ECGs, there's transferring babies out, there's sending babies to radiology for scans, there's sending babies to audiology. Err… There's just a lot of activity. Sometimes when you do get a chance, you bathe the babies, and most importantly, cleaning the incubators every start of the shift, which we try, but yeah. Then there's obviously giving off the medications, attending to other managerial or admin things that will be looking for overtime staff, doing other paperwork, and then also helping in high care, because we have high care, and then sometimes we have a high care supervisor, sometimes we don't. Then there's a professional nurse who's expected to assist with giving off bloods in high care, also helping the ENAs in the KMC with medication, be it oral- oral medication, helping with uh immunizations of babies, and also discharges, because that's what a professional nurse needs to oversee, the discharging and the immunizations of babies in high care. Even if you're having babies in ICU, you'll still be expected to oversee some of the activities in high care. Then obviously there'll be the drug counting, fetching of drugs, ordering, making of off duties, entering them, corresponding with the matron in terms of any other challenges that we might be encountering during the day, yeah.

Interviewer: Hmm… Because of the long list you've been named, do you feel that you are overwhelmed in your duties?

Interviewee: Yes, I feel I am, because as a professional nurse on duty working 7-7, I can have six babies, and all the other things that I've just mentioned that I need to do. And sometimes you'll have a very hectic day where there'll be resuscitations from high care, and remember, it's staff nurses that are working in high care then as a professional nurse, you need to take over that baby, there would be mothers who are not well, who are in our lodger facility that you need to take to casualty, call the gynae doctor. So I feel it is overwhelming when everything as a professional nurse looks upon you or is dependent on you, and you have nowhere else of loading, yeah.

Interviewer: Do you have support from the institution?

Interviewee: Ooh, no, I would say no. I've- I've never personally encountered having a session or rather a debriefing session, especially with umm nursing babies that are premature or big babies that demise, and you you've- yes, you know it's your duty to counsel the mother and see that they're emotionally er- er- attended to, but then what about you as a nurse who has nursed these babies, be it for one day, and I feel as a young person as well, I don't have a baby myself, but seeing young women at my age losing their babies, it takes a toll on you emotionally to think, what if it would be me, you know? And what- what support am I receiving now as a nurse that would not let me think of not having babies in the future because of what I see other people of my age experiencing?

Interviewer: So being in this, don't say role neh, has had an emotional toll on you?

Interviewee: Yes, it does, it does, especially when you- when you are not debriefed and… merely appreciation more than anything, just to say thank you and seeing the hard work that they're doing. I think that also goes a long way. So when you're not appreciated and you know- when you have no door to knock on to say, please offload, I am overwhelmed. I think thatthat does make it a bit emotional straining.

Interviewer: Hmm… Okay… In terms of other measures of support, do you get it from the institution? Kind of like you said that you might hold six babies, overwhelm with your work duties, does the institute assist in those areas?

Interviewee: (Laughs)… I don't know if it's safe to say this, but they always say stretch.

Interviewer: It's fine… Yeah.

Interviewee: Stretching means I can have 10 babies alone. I- I- I- don't want to say they assist because if you're on duty at- at the the starting of the shift and we are seven and there's 49 babies or 54, regardless of the number.

Interviewer: And it's an ICU.

Interviewee: Yeah, regardless of the number, you're having uh five ventilators or four CPAPs and you're only five RNs on duty. I mean, then you'll sit to finish. You'll overstretch, you'll ensure. And remember now, SANC says, you sign the delegation, you are responsible. And I won't turn away from work and let the babies suffer because we're only seven on duty. So I will nurse the seven babies or the 10 babies and do all the other work that I'm expected to do!

Interviewer: Do you feel like now you're being put in between a rock and a hard place? Because this side, you have babies that are ill, you can't just ignore them. And also this side, you don't want to take full responsibility for something that is an institution's problem and not well...

Interviewee: It is hard… and rocky kind of place because as much as I'm a professional nurse, I think my pledge comes first above everything. Then is the staffing issue, which is not really my problem as a professional nurse on duty, but I think it's an institutional thing. And then whenever you bring up staff shortage as- as- as- a topic or as an agenda in a meeting, it is always said it's a problem all over. Therefore, it's not something that will be addressed by the institution or by you or your unit manager. So yeah, it is kind of... Yeah…

Interviewer: Is having mothers- Is having mothers in the unit been an extra stress on work on top of the duties or been a relief of work and duties?

Interviewee: I think best of both. Relief in terms of feeding. Imagine having to have six babies that I would have to feed and change nappy. I think there it is the relieving part of it. But yet again, I don't want to generalize. They… You do find two types of mothers in the wards. You would find a mother who is quiet, taking instructions well and do what is expected of them. And as much as they might have emotional umm disturbances, they'll always maybe voice them out or report, or you will see as a nurse to say, okay, this mother's mood has changed during the week. Then you will refer accordingly.But then you would find difficult mothers who makes their presence felt in a very negative way. I'm saying that because of personal experience, I've had to deal with mothers who are just rude, who do not want to listen, be it is the doctor, be it is the nurse, be it is the other mothers trying to calm them down. And it's not always that they have psychological problems. It's just unfortunately an attitude that comes from home and is then in the institution. That sometimes it can be overwhelming. And the unfortunate part, sometimes you find yourself in an argument, as much as you try to avoid it, you end up having to argue with this mother or even not argue, but you try to make them see reason. And even if they would answer you in a rude manner that is unhealthy, youyou as a nurse have no way to say, I have been physically or verbally abused by this mother. That is, I think, one of the worst things ever to say. As a nurse, you have no way to report to. And even if you would report, you would some- see at the end of the day, some mothers will have these unspoken favours. And then you would wonder, but I have reported this mother, but there's no change. Or instead of change, they now have these favours to say, no, I spoke to the senior and she said, it's okay. I can have visitors more than once a week. And our protocol says the mother, the father, the father

of the baby, the two grandmothers, the maternal and the paternal grandmother and grandfather only visit the baby once. And if is a change in condition, the father would be allowed to come. But now there would be those certain things. So now it's it's a matter of a nurse patient relationship that is not working out or nurses to nurses. We are not on the same path or par in regards to the different patients that we have.

Interviewer: hmm

Interviewee: hmm

Interviewer: …So you feel like they are different. Let's just say wena you say something to them, then they go to someone else and then …

Interviewee: …they get a different story…true.
Interviewer: It just causes conflict.

Interviewee: Conflict… Yes, because I would say one thing, the other nurse would say one thing and then there will definitely raise conflict in the ward because then you will be seeing if you would be correcting something that is wrong as if you are the nurse that is uh problematic. You see, yeah.

Interviewer: Besides the barriers in communication, is there anything else that the mothers being here adds to your work or adds to?

Interviewee: Uhhh… Yes. You mentioned barriers of communication, which is what we get a lot with our foreign national mothers, as well as the attendance to personal hygiene because it is us who needs to encourage them attending to that. Uh… Their social problems. They have a lot of social problems that you would need to attend to, especially during the weekends and in the evenings when the social worker is not around. So yeah, those are the things that I think can be a bit of a heavy nyana with the mothers, yeah.

Interviewer: Okay. So the mothers, you said they come here every three hours. For how long?

Interviewee: They stay here for an hour. If they come in at nine, they will leave at ten. So it's three hourly for every 24 hours.

Interviewer: And how long do they usually stay?

Interviewee: An hour, but...

Interviewer: No, I mean like in the hospital.

Interviewee: In the hospital?

Interviewer: yeah.

Interviewee: Yoh… It varies. For term babies that are just on normal oxygen, a week max that I've seen. But then you must remember that within that week, we'll be- the doctors will be taking blood tests. They can be having sepsis or they're changing conditions. And then with your micro-prem babies that will be weighing like 830 gram, they can stay up to three months. Or the longest, yeah, the longest was 90 days that I've seen, 90 something days. So yeah, it varies from baby to baby. Then you've got your normal jaundice babies that will stay for three days or so. But if their uh uh jaundice has ABO incompatibility, that would need polygam transfusion, that could be more. Yeah.

Interviewer: Okay. I just wanna double tap on the 90 days, 90 something days. Do they still continue the cycle, even though they are staying 90 days or something?

Interviewee: Yes, they still continue the cycle of coming three hourly. Unfortunately, we do have pass outs for mothers to go home, but it is under serious, serious circumstances. Maybe a funeral uh at home or where they would just have to go maybe to the UIF office or something. But it must be a very, very serious reason that the mother would need to go home. Or even if it's for a day, I have seen where we've let a mother go home for a weekend. I think it was the mother who stayed the longest, yeah. 90 something days was one weekend. The baby was already on formula. So they let her go just for a weekend. And… Fortunately, the mother came back because if the mother doesn't come back, then it is an issue that involves the South African police. Yeah, and we will now treat it as abscondment because you do agree with the mother to say that you'll come back on this day… hmm.

Interviewer: Hmm…And seeing that they come every three hours for one hour and sometimes it's a very long period of time. How- How is their health? How is their sleep? Umm…

Interviewee: Umm… Their health, it varies. With chronic… uh mothers on chronic medications or with chronic illnesses, uh like I said, we do have lodger mothers that we will have to now refer to emergency department because they'll be needing refill of medication and all that. And then they have, I feel, okay, most of the time, I think postnatal for NVD mothers, they discharge after six hours. With C-sections, I think it's 24 or three days, I think. Now, it differs from patient to patient. There are some mothers, you would- they would fall ill in the ward. We've had a patient that we had to resus in KMC once. The mother was ill, we had to put in drips. The mother had to go to casualty… Their sleep, I must say, is really disturbed because, I mean, they're coming three hourly, even during the night, meaning at 9 p.m. they'll be here until 10. At 10, they go back to sleep. At midnight, at 12, we're expecting them to be here. They sleep in different units. Others are sleeping in the gynae ward. Others are sleeping in postnatal. Others are sleeping in a ward we call step-down ward, which is like outside of the main hospital building, meaning they have to walk outside to access the ward and come back inside the hospital to feed their babies at those hours. Well, there is securities during the evening, but, yeah, I must say their sleep disturbances is really, really affected, and it does take a toll on them eventually, emotionally, especially now that you will be here for more than 20 days and all that, and sometimes you see that your baby's not ill, so it does take a toll on them. I must say.

Interviewer: What measurements does the hospital have for it taking a toll on them?

Interviewee: Well, most of the time, it would be us nurses maybe seeing the change of behaviour or the change of mood in the mother, and most of the time, we just refer to the psychologist. That's the most that I do.

Interviewer: The problem is like sleep, so i-psychologist, what- what do they do?

Interviewee: Oh, I don't wanna lie, I don't know, but I think with the sleep one, we are not winning or we are not helping them in- in anything unless I've seen with mothers that take medications at 10, that would be maybe sleeping tablets that would be prescribed by a psychiatrist, maybe because the mother was referred to the psychologist, the psychologist referred to the psychiatrist. I've seen that we allow them to sleep until uh maybe at six in the morning, then their last visit would be at nine, and

then they'll come back the following day at 6 a.m., but for the rest of the mothers that are not medication, we do not help them.

Interviewer: Why is that?

Interviewee: I don't know. Umm… I found the system like that, umm and I think it would be hard to change the system umm because of the human resource factor. I think that would be the greatest contributing factor for us not to allow the mothers. I know some hospitals, they do allow the mothers to end their visit at nine and only come back at six, but their patient-nurse ratio allows them to be able to feed their babies and change their nappies, position changing, pressure care, and everything. So I think the biggest factor with us not being able to maybe change that from- to other hospitals would be the human resource factor. Yeah.

Interviewer: Okay, do you think it's a good thing for mothers to be involved in the care of their child so actively as they are?

Interviewee: I think it is good umm to some extent. It is that unfortunately, as people we are not the same, what I can take mentally, you cannot take mentally. Other mothers seeing their babies every day, seeing the progress or the deterioration means something to them. For other mothers seeing their babies on the vents, they see the worst. So I think for me as a nurse and as a person, I think it's best that they're here to see daily what is going on with their babies. Unlike on the phone, yeah, your baby's off oxygen or your baby changed condition and is now on a vent. I think if they're here, they will be able to see the escalation that is being done. And especially if maybe the baby has just aspirated, when the mother's feeding, they will be able to see the nurse uh suctioning the baby. If the baby needs, she will be able to see that whole process to say, they tried or they have actually intervened in whatever nursing need that my baby has. So I think it is positive if they're able to take it mentally, but it is detrimental for the mothers that are unable to- to- to cope with with the situation. I mean, some other mothers, it's the first time having a prem baby. For other mothers, they are primigravidas and they're already having an 830-gram baby. So I think it- it even if it's your first time, be it your second time, I think every hospital admission has its own effect on you as a person. So I think to some extent, it is good that they're here. They're seeing that we are working, we are doing. For some, it's good. For some others, unfortunately, it is kind of impacting negatively on their mental health and emotional zone, yeah.

Interviewer: You mentioned something about different compartments where the mothers stay.

Interviewee: Hmm

Interviewer: So they stay at the hospital, they don't go?

Interviewee: Yes, they are at the hospital until the day of the baby's discharge. Even when they are discharged from postnatal ward, they're still expected to stay at the hospital until their babies are discharged.

Interviewer: And the measures of like, let's just say they have umm a baby at home, they have school, maybe they have a sick parent that they are the ones taking care of. They're taking care of. What happens in those moments where they have to be here?

Interviewee: But they're needed somewhere else…

Interviewer: Yeah. As equally important.

Interviewee: Important

Interviewer: Yeah

Interviewee: yes. We always encourage finding help from other family members because especially, let me give an example. With a teenage mother who is in grade 10, they are now a mother. That is the unfortunate situation that we are in and they are now expected to carry on their duties and responsibilities of being a mother. So we would rather encourage the mother to find someone to carry out the other as important duties at home.

Yeah, that's what I've- we've been doing.

Interviewer: How do you find someone to carry out the duties of school?

Interviewee: And another, oh, well, with school, they don't go to school. We'd rather write them a letter to inform the school that the mother, or rather the baby, the mother has a baby and the baby is admitted and date of discharge is not known, but even when the mother is discharged after three months or two months, we still give them a letter to account for the days the mother has missed school.

Interviewer: Okay… and the one with the parents and the children, if there's no support system, what happens?

Interviewee: I think usually we would start the process and they would usually start with us informing the social worker, especially in situations where there is, maybe the mother just uh doesn't have any family around, the family is mostly in Limpopo, so we

would hand it over to the social worker who will be the one to liaise as to if there was to be someone to take care of that sick parent or that small kid. It usually ends up in the social workers officer. I'm not sure what is usually the end result in that regard.

Interviewer: Hmm… Okay, parental presence, both parents, what about the father?

Interviewee: The father is allowed to visit the baby once and if there's any change in condition of the baby, the father is allowed to come for counselling session and I personally, and I've seen other nurses have now picked up the trend of ensuring that we also refer the father for psychology as well. So yeah, the father is not as involved as the mothers, but we do encourage the mother to say, if the doctor speaks to you, being it is just a small thing to say, okay, mommy, we've weaned off the baby, I've stopped antibiotics, to inform the father to say, okay, this is where we are with the baby, so that they're also not anxious at home to say what is going on.

Interviewer: Okay. At the current moment with the whole policy on how you involve mothers in the neonatal, are you currently happy with the?

Interviewee: Involvement.

Interviewer: Yeah, no, I mean the current policy.

Interviewee: The current policy?

Interviewer: Yeah, on the involvement of the mother.

Interviewee: Umm… Yes and no. Yes, because they're here and we appreciate their presence, especially now when they're able to feed and remember, feeding time is bonding time for them as well. So they're not losing the time, the babies are in the hospital to bond with their babies, but they're here, they're bonding with the babies. No, because I feel there is maybe room to do more. I believe, and also with the fathers as well, I mean. Well, I mean, they never get to hold their babies, some of them, until maybe the baby's two months old already and only been discharged then. So I think in other hospitals I've seen they would allow the daddies to come in and kangaroo their mother- babies, premature babies. So I think there is room for improvement. Uhh… I think infrastructure can be one of the hurdles because our rooms are small and it can fill up to 16 to 20 babies depending on the number of admissions and we having and all that. So I think there is definitely room for improvement in involving them more. And I mean, we don't bath our babies because we're avoiding burns and we also don't have the proper infrastructure of bathing our babies. So I think infrastructure, uh uh nurse-patient ratios are the

hindrances of us not involving them more. But there is that room that we can create to- to allow the mothers and father, equally so, to be involved in their baby's care.

Interviewer: Okay. I wanna double tap on the environment neh. You said that you could even admit up to 60. How much is the ward supposed to have? Like, looking at the infrastructure.

Interviewee: Okay, um… we've got two ICUs. We've got two high-cares and two KMC rooms neh. And we have a lodger facility that is six-bedded. Our KMC room has eight beds, but because of twin babies, you'd end up having seven mothers, but with 10 babies neh… because of the set of twins. And then, in our ICU one, we are expected to admit or to only have eight babies, but you can go up to 13 in ICU one. You're expected to have maybe 10 to 15 in ICU two, but you can go over that.

Interviewer: Oh, 10 to 15 babies?

Interviewee: 10 to 15 babies in one room. And our isolation is three rooms, and then we can have it that full. And then when we have a fourth baby that needs to be isolated, you will just have them in an incubator-a closed incubator in whatever room they're placed in, be it high-care or ICU.

Our high-cares, there is one SOP that came out, I think in 2022, that mentioned that we need to have 45 babies in total in the ICU, in the unit, in the total unit. And it was said that the moment we have five ventilators, regardless of the number of babies, or 45 babies regardless of the ventilators, we are allowed to report to the consultant or medical doctor to have closure, to say we must not be accepting mothers that can deliver premature babies or whatsoever, or mothers that have pathologies need to be referred to another institution. So that practice is not being done, maybe because of other factors that may not be known to me, but you can have 60 babies, you can have 50-something. There was one year we even ended up at 70-something with more than five ventilators. So that is oneone of the biggest challenges that we face, that there is clearly overcrowding, which- which increases our infection rates, because then how do you control the IPC, Infection Prevention and Control, in an overcrowded area with the shortage of resources like your paper towels, sometimes you wouldn't have your hibiscrub to wash hands. So those are the factors that would be contributing to a lot of other things that we face in the ward.

Interviewer: Okay, thank you very much. Respecting you and your time.