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The lived experiences of South African parents during the prolonged hospitalisation of their premature baby

Linda Goldberg

Student number 8900415w

Supervisors:

Dr Janine van der Linde (OT)

Dr Jacqui Bezuidenhout (Clinical Medicine)

A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand Johannesburg in partial fulfillment of the requirements for a degree of Master of Medicine.

Ethical clearance number: M211152

Johannesburg 2024

DECLARATION

I , Linda Goldberg, declare that this research report is my own unaided work except for the help given by my supervisors and editor, as mentioned in my acknowledgements. The report is submitted in partial fulfilment of the requirements of the degree of Master of Medicine (Child Life and Psychosocial Care) at the University of the Witwatersrand and has not been submitted before for any other degree or examination in any other university.

Signed this day in Johannesburg.



_____

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Faculty of Health Sciences, Postgraduate Office
Phillip V Tobias Building, 2nd Floor
Cnr York & Princess of Wales Terrace, Parktown 2193
Tel: (011) 717 2745 | Fax: (011) 717 2119
Email: Mathoto.senamela@wits.ac.za

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ABSTRACT

The act of becoming a parent has been described as an evolutionary significant life event; however, with the premature arrival of a baby, this transition can be altered abruptly, with short- and long-term consequences for both the parents and the premature baby. This study aimed to explore the lived experiences of South African parents during the hospitalisation of their premature babies in a Neonatal Intensive Care Unit (NICU) at a private hospital.

The research study followed a qualitative phenomenological study design using purposive sampling to identify participants in Johannesburg. Forming the eleven semi-structured interviews - eight mothers and three fathers were interviewed on a single occasion. Within this sample, three of the mothers and the three fathers interviewed were married and cohabiting. An inductive thematic analyses was performed to establish emerging codes, categories and themes. The codes were developed using MAXDA software.

Three themes emerged, highlighting the experiences of 11 parents during a NICU admission period. The themes were 1) Journey to NICU—context of pregnancy, 2) Transition to parenthood in NICU—Parenting in an unnatural environment, and 3) Coping with the emotional journey during a prolonged NICU stay. The findings contribute to available research pertaining specifically to the South African private health care setting as well as highlighting similarities and differences within the global body of research.

ACKNOWLEDGEMENTS

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Dr Janine van der Linde and **Dr Jacqui Bezuidenhout** for their supervision, guidance, and encouragement.

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My husband **Jonathan**, and my children **Ariel, Talli, and Ilan**. Thank you for your constant patience, support, and endless love. You saved me on so many occasions when I was ready to give up. This research is dedicated to you.

LIST OF ABBREVIATIONS

Abbreviations below are used in the text presented in future chapters.

ACE	Adverse Childhood Events
ART	Antiretroviral Therapy
ASD	Acute Stress Disorder
C-SECTION	Caesarean Delivery
CBT	Cognitive Behavioural Therapy
CLS	Child Life Specialists
CPP	Child-Parent Psychotherapy
FCC	Family-Centred Care
FCDCP	Family-Centred Developmental Care Programme
GA	Gestational Age
HIV	Human Immunodeficiency Virus
HPA Axis	Hypothalamic Pituitary Adrenal Axis
IQ	Intelligence Quota
IPTB	Iatrogenic Preterm Birth
LMC	Last Menstrual Cycle
NICU	Neonatal Intensive Care Unit
PCC	Person-Centred Care
POPI	Protection of Personal Information
PTSD	Post-Traumatic Stress Disorder
PVL	Peri ventricular Leukomalacia
RCT	Random Controlled Trials
SFR	Single-Family Room

SPTB	Spontaneous Premature
WHO	World Health Organization

OPERATIONAL DEFINTIONS

Term	Definition
Adverse childhood event-ACE	Negative events or life circumstances occurring during childhood that can impact long-term mentally and physically
Acute stress disorder-ASD	A short-term mental health response characteristically occurring within a month post exposure to a traumatic event or experience
Bronchopulmonary dysplasia	A chronic lung disorder characteristically associated with prematurity
Cerebral palsy	A non-progressive movement and posture disorder associated with an insult to the developing brain
Child life specialists-CLS	A member of the health care team that assists parents and children navigate hospitalisation, illness and trauma
Family centred care-FCC	An approach to health care suggested within the NICU environment , encouraging parental involvement and participation
Gestational age	Time period that foetus develops and grows within the uterine environment
HPA Axis	Interactive feedback system involving the Hypothalamus, pituitary gland and adrenal gland, affecting several body systems and stress
Hyaline membrane disease	Respiratory distress syndrome often associated with premature birth
Hypoxic Ischaemic encephalopathy	An injury to the brain that may occur during pregnancy, at birth and post natally, associated with reduced blood flow and decreased oxygen supply to the brain
Iatrogenic Preterm birth	Premature delivery associated with a planned delivery in the absence of labour. Generally associated with caesarean deliveries .
Kangaroo care	The practice of holding the baby to a person's chest, usually the parents, to assist with the baby's autonomic regulation and development
Neonatal Intensive care unit- NICU	A specific unit in a hospital where premature and/or sick babies are cared for immediately post delivery

Medical fragility	Health status/conditions requiring 24hour medical supervision by trained nurses and doctors.
Periventricular leukomalacia-PVL	White matter brain injury often associated with prematurity
Person centred care-PCC	Treating parents as individuals during a hospital admission and including them as equal partners in the care of their premature baby
Prolonged admission	In the context of the research- an admission longer than 4 weeks
Post traumatic stress disorder-PTSD	Long lasting mental health condition associated with experiencing a traumatic event. Symptoms include anxiety, flashbacks and nightmares
Prematurity	Arrival of a baby less than 37 weeks completed gestation age.
Spontaneous preterm birth	Unintentional premature arrival of a baby, generally without a specific cause
Trauma informed care	Providing care to people with the knowledge and understanding of the effects of trauma on a person's life.

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CHAPTER 1: INTRODUCTION

The premature arrival of a baby can compromise the anticipated positive transformation to parenthood that all parents desire. The fragile medical status of the baby, uncertain developmental trajectory and extended hospital admission period are all factors that disrupt this transition (Tooten *et al.*, 2014). A gamut of parental and environmental influences affecting a successful transformation underlie the challenges of this evolution to parenthood within a neonatal intensive care unit (NICU). The literature highlights that this altered shift to the parental role and its effects on the psychological well-being of the parents are the most significant consequences of the admission of their premature infant to a NICU (Lundqvist, Weis and Sivberg, 2019). This research aims to explore and understand the lived experiences of South African parents during the admission of their preterm baby in the NICU environment.

The Oxford Dictionary defines lived experience as ”Personal knowledge about the world gained through direct, first-hand involvement in everyday events rather than through representations constructed by other people. It may also refer to knowledge of people gained from direct face-to-face interaction rather than through a technological medium” (Chandler and Munday, 2020).

Previous research describes diagnostic signs and symptoms of post-traumatic stress disorder (PTSD), acute stress disorder (ASD), and anxiety and depression in parents both during and post-discharge from a NICU (Harrison, 1993; Pace *et al.*, 2016; Roque *et al.*, 2017; Treyvaud *et al.*, 2019). Roque *et al*. (2017) note that increased research over the past ten years has identified that 23–28% of parents meet the diagnostic criteria of ASD following the admission of their infant to a NICU (Roque *et al.*, 2017). The increased mental health challenges appear to be caused by a multi-faceted array of reasons particular to the NICU environment and the nature of prematurity with its associated medical ramifications.

Both intrinsic and extrinsic factors influence parental perceptions and experiences in the NICU. Intrinsically, parents feel a strong sense of separation and constrained opportunities to participate in parenting roles (Fegran, Helseth and Fagermoen, 2008; Roque *et al.*, 2017; Petty, Jarvis and Thomas, 2019). Parents have reported this separation as one of the factors that increases anxiety, fatigue and depression (Treherne *et al.*, 2017). Extrinsically, the physical neonatal environment and their

infants' appearance and behaviour patterns may provide negative experiences (Petty, Jarvis and Thomas, 2019). Physical distance and reduced opportunities to participate in daily care routines create a physical and emotional separation whereby parents feel like visitors and not parents (Treherne *et al.*, 2017).

The psychosocial fallout accompanying NICU admission and post-discharge has an impact on both the parents and the baby. Parental relationships and the bond with their baby are impacted, ultimately affecting the baby's developmental trajectory (Loewenstein, Barroso and Phillips, 2019). Globally, there has been a shift in the focus of care within the NICU environment (Skene *et al.*, 2019). Guidelines for FCC specific to the South African NICU environment have been developed (Lubbe, 2010). However there is very limited research into the implementation of FCC within the NICUs in South African hospitals, both private and government (Maree *et al.*, 2017a; Abukari and Schmollgruber, 2023). With the introduction of the Family Centred Care (FCC) approach, the medical fragility and care of the preterm baby is no longer the sole priority within the NICU. Parental involvement and partnership have become a focal point of importance during the admission of a preterm baby in the NICU (Hall *et al.*, 2017).

1.1 Problem Statement

The experience of having a baby born prematurely and the subsequent admission of their newborn infant into a neonatal intensive care unit (NICU) can be a traumatic and distressing experience for their parent (Treyvaud *et al.*, 2019). However, Petty, Jarvis and Thomas (2019) report that parents have both positive and negative emotional experiences during the NICU admission of their infant, and both are significant to the parent and their ability to cope with this period of their admission. The authors highlight the limited availability of literature focused on reporting positive parental experiences (Petty, Jarvis and Thomas, 2019). By understanding both the positive and negative experiences, holistic, multi-disciplinary care can be achieved for both infants and parents during this stressful time (Petty, Jarvis and Thomas, 2019).

Worldwide, the philosophy of family-centred care (FCC) within the NICU environment is gaining momentum (Skene *et al.*, 2019). The FFC philosophy underpins the need for healthcare professionals to understand and consider parental experiences in the NICU to create an environment in which parents are supported and partnered with in infant care (Skene *et al.*, 2019). This partnership of FCC is one of the cornerstones of

neuro-protective infant care in the NICU (Altimier L, 2013). The link between FCC and improved emotional support and positive emotional experience for parents in NICU has been described in the literature (Franck and O'Brien, 2019; Abukari and Schmollgruber, 2023). One of the pillars of FCC, the promotion of information sharing has been shown to reduce stress, anxiety and depression amongst parents in the NICU (Franck and O'Brien, 2019).

Furthermore, research highlighting the lived experiences of parents in the South African context is limited (Steyn, Poggenpoel and Myburgh, 2017), highlighting the need for further research, both in the private and government sectors of the healthcare system. Steyn, Poggenpoel and Myburgh (2017) explored the lived experiences of parents in a single private NICU facility in Johannesburg and Nyaloka, et al. (2024) explored parental experiences in a single government facility in Limpopo. The latter research focused on cultural determinants of caring for a preterm infant in NICU.

1.2 Research Question

What are the experiences of South African parents during the prolonged hospitalisation of their preterm infant in the neonatal intensive care unit?

1.3 Aims of the Study

To explore the experiences of South African parents during the admission and hospitalisation of their preterm baby in the neonatal intensive care unit.

1.4 Objectives of the Study

- To explore the parental experiences during the NICU admission of their preterm baby in a private medical facility .
- To compare the emerging themes with existing research findings from other countries.

1.5 Significance of the Study

"Understanding the emotional experience of having a premature baby from the parent's perspective should be an essential part of neonatal education worldwide" (Petty, Jarvis and Thomas, 2019:1911). Providing a high level of care in the NICU environment depends on a multidisciplinary team acquiring the knowledge to care for both the

neonate and their parents (Petty, Jarvis and Thomas, 2019). Child life specialists (CLSs) are members of a multidisciplinary team providing family- and child-centred care in some NICU settings (Romito *et al.*, 2021a). Parental anxiety related to their child's illness, diagnosis and treatment procedures is known to affect the child; consequently, the role of the child life specialist is to offer psychosocial support and impart coping mechanisms to the parents (Romito *et al.*, 2021a).

Jackson, Ternestedt and Schollin (2003) conceptualised a framework describing the interacting factors that influence parental experiences with a premature baby. These include parental perceptions of themselves, their parental role, and perceptions of the child and the NICU environment. The stressful parental experiences associated with prematurity affect the quality and type of attachment between parents and their infants (Forcada-Guex *et al.*, 2011). Identifying the context-specific experiences of parents in South African NICU settings is vital for informing policy, promoting family-centred care in our NICU environments and ensuring appropriate neonatal education for the multi-disciplinary team. This research is significant in that a single private sector NICU facility was not chosen as a source of the sample of parents, but rather purposive sampling resulted in four different units forming the backdrop to the NICU admission.

1.6 Outline of This Research Report

The research report consists of five chapters. Chapter 1 provided the introduction. Chapter 2 provides an in-depth literature review of the key components of the study. Chapter 3 reports on the methodology used for this research report, including the search strategy and data collection process. The results and discussion are discussed In Chapter 4 . The conclusion and recommendations are discussed in Chapter 5 highlighting the implications of this study for clinical practice and recommendations for future research. Figure 1.1 contains the outline of this research report.

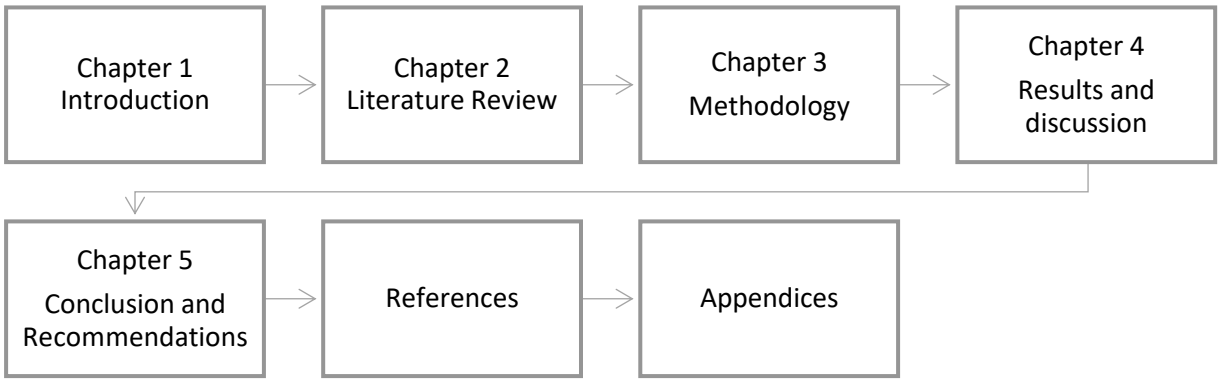


Figure 1.1 Outline of Research Report

CHAPTER 2: LITERATURE REVIEW

Becoming a parent is described as a major life event. With the premature arrival of their baby, this transition from a partner, husband and wife to a parent, mother and father might be both stressful and prolonged (Tooten *et al.*, 2013; Maree *et al.*, 2017b; Martins, 2019).

Due to the plethora of multi-system complications that might follow a premature delivery, the admission of the baby into a NICU might be essential to delivering the specialised lifesaving medical care the baby requires. However, this environment may not be ideal for facilitating the new parents' desired transition to parenthood (Maree *et al.*, 2017b), resulting in increased stress and challenges to existing relationships (Roque *et al.*, 2017). Parents yearn to be active participants in the care and decision-making of their newborn premature baby while navigating the uncertainty of prematurity, ultimately hoping for positive neurodevelopmental outcomes (World Health Organisation, 2022). Exploring the lived experiences of parents during this life event allows us to understand and appreciate the impact and significance for the parents and baby (Lundqvist, Weis and Sivberg, 2019).

Lived experience refers to events someone has experienced themselves, especially when these furnish the person with knowledge or understanding not possessed by people who have only heard about such experiences (Cambridge Dictionary, 2023).

The literature review explored research pertaining to the lived experiences of parents during the admission of their newborn premature baby to the NICU environment. Research and information pertaining to classification of prematurity, prevalence of prematurity , risk factors and medical considerations (short-term and long-term ramifications of prematurity on the baby) was presented to give further context to the parental experiences.

2.1 Classification of Prematurity

2.1.1 Classification by gestational age

The WHO classifies a premature birth as any live birth before 37 completed gestational weeks or fewer than 259 days from the first date of the last menstrual cycle (LMC). The WHO further divides prematurity into three gestational age (GA) categories:

- Extremely preterm: Infants born at fewer than 28 weeks GA.

- Very preterm: Born at gestational ages of 28–32 weeks GA.
- Moderate to late preterm infants: Born at 32–37 weeks GA.

(World Health Organisation, 2023).

As fetal growth is variable, this definition of fewer than 37 weeks gestation has been set arbitrarily for epidemiological and research purposes and not on specific developmental parameters (Vogel *et al.*, 2018). The gold standard for determining GA is by early pregnancy ultra-sound; however, in low-resourced countries, various other indicators are used, such as date of LMC, symphysis-fundal height and postnatal examinations of the newborn (Vogel *et al.*, 2018). The reliability and variability of methods of estimating and determining GA affect the reporting of incidence and rates of prematurity, thus making it challenging for research outcomes and medical services planning (Vogel *et al.*, 2018; Ramokolo, V. et al., 2019). According to Walani (2020), 84% of premature births occur at 32–36 weeks gestation, 10% in the 28–32 weeks bracket and 5% below 28 weeks gestation.

The significance of this classification to the parental experience in NICU, is the evidence that suggests that the level of prematurity at birth may impact the severity of parental psychological distress post-delivery. The possible mediating factors include the increased medical fragility , longer admission period and possible long-term disability associated with a GA at birth (Vigod *et al.*, 2010).

In addition to classifying prematurity according to GA, the aetiology and phenotype of prematurity have also been highlighted as a form of classification. (Villar *et al.*, 2012; Vogel *et al.*, 2018). Villar *et al*. (2012) suggest that in understanding the aetiology of prematurity, one has to recognise that there is no single cause of prematurity but rather an array of overlapping factors resulting in a premature birth (Villar *et al.*, 2012).

2.1.2 Classification of prematurity by phenotype

Villar *et al*. (2012) suggest classifying preterm birth according to phenotypes, including maternal characteristics, foetal characteristics, placental characteristics, signs of labour and the route to delivery (Villar *et al.*, 2012). This classification has been updated into a nine-phenotype classification system, facilitating easier identification of possible aetiologies of premature birth. The nine phenotypes include:

- infection/inflammation

- decidual haemorrhage
- maternal stress
- cervical inefficiency
- uterine distention
- placental dysfunction
- preterm rupture of membranes
- maternal comorbidities
- familial factors

(Ramokolo, V. et al., 2019)

Prematurity is also classified in terms of spontaneous preterm birth (SPTB) and iatrogenic preterm birth (IPTB) (Purisch and Gyamfi-Bannerman, 2017). SPTBs account for 67% of premature deliveries, causes of which include preterm labour, premature rupture of membranes and spontaneous delivery in the second trimester. IPTBs occur as a result of a plethora of maternal and fetal medical complications, such as preeclampsia, uncontrolled diabetes, abnormalities in the placenta and intra-uterine growth restriction (Purisch and Gyamfi-Bannerman, 2017). These complications associated with IPTB are often such a significant threat to either or both mother and baby that obstetric intervention is considered, even at the known risks of prematurity (Platt, 2014).

2.2 Prevalence of Prematurity

In 2020, an estimated 13.4 million babies were born prematurely, with a rate of 9,9% of live births. This rate has not changed significantly between 2010 and 2020 (World Health Organisation, 2023). The prevalence appears to be higher in low- and middle-income countries, with Asia and sub-Saharan Africa accounting for 81.8% of premature births in 2014 (Chawanpaiboon *et al.*, 2019; Walani, 2020). In 2020, the preterm birth rate in sub-Saharan Africa was 10.1% (World Health Organisation, 2023). The World Health Organisation (WHO) estimates that in 2020, 10–15% of babies were born prematurely in South Africa. This rate signifies an increase from the 2014 estimate of 12.4 premature births per 1000 live births (Chawanpaiboon *et al.*, 2019; Ramokolo, V. et al., 2019; World Health Organisation, 2023). Comparing preterm birth rates by region is challenging due to limited reporting, varying definitions of prematurity, and possible discrepancies between live birth and stillbirth reporting. A

live birth indicates that there were signs of life within the first hour post-delivery (Ramokolo, V. et al., 2019), irrespective of the gestational age, whereas a stillbirth is defined as death after 28 weeks of pregnancy either before or during the birthing process (WHO, 2021).

2.3 Risk Factors Associated with Premature Birth

Reducing the risks of premature birth requires an understanding of context and country-specific risk factors for premature delivery. High-income countries have achieved some success in reducing preterm birth; however, this is not reflected globally (World Health Organisation, 2023). The exact aetiology and interaction of risk factors and premature delivery remain elusive and require further research (Vogel *et al.*, 2018; Ramokolo, V. et al., 2019).

In their report “Born Too Soon”, the WHO identified a variety of risk factors associated with an increased risk of premature birth (World Health Organisation, 2023). Risk factors associated with increased SPTB include the age of the mother, spacing of pregnancies, multiple pregnancies, maternal infections, maternal nutritional status, underlying maternal chronic medical conditions, alcohol consumption, drug usage, maternal psychological stress, violence, genetic predisposition, and adverse childhood events (ACE) (World Health Organisation, 2023).

In South Africa, several known lifestyle and medical risk factors increase the occurrence of premature birth. These include smoking, the use of illicit drugs, illegal terminations, Human Immunodeficiency Virus (HIV) and the use of antiretroviral therapy (ART) regimes (Ramokolo, V. et al., 2019).

The risk of premature birth is not exclusive to high-risk pregnancies and unwell mothers. Well-nourished women with low-risk pregnancies still have a 4% risk of delivering prematurely (Vogel *et al.*, 2018). Therefore , not being able to prevent the occurrence of premature births, highlights the importance of health professionals understanding parental experiences in NICU and the best manner in which parents need to be supported.

2.4 Medical Considerations of Prematurity

The WHO (2023) reports a large discrepancy in the survival rates of premature babies globally, ultimately depending on adequate provision of appropriate medical care and resources. In well-resourced, high-income countries, nine out of ten babies born extremely premature (fewer than 28 weeks GA) survive. Conversely, in low-income countries, nine out of ten extremely preterm babies do not survive (World Health Organisation, 2023). A baby born at 32 weeks gestation in a low-income country has only a 50% survival rate, whereas in the United States of America, 50% of babies born as early as 24 weeks gestation survive (Walani, 2020).

Ramokolo *et al.* (2019) quote Seri *et al*. (2008) in defining the minimum viable GA as the GA at which 50% of infants born have a reasonable chance of survival. In South Africa, this rate is currently 27 weeks GA, whereas in high-resource settings, 23–24 weeks GA is considered viable (Vogel *et al.*, 2018; Ramokolo, V. et al., 2019). Traditionally, in South Africa, in the governmental hospital setting, birth weight and not GA has been the admission criterion. This standard has possibly denied care to viable preterm babies. While weight at birth is still a considerable factor in admission policies, it has decreased from the original 1kg minimal weight in the 1990s to 800g currently (Ballot *et al.*, 2019).

Prematurity and its complications account for the highest cause of mortality in children under the age of five (World Health Organisation, 2023). In 2016, estimated complications due to prematurity accounted for 16%–18% of global deaths under five and 35% of deaths in the newborn period (first 28 days of life) (Vogel *et al.*, 2018; Walani, 2020). In South Africa, complications relating to prematurity are the highest cause of neonatal death (Masaba and Mmusi-Phetoe, 2020). Premature births account for 49.2% of neonatal deaths in South Africa (South African Department of Health, 2021). The South African medical landscape is characterised by a dual system of private and government services. Ballot *et al*. (2019) highlight the challenges of neonatal care within the government sector related to staff shortages, cost of care and limited NICU availability (Ballot *et al.*, 2019).

A panoply of complications affects the preterm baby because of their immature organs and unstable physiological and anatomical systems. These complications are evident in the short term and extend into the baby's adult life. The newborn premature baby often experiences respiratory complications requiring mechanical ventilation (hyaline

membrane disease, bronchopulmonary dysplasia), digestive and feeding challenges (necrotising enterocolitis), systemic (infections) and neurological complications (periventricular leukomalacia, seizures, hypoxic ischaemic encephalopathy, cerebral palsy, and visual and hearing impairments) (Morniroli *et al.*, 2023). Long-term, researchers have been able to identify the consequences of prematurity on the cognitive, emotional, behavioural and motor developmental trajectories of premature babies (Vogel *et al.*, 2018; Miguel *et al.*, 2019; Givrad, Hartzell and Scala, 2021; Morniroli *et al.*, 2023).

Studies denote a relationship between GA and several neurodevelopmental outcomes associated with prematurity. In their study of infants born within specific GA categories, Sansavini *et al*. (2011) demonstrate that GA influences developmental trajectories. Babies born ≤28 weeks GA demonstrated detectable motoric delays as early as within their first year of life. Importantly, these motor delays were present even in the absence of a cerebral palsy diagnosis. Babies born between 29–32 weeks GA exhibited fewer significant impairments that became more apparent only after the second year post-delivery. That study used the Griffiths assessment tool to assess the babies at intervals of six, 12, 18, and 24 months (Sansavini *et al.*, 2011).

In their meta-analyses of intelligence quotient (IQ) corresponding to prematurity, Kerr-Wilson et al. (2011) find a constant relationship of decreasing IQ with decreasing GA (Kerr-Wilson *et al.*, 2012). Pierrat *et al*. (2017) demonstrate the inverse relationship between GA and the rate of CP. Babies born between 24–26 weeks GA had a rate of 6.9%, 27–31 GA had 4.3%, and 32–34 GA had 1% (Pierrat *et al.*, 2017).

The effects of prematurity on organ development have been associated with chronic health conditions, affecting the renal and cardiovascular systems and may extend into adulthood (Morniroli *et al.*, 2023). Among young adults born extremely prematurely (<28 weeks), there is a 40% higher mortality rate due to the long-term effects of prematurity on the respiratory, endocrine and cardiovascular systems (Luu, Rehman Mian and Nuyt, 2017).

Prematurity not only presents direct medical and neurodevelopmental challenges for the infant, but the admission to a NICU environment in itself presents a cascade of distressing experiences and environmental challenges, impacting the infants and their families (Kim and Kim, 2022). The premature arrival of a baby, often requiring an emergency delivery, may be incongruent with the parents' expectations and hopes for

their pregnancy, delivery, and discharge plan with their newborn baby. In a systematic review of qualitative studies exploring the lived experiences of parents during their baby's NICU admission, Al Maghaireh (2016) identified the increased psychological stress experienced by the parents with common themes emerging, namely the challenges with their emerging role as parents, the precarious medical condition of the baby and the NICU physical environment. This study discusses these elements of the parental lived experience during the admission of their premature baby in NICU in greater detail in paragraph 2.6.

2.5 Socioeconomic, Cultural and Racial Considerations Impacting Prematurity

Scholars have highlighted the impact of race, segregation and inequality of healthcare on preterm infants in the USA (Beck *et al.*, 2020). A sociodemographic disadvantage, inequitable healthcare and race-specific increased risk affect preterm infant outcomes (Beck *et al.*, 2020). In the United States of America, Black non-Hispanic women are at a significantly higher risk of having a preterm birth than white non-Hispanic women (Manuck, 2017). In England and Wales, ethnicity and race differences have also been noted. Black African mothers and Black Caribbean mothers have a higher percentage of premature deliveries than the average population rate. However, this data is tempered by emerging research that mothers of Black Caribbean and Black African origins might indeed have naturally shorter pregnancies, by six days, than women of white European origin (Platt, 2014).

Ramokolo *et al*. (2019) do not mention racial differences in preterm birth in their landscape analysis of preterm birth in South Africa (Ramokolo, V. et al., 2019). However, the authors highlight the decreased availability of appropriate healthcare within the governmental healthcare system, with only tertiary hospitals in large centres providing appropriate NICU care (Ramokolo, V. et al., 2019). This research was based on government health provision and did not highlight healthcare in the private sector. The dearth of information about prematurity in South Africa should be addressed and requires further research in both the public and private health sectors.

2.6 Exploring the Lived Experiences of Parents

Common themes emerge from exploration and research into the lived experiences of parents during the admission of their preterm baby in the NICU. Psychological distress and challenges in achieving the parental role appear to be two universal themes; however, there exist context-specific differences often related to individual resources available, economic influences and maternal/paternal differences (Al Maghaireh *et al.*, 2016; Steyn, Poggenpoel and Myburgh, 2017; Trumello *et al.*, 2018; Lundqvist, Weis and Sivberg, 2019; Namusoke *et al.*, 2021; Adu-Bonsaffoh *et al.*, 2022). This study discusses these two themes in more detail further on.

Lasiuk Comeau and Newburn-Cook (2013) succinctly expressed the lived experiences of parents during the admission of their premature babies to the NICU. The authors describe the parents as living in a state of ambiguity and disorientation: “They existed in a liminal state, in which their babies had been born and yet not quite born and they were parents, but not really able to parent.” (Lasiuk, Comeau and Newburn-Cook, 2013).

2.6.1 Parental psychological distress and mental well-being

The parental mental health challenges experienced during their baby’s admission to the NICU and post-discharge are known to impact the baby’s development and general health in the long term (Garfield *et al.*, 2021). Hynan and Hall (2015) describe the NICU environment as “akin to a trauma centre for all participants. Fragile babies struggle to survive and grow. Parents and families worry constantly whilst trying to maintain optimism and hope… ” (Hynan and Hall, 2015:1). A traumatic event, as described by the American Psychological Association, threatens one’s own life or that of a family member and is accompanied by distress and vulnerability (Lasiuk, Comeau and Newburn-Cook, 2013).

With repeated exposure to stress, whether short- or long-term, the body responds on a multi-systemic level with the activation of the sympathetic, parasympathetic and hypothalamic–pituitary–adrenal axis (HPA), creating an internal environment where cortisol influences and mediates the flight and fight response seen with stress (Sanders and Hall, 2018).

Existing research describes the diagnostic signs and symptoms of post-traumatic stress disorder PTSD), acute stress disorder (ASD), and anxiety and depression in

mothers and fathers during and after discharge from the NICU (Harrison, 1993; Pace *et al.*, 2016; Roque *et al.*, 2017; Loewenstein, Barroso and Phillips, 2019; Treyvaud *et al.*, 2019). In examining the likelihood of postpartum depression (PPD) in mothers following preterm delivery, the risk is between 28% and 40%, which is double the rate post-full-term delivery, and paternal risk is noted at 2%–19%. The research notes no GA or reference to NICU admission (Garfield *et al.*, 2021). Roque *et al*. (2017) comment on the inverse relationship between lower GA and increased symptoms of depression in mothers. The authors propose that other risk factors for increased risk of depression include longer admission periods and increased medical fragility, which are often associated with lower GA (Roque *et al.*, 2017).

It is often difficult to correlate research on parents' emotional and mental well-being, for various reasons. Researchers employ several methodologies, including quantitative, qualitative, and mixed methods approaches. In addition, GA, the timing of research interventions, the location of the study and the study participants often not being consistent, and the over-representation of mothers can make it challenging to compare findings (Ireland *et al.*, 2016; Roque *et al.*, 2017; Loewenstein, Barroso and Phillips, 2019).

Understanding the trajectory of stress, anxiety, and depressive symptoms during admission and after discharge would allow for planning interventions. Pace *et al*. (2016) offer insight into changes in parental depression and anxiety symptoms over time, during the NICU admission. This research specified gestational age (<30 weeks gestational age), and the timing of the research (up to 12 weeks post-delivery) and included a control group of parents of full-term healthy babies. The results indicated that both parents experienced increased symptoms, most notably early on after delivery, with a decrease at 12 weeks post-delivery. Despite the decrease, there was still a notable difference between the research and control group, even at six months post-discharge (Pace *et al.*, 2016). This result is similar to Garfield *et al*. (2021), who found initially increased diagnosable signs of depression after delivery in both mothers and fathers of preterm babies (≤37 weeks GA) admitted to the NICU. Post-discharge, maternal symptoms of depression decreased with time (up to 30 days post-discharge of the baby from the NICU); however, the fathers continued to display increased signs of stress symptoms, with a smaller difference between the admission period and 30 days post-discharge. These findings suggest the need for monitoring both parents during and after the NICU admission (Garfield *et al.*, 2021; Shovers *et al.*, 2021).

Ireland *et al*. (2016) further report that fathers of babies born at fewer than 30 weeks GA are more prone to signs of depression than fathers of full-term babies.

Trumello *et al*. (2018) further highlight that the majority of research on identifying stress and mental well-being of parents during the admission period is focused towards parents of babies born extremely preterm, whereas there is less research on parents with babies born in the later preterm categories (Trumello *et al.*, 2018). This imbalance may be due to the length of stay of the extremely preterm babies compared to babies born between 32 and 37 weeks GA (Tooten *et al.*, 2013). There does not appear to be a consensus on whether GA is a significant factor in influencing parental mental health signs and symptoms. Trumello *et al*. (2018) demonstrated that GA was not a determining factor in the levels of anxiety and stress experienced by mothers during NICU admission (Trumello *et al.*, 2018). However, Tooten *et al*. (2013) found that lower GA indeed had a greater impact on parental experience and emotional well-being (Tooten *et al.*, 2013).

An array of factors with an influence on parental mental health and distress during the NICU admission period have emerged in the research. The most common themes include, in no particular order of importance or significance:

Transition to the parental role

The NICU environment—sounds, equipment, artificial lighting

The medical fragility and physical appearance of the baby

Physical separation

Prevalent attitudes and cultural beliefs on fatherhood and the role of fathers

(Fegran, Helseth and Fagermoen, 2008; Ireland *et al.*, 2016; Roque *et al.*, 2017; Treherne *et al.*, 2017; Petty, Jarvis, and Thomas, 2019; Kim and Kim, 2022).

Concurrently, researchers have highlighted personal and sociodemographic parameters with a mediating effect (Roque *et al.*, 2017; Sanders and Hall, 2018; Givrad, Hartzell and Scala, 2021):

- Parental coping skills and styles
- Individual stress responses
- Maternal marital status and age
- Economic status, i.e., effect on visitation opportunities and return to work.

- Extended family support
- Parental exposure to adverse childhood events (ACE)
- Pre-existing and family history of mental health challenges and diagnoses
- Pre-existing parental relationship challenges

The presence of additional siblings at home needing care impacts the amount of time spent by parents visiting their baby in the NICU (Pineda *et al.*, 2018; Bourque *et al.*, 2021). This factor indirectly affects parental mental well-being by increasing the physical separation from their newborn premature baby in the NICU.

Researchers have attempted to identify the differences and similarities between maternal and paternal expression of psychological challenges and mental well-being during the admission period. Pace *et al*. (2016) found comparable symptoms between fathers and mothers, thereby highlighting the need for both maternal and paternal support. Both mothers and fathers experience a gamut of conflicting emotions accompanying the birth of a premature baby and admission to the NICU (Loewenstein, Barroso and Phillips, 2019). However, some differences have been identified and require further examination.

Lundqvist Weis and Sivberg (2019) identified maternal feelings of isolation fuelled by feelings of inadequacy as a mother and guilt about the premature delivery of their baby. In addition, their baby's medical fragility featured higher among mothers' concerns (Loewenstein, Barroso and Phillips, 2019).

Post-delivery, fathers often have the dual task of caring for their partner as well as their newborn infant in the NICU, frequently requiring a difficult choice about who to attend to first (Merritt, 2021; Ocampo, Tinero and Rojas-Ashe, 2021). This challenge often ensues in addition to the necessity to maintain financial stability and work commitments (Loewenstein, Barroso and Phillips, 2019; Lundqvist, Weis and Sivberg, 2019). The burden of balancing all these commitments is often the catalyst for their feelings of helplessness, disconnection and loss of control while trying to be the reliable and constant member of the new family (Merritt, 2021). Despite their often reduced availability compared to mothers, fathers desire to be seen as equal partners in this journey of care for their baby in the NICU (Merritt, 2021).

In some countries, parents are responsible for contributing huge financial resources to keep their baby in their NICU and the provision of adequate medical care. This task

often befalls the father, compelling his return to work (Dadkhahtehrani *et al.*, 2018; Adu-Bonsaffoh *et al.*, 2022). Consequently, limited visitation opportunities due to added paternal responsibilities outside the hospital create fewer opportunities for bonding and interaction with the newborn baby (Ireland *et al.*, 2016).

Lowenstein Barroso and Phillips (2019) report that not all feelings are negative, but that parents express happiness and joy at their baby's survival in conflict with their feelings of guilt and blame.

Understanding the psychosocial ramifications of parents during a NICU admission might assist in developing and identifying appropriate screening interventions and healthcare professional education, which would enhance future outcomes for the family unit (Loewenstein, Barroso and Phillips, 2019).

There appears to be a dearth of research about same-sex couples and nonbirth parents (Loewenstein Barroso and Phillips, 2019; Merritt, 2021). This deficit highlights a limitation in the available research.

The adolescent parent constitutes another population of parents who should be highlighted. Compounding the stressful transition to parenthood, the adolescent mother or father has to navigate the premature transition to adulthood simultaneously (Rosenstock and Van Manen, 2014). The available research highlights an increased risk of adolescent mothers requiring NICU admission for their babies. However, the research does not specify prematurity as the cause of admission; therefore, further research is needed.

2.6.2 Parental resilience and coping strategies in the NICU

The vulnerability parents experience during the NICU admission period requires them to embrace and develop coping mechanisms to build resilience. Resilience and coping are not synonymous but are often used interchangeably in the literature (Rossman *et al.*, 2017). The American Psychological Association define coping as "the use of cognitive and behavioural strategies to manage the demands of a situation when these are appraised as taxing or exceeding one's resources or to reduce the negative emotions and conflict caused by stress" (*APA Dictionary of Psychology*, 2023). Using coping strategies involves a "conscious and direct approach to problems" (*APA Dictionary of Psychology*, 2023). Coping is regarded as a dynamic way to search and implement choices, which are not always easy in a difficult and taxing situation, with

the hope of positive change (Lundqvist, Weis and Sivberg, 2019). Furthermore, coping is considered an element or feature of resilience (Rossman *et al.*, 2017).

Rossman *et al*. (2017) suggest the following two constructs to characterise resilience: 1) Identifying the possible traumatic experience or event and 2) the ability to adapt positively to this potential threat. Rossman *et al*. (2017) further state that resilience is characterised by "the ability to bounce back or rebound from extremely adverse experiences by remaining flexible and developing coping strategies that result in positive outcomes and enhance quality of life" (Rossman *et al.*, 2017).

Loewenstein Barroso and Phillips (2019) propose a process whereby parents can initiate coping mechanisms and actions, as illustrated in Figure 1 below.

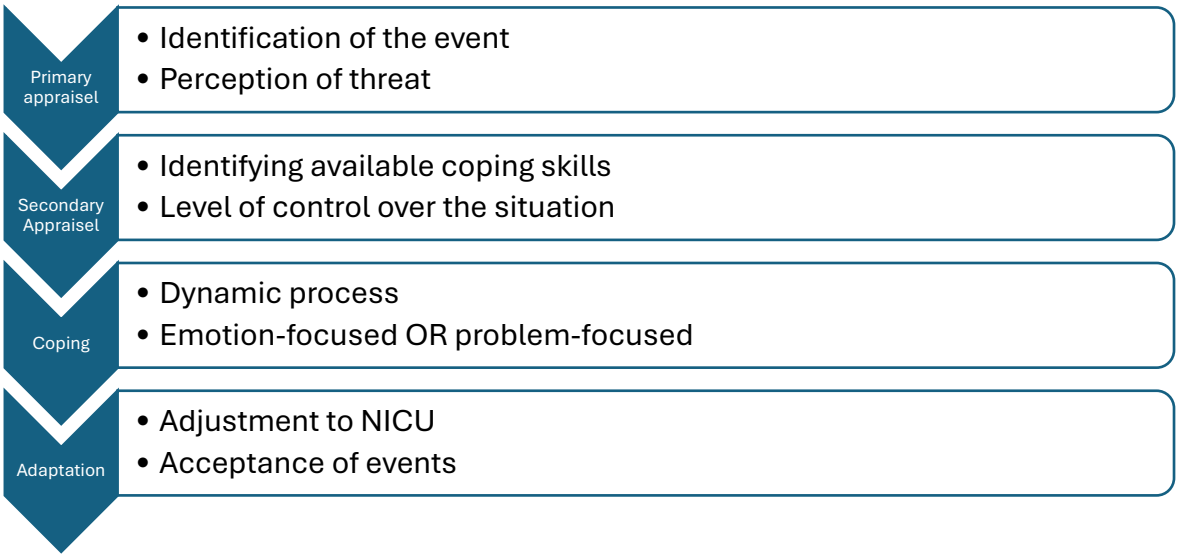


Figure 2.1: Process of problem appraisal and coping

(Adapted from Loewenstein et al., 2019)

Both positive and negative factors influence parental coping abilities (Hagen, Iversen and Svindseth, 2016; Roque *et al.*, 2017; Sih, Bimerew and Modeste, 2019). Positive factors include the presence of the father and the involvement of the parents and the nursing staff recognising their skills and competencies as essential role players in the care of their baby (Hagen, Iversen and Svindseth, 2016). Previous experience of either or both the birth of a medically fragile baby and a history of the loss of a baby, albeit not necessarily with admission to the NICU, contributed negatively to coping skills and coping abilities (Hagen, Iversen and Svindseth, 2016). In assessing the coping strategies of mothers with premature babies admitted to a public hospital NICU in Cape

Town, Sih Bimerew and Modeste (2019) observed that religion and faith played an important role. Nevertheless, there is limited research available exploring the role of religion and faith as a coping mechanism and the effects on parental mental health during NICU admission (Brelsford and Doheny, 2016; Loewenstein, Barroso and Phillips, 2019).

Parents employ various coping methods based on individual contexts, requirements, principles and beliefs (Lundqvist, Weis and Sivberg, 2019). Mothers and fathers tend to utilise different coping strategies. Mothers seek more emotional support from other parents in the NICU, whereas fathers seek support more from staff and gathering information (Roque *et al.*, 2017). Moreover, mothers are inclined to look at the more positive aspects of the experience in the NICU to foster coping, and fathers tend to rely on problem-solving (Hagen, Iversen and Svindseth, 2016). Patterns of engagement and coping strategies between parents exhibiting PTSD and depression range from extreme parental engagement (PTSD) to withdrawal from the situation (depression) (Tooten *et al.*, 2013).

Hall *et al*. (2017) suggest that advances in the field of neonatology and the promotion of positive infant outcomes do not rely on technological advances only but also on developing, highlighting and maintaining the "family–infant relationship" within the NICU environment (Hall *et al.*, 2017).

2.7 Transition to Parenthood

Transition to parenthood and achieving the parental role has emerged frequently as a stressor for parents in the NICU environment (Al Maghaireh *et al.*, 2016; Roque *et al.*, 2017; Loewenstein, Barroso and Phillips, 2019). This transition begins during pregnancy; women undergo both a physical and "psychological pregnancy" in which they prepare emotionally for their identity transition towards becoming a mother (Stern, 1999). Givrad Hartzell and Scala (2021) and Kim and Kim (2022) refer to "maternal self-representation", whereby the parent attaches a meaning to their unborn baby and the identity of their emerging role as parents. Maternal self-representation encompasses both the mother's cognitive and emotional expectations of her abilities to parent and the expectations of the new infant (Kim *et al.*, 2020; Givrad, Hartzell and Scala, 2021). However, this event is not exclusive to the mother; fathers are also

known to experience the pregnancy, with consequent personal, physiological and psychological changes (Ettenberger *et al.*, 2021).

Throughout the pregnancy, a relationship grows between the developing foetus and the parents. This relationship is reinforced with time, especially as fetal movements increase and the third trimester arrives (Ettenberger *et al.*, 2021). Smorti *et al*. (2019) describe this “pre-natal representation“ process and pre-natal attachment not only as the foundation for the transition to motherhood but also as an influencing factor in the post-natal attachment process. However, the impact of prenatal attachment concerning post-natal attachment and the transition to motherhood is closely mediated by the childbirth experience (Smorti *et al.*, 2020), thereby highlighting the possible impact of prematurity and unexpected delivery. When the transition to parenthood happens within the NICU environment, it often requires adaptations and changes in the new parents’ parental expectations (Heydarpour, Keshavarz and Bakhtiari, 2017). The premature arrival and the above-mentioned factors all create a platform for attachment within the NICU environment.

2.7.1 Attachment and Bonding

Attachment is an essential component of defining and transitioning into a parental role by creating a physical and emotional bond between parent and baby (Fegran, Helseth and Fagermoen, 2008). The premature arrival of an infant, which may often be traumatic for both parent and infant, disrupts this early process of relationship building and attachment (Givrad, Hartzell and Scala, 2021).

Humans inherently seek attachment to their babies, protecting and nurturing them and, ultimately, preserving the human species (Alhusen, Hayat and Gross, 2013). The concept of attachment, as described by Bowlby and Ainsworth, emanates from the study of and evolution of animal behaviour in their natural environment(Ainsworth MDS; Bell SM, 1970) The scholars define attachment as the affectional tie that one person or animal forms between themself and a specific other—a tie that binds them together in space and endures over time (Ainsworth and Bell, 1970). Typical attachment behaviours in infants include those promoting and seeking physical connectivity with their caregiver (Ainsworth and Bell, 1970). A child with a secure attachment to its caregivers feels safe, protected and is able to explore their world and develop cognitively and emotionally (Trombetta *et al.*, 2021). Attachment, specifically

the quality of attachment, directly impacts a baby's future cognitive and psychosocial development into adulthood (Kim and Kim, 2022).

The literature tends to use the terms and concepts of attachment and bonding interchangeably. However, there is a difference, which should be acknowledged in the research arena (Ettenberger *et al.*, 2021). Attachment contrasts with bonding, whereby bonding focuses on the parent's emotional, physical, and cognitive behavioural availability and response to their infant/child. In contrast, attachment focuses on the relationship the baby/child develops with their primary caregiver (Ettenberger *et al.*, 2021; Kim and Kim, 2022). While both concepts are essential within the framework of transitioning to the parental role, there is a difference regarding the time frame within which attachment and bonding can occur, which is particularly relevant to parents during NICU admission. Attachment is less time-sensitive and can develop up to a year after birth (Ettenberger *et al.*, 2021), whereas bonding commences as early as the second trimester of pregnancy and is consolidated within hours post-partum up to four weeks after birth (Fernández Medina *et al.*, 2018; Ettenberger *et al.*, 2021). Attempting to understand the factors mediating bonding and attachment within the context of NICU admission and beyond discharge is challenging due to the interchangeable use of these terms in the literature.

Bonding appears to be affected primarily by unexpected and traumatic early delivery that creates a physical separation between mother and baby. The physical separation in the NICU further impacts the bonding process, together with feelings of emotional separation and distress (Fernández Medina *et al.*, 2018; Ettenberger *et al.*, 2021). The quality and type of attachment between a baby and their primary caregiver is typically set by the first year of life. By then, the baby would have defined their sense of whether that caregiver is a "secure base from which to explore the environment" (Lopez-Maestro *et al.*, 2020). Attachment style and quality affect psychosocial development into adulthood (Lopez-Maestro *et al.*, 2020). Ettenberger *et al*. (2021) describe two attachment styles, as proposed by Mary Ainsworth, namely secure and insecure attachment. Further refinement of insecure attachment evolved into three more types of attachment styles, namely 1) secure, 2) insecure avoidant, 3) insecure ambivalent-resistant, and 4) insecure disorganised (Ettenberger *et al.*, 2021). The currently available body of evidence and literature does not sufficiently highlight the type of attachment style most commonly found in preterm babies, nor does it focus on babies born before 32 weeks GA (Lopez-Maestro *et al.*, 2020). In addition, Lopez *et al*. (2020)

contend that the body of research is outdated as it was mostly conducted before the increase in awareness and implementation of developmentally sound care principles in the NICU environment. Their research identified the predominance of a secure attachment style in their cohort of 117 babies born at ≤32 weeks GA and either or both weighing less than 1500g. Notably, as GA decreased to ≤27 weeks, so did the dominance of a secure attachment pattern, while avoidant attachment was the least frequent attachment style in this cohort (Fernández Medina *et al.*, 2018). Other studies found disorganised attachment prevalent in babies born at fewer than 32 weeks GA and either or both weighing less than 1500g (Wolke, Eryigit-Madzwamuse and Gutbrod, 2014).

In their systematic review of randomised controlled studies (RCT), Kim and Kim (2022) highlight that this attachment process between baby and parent indeed is not a natural process but rather a process that can be both individualised and influenced by interventions and circumstances in the NICU (Kim *et al.*, 2020), thereby reinforcing the influence of environmental factors in the NICU environment, which might affect bonding and attachment and the consequent transition to a parent role.

Full-term infants give positive and reinforcing behavioural cues that parents can understand and react to, creating an effective reciprocal communication platform for effective and life-sustaining interaction. However, the neurological immaturity associated with prematurity and medical fragility may hamper this reciprocity between parent and baby due to changes in the nature and type of cues the infant gives. (Givrad, Hartzell and Scala, 2021). In their review of the evidence, Givrad Hartzell and Scala (2021) summarise that the parental psychological state, parental representation of their premature infant, their perception of their parenting capabilities and ability to read their baby's behavioural cues all affect the parents' ability to initiate interactions with their baby. The greater the interaction between parent and baby, the more opportunities there are for the infant to practise the reciprocal relationship and consequent bonding and attachment (Givrad, Hartzell and Scala, 2021).

2.8 The NICU Environment

The physical NICU environment should promote essential medical outcomes as well as foster improved attachment and parent–infant interactions. These two criteria are not mutually exclusive; rather, they are interdependent. Ainsworth and Bell (1970)

acknowledge that environment has a mediating influence on the quality of attachment (Ainsworth and Bell, 1970).

Overcoming the essential lighting and increased noise levels experienced in the NICU is always highlighted when investigating the fostering of appropriate parent–infant interaction (Givrad, Hartzell and Scala, 2021). Physical separation from parent/s, changes in nurses/caregivers and repeated exposure to painful procedures without support are all considered possible ACEs that would impact the preterm baby physiologically, with long-term effects on such babies' ability to cope with stress. Significantly, repeated exposure to painful procedures in premature infants directly impacts the grey and white matter maturation patterns at corrected term age (Sanders and Hall, 2018).

Single-family rooms (SFRs) in the NICU have been advocated for in controlling sensory stimulation and its effects on the developmental considerations of a preterm baby (White, 2010). The creation of a private space for parents to interact and physically connect with their babies is an additional benefit of creating single-family rooms within the NICU (White, 2010; Shaheidari and Homer, 2012). Having a space where parents can express their emotions privately and are not exposed to other parents' emotional displays has a beneficial effect on parents (Shaheidari and Homer, 2012). A reduced hospital stay and increased parental involvement have been associated with single-family rooms compared to the open-bay NICU environment (Shaheidari and Homer, 2012).

2.8.1 Parent and staff interaction

Communication and the quality of interpersonal relationships between staff and parents are mediating factors affecting parental stress and anxiety levels as well as parental participation levels in the daily care routine (Roque *et al.*, 2017; Loewenstein, Barroso and Phillips, 2019; Kim *et al.*, 2020; Whitehill *et al.*, 2021). Generally, there is a distinct difference in the knowledge and experience of parents and medical staff, creating a forced relationship of trust parents have to develop. However, within this relationship, parents must be given opportunities to develop their knowledge and become part of their baby's care (Mause *et al.*, 2022). Parents feel comforted when they can share information and experiences about their babies (Treherne *et al.*, 2017) with the nurses. However, NICU staff might unintentionally, or because of a baby's medical fragility, create an environment in which care procedures are not shared

appropriately between parents and nursing staff, thus affecting the parental role through physical and emotional separation (Treherne *et al.*, 2017, 2017). Nursing staff play an essential part in understanding parent's abilities and insecurities regarding infant care, and consequently, facilitating parents' involvement and introducing strategies to facilitate the transition into parenthood and fostering more intimate involvement of parents in procedures and infant care (Treherne *et al.*, 2017; Givrad, Hartzell and Scala, 2021). Ultimately, medical staff are tasked with creating an environment that not only promotes and ensures appropriate medical safety for the baby but also one that meets parental needs (Feeley *et al.*, 2016).

2.8.2 Infant physical appearance

The size and physical appearance of the premature baby might influence the quality and quantity of parental interaction with their baby (Treherne *et al.*, 2017; Givrad, Hartzell and Scala, 2021). Depending on gestational age, various aspects of the baby's appearance will differ to a full-term baby. Commonly the skin, eye lids, ears, and genitalia vary in appearance and may distress the parent (Gudauskyte, 2021). The physical appearance of a baby precipitates feelings of shock, guilt, blame and inadequacy (Loewenstein, Barroso and Phillips, 2019).

2.8.3 Medical fragility

Prematurity creates a dichotomy between the imagined and the existent baby. The medically fragile baby and the need for admission to NICU might precipitate feelings of inadequacy as a mother. It becomes incumbent on the mother to actively shape her role and participate in this transition within the NICU environment. Stern (1999) suggests the mother of a preterm infant is a premature, disappointed, and isolated mother (Stern, 1999). The fear of the loss or death of their newborn baby and doubts regarding parenting capabilities are all constant realities. In attempting to cope with this, parents might be hesitant to create an attachment to their newborn baby (Givrad, Hartzell and Scala, 2021). The medical fragility of a premature baby is universal and often cited as a significant cause of distress, especially if a parent has been obliged to witness regular painful procedures or resuscitative efforts performed on their child (Tooten *et al.*, 2013; Roque *et al.*, 2017; Steyn, Poggenpoel and Myburgh, 2017; Lundqvist, Weis and Sivberg, 2019; Namusoke *et al.*, 2021; Adu-Bonsaffoh *et al.*, 2022).

2.8.4 Physical separation

Immediately post-delivery, the urgency to know if a baby is healthy transforms into the need to touch, smell and hold the baby. This urge cements the transition into motherhood.

The medical fragility of a preterm infant often necessitates specialised equipment, bedding, and restricted physical touch, creating a separation between parent and infant (Feeley *et al.*, 2016). Early physical contact within the first hours, days and weeks of life is essential for the bonding process to occur (Fegran, Helseth and Fagermoen, 2008; Feeley *et al.*, 2016). Physical contact with their baby underpins parents' ability to experience mastery over their environment and the situation in which they currently are (Merritt, 2021).

Due to ethical considerations, researchers have relied on animal studies to understand and explore the negative effects on juvenile animals separated from their mothers soon after birth. The results from such studies indicate alterations in both the neurological and biological systems of the separated animals (Givrad, Hartzell and Scala, 2021).

Close physical interaction, such as skin-to-skin interaction between baby and parent, sets up the ideal moment for coregulation, during which there is a complex interaction between their neural systems, autonomic systems and social communication (Sanders and Hall, 2018). In this position of safety, there is stability in essential autonomic parameters of respiratory rate, oxygen saturation, and heart rate. In contrast, the change back to a state of physical separation in the isolette or incubator is accompanied by changes in these autonomic parameters, indicating distress in the baby (Sanders and Hall, 2018).

Skin-to-skin intervention, also known as kangaroo mother care ((KMC), was initially purported as a low-cost solution for staff shortages and increased mortality rates due to infection and hypothermia in a Colombian NICU (Franck and O'Brien, 2019). However, it benefits both the parent and the baby. For the baby, skin-to-skin exposure positively affects their sleep development and regulation, brain maturation and response to stressful stimuli in the NICU environment. For the parent, skin-to-skin contact is elemental for bonding, reducing stress and facilitating transition to the parental role (Feeley *et al.*, 2016).

Worldwide, hospitals are choosing to allow unrestricted visitation for parents, and the physical design of the NICU environment is slowly moving towards accommodating parents more comfortably in single-family rooms (Flacking *et al.*, 2012; Franck and O'Brien, 2019). One of the benefits of this NICU design is the possibility and option to allow parents unrestricted access to their preterm baby (Flacking *et al.*, 2012).

The separation between parents and infant might be due to additional factors, not solely the physical environment and medical fragility of the baby. The extent of physical closeness depends on individual hospital visitation policies, distances to travel, limited paid leave and inappropriate or absent overnight accommodation at the bedside or in the hospital, all contribute to physical separation (Treherne *et al.*, 2017; Yu and Zhang, 2019; Bourque *et al.*, 2021; Givrad, Hartzell and Scala, 2021; Adu-Bonsaffoh *et al.*, 2022). Flacking *et al*. (2012:1) summarise the concepts of the physical and emotional proximity of parents in the NICU with the following statement: "Although physical closeness may facilitate emotional closeness and vice versa, there may be occasions when parents can be physically close but feel emotionally detached, or even physically remote but still feel emotionally connected".

Understanding the lived experiences of parents during the admission of their baby to the NICU provides insight into the need to establish an appropriate environment of support for parents. Treyvaud *et al*. (2019) suggest a multilayered approach encompassing three layers of intervention:

- Individual management of the psychosocial health of the parents,
- peer-to peer-support, and
- the introduction of a family-centred care (FCC) approach in the NICU environment (Treyvaud et al., 2019).

2.9 Family-centred care

The literature suggests that FCC is the gold standard for providing appropriate medical care and environmental support for both the parent and the baby (Franck and O'Brien, 2019; Yu and Zhang, 2019). In the NICU context, the essential principles of FCC include fostering dignity and respect between team members and parents, encouraging and facilitating parental involvement, and communication and partnership in decision-making during medical care (Yu and Zhang, 2019; Abukari and Schmollgruber, 2023).

The literature review by Yu and Zhang (2019) highlights that FCC reduces hospital stays. This reduction was mediated by improved parental participation and confidence in their ability to care for their preterm baby (Yu and Zhang, 2019). The transition into the parental role, as previously highlighted, is an essential component of parents' lived experiences.

Within the context of delivering FCC in the NICU, Franck and O'Brien (2019) further highlight three individual layers of intervention focused on parents that ultimately improve parental coping strategies and quality of care. The three separate yet interacting concepts include:

- Psychoeducational support aimed at parents to reduce their stress levels and improve coping in the NICU. Such support may include education, journaling, cognitive behavioural therapy and peer-to- peer support (to be discussed in greater detail).
- Interventions to improve and increase communication between the health team and the parents, parental involvement in daily care routines and daily ward rounds.
- Creating an appropriate physical environment that enhances the parental role, i.e., overnight accommodation and single-family rooms (Franck and O'Brien, 2019).

Interventions have focused on different maternal outcomes, which include improving mental health, improving the mother–baby relationship as well as education and development (Treyvaud *et al.*, 2019). Reviews of the latest research show the benefits of interventions on maternal outcomes; however, best practices remain elusive as there are too many variables in the types and timing of these interventions (during admission and post-discharge).

Intervention programmes aimed specifically at fathers are under-researched and -reported. Interventions aimed at fathers are often more related to education regarding developmental and care routines (Ocampo, Tinero and Rojas-Ashe, 2021). Even though one could assume that programmes suggested for mothers would also be applicable and appropriate for fathers, further research is required to ascertain fathers' specific needs (Treyvaud *et al.*, 2019). Fathers might have unique sets of needs and expectations after their babies' admission to the NICU. Limited visiting capacity due to

external work commitments, the need to support their partner, cultural and gender biases, as well as societal expectations of resilience and stoic behaviour might all contribute to their challenges and dichotomous feelings (Ocampo, Tinero and Rojas-Ashe, 2021). The common thread in FCC is improving parents' psychosocial and mental well-being.

2.10 Person-Centred Care

A further philosophy of care, not mutually exclusive of FCC, is person-centred care (PCC). PCC centres around understanding the parents' cultural beliefs, values and needs and incorporating them into appropriate care interventions (Lundqvist, Weis and Sivberg, 2019). Such understanding highlights that FCC needs to be delivered appropriately within the context of each environment, considering parents' social and cultural uniqueness. Akubari and Schmollgruber (2023) identify the disproportional research of FCC within the context of developed countries and high-resource environments (Abukari and Schmollgruber, 2023).

Givrad, Hartzell and Scala (2021) suggest that within the family-centred care model in the NICU, there needs to be a three-pronged focus, of which all three are mutually beneficial developing the infant–parent relationship, reducing parental stress and optimising the medical and developmental outcomes of the baby. Accordingly, the authors suggest the need for a family-centred developmental care approach (FCDC), in which the quality of parental attachment is also regarded as an essential outcome of the intervention (Givrad, Hartzell and Scala, 2021).

All of the interventions above are supported in the literature, albeit with very little research into the impact and validity of FCC across a multiculturally and religiously diverse environment.

2.11 Psychological and psychosocial interventions for parents

2.11.1 Screening for signs of mental distress

Screening all parents with babies admitted to the NICU is both essential and beneficial to identifying parents at risk of psychological and psychosocial distress. Naturally, such screening is only beneficial if the parents have access to interventions (Treyvaud *et al.*, 2019; Garfield *et al.*, 2021). Following a traumatic event such as preterm delivery,

parents respond in different ways; there is no universal response. Understanding different trajectories and patterns of symptoms, as well as coping and resilience, underscores the benefit and need for ongoing and repeated screening of parents throughout the baby's NICU admission and beyond discharge. Bonanno, Westphal and Mancini (2011) describe four possible routes of parental response:

- Continuing high levels of psychological distress throughout the admission.
- Slower to develop signs and symptoms throughout the admission, with an increasing intensity of distress over time.
- Some parents display a decrease in signs and symptoms throughout the admission, signalling recovery from initially high stress levels.
- Minimal or manageable signs and symptoms throughout the admission, indicating signs of resilience and appropriate coping skills (Bonanno, Westphal and Mancini, 2011).

2.11.2 Individual psychosocial interventions

Psychosocial intervention can be delivered by a variety of health professionals with varying levels of training. Psychiatrists, psychologists and social workers can be included in the available referral base. The intervention can take place within the NICU environment or outside of the hospital. All parents should at least receive intervention and support from a social worker, with further referral to either or both a psychologist and a psychiatrist, if warranted (Hynan *et al.*, 2015; Treyvaud *et al.*, 2019).

The researched, albeit not extensively, therapy and counselling modalities and approaches include cognitive behavioural therapy (CBT), child–parent psychotherapy (CPP), and psychologist-facilitated group therapy (Treyvaud *et al.*, 2019; Ocampo, Tinero and Rojas-Ashe, 2021)

2.11.3 Peer-based support

Peer support can be an intervention within the framework of providing parental support. Such support could take many forms; further research is still required to identify the most effective way of delivering peer support (Treyvaud *et al.*, 2019). Peer support should be considered a standard intervention available to all parents (Hynan *et al.*, 2015). The support might happen in person within the NICU environment between

parents with babies concurrently in the NICU or between parents who have previously been admitted and have knowledge and experience of NICU admission (Treyvaud *et al.*, 2019).

2.11.4 Trauma-informed care

Understanding the importance of ACEs and their impact on a baby's current and future health and development is the foundation of providing trauma-informed care within the NICU environment. The proposed principles of trauma-informed care in the NICU environment encompass several principles, including:

- Safety (physical and psychological)-respect, confidentiality, and privacy
- Trustworthiness and transparency in communication and information sharing
- Peer support: individual and group settings
- Collaboration and partnerships between parents and the healthcare team
- Empowerment for parents in decision making, care routines and emotional support
- Considerations for cultural, age and gender issues (Sanders and Hall, 2018).

2.12 Psychosocial Support Offered by Healthcare Professionals

Providing psychosocial support in the NICU environment has traditionally been the domain of psychiatrists, psychologists and social workers (Hynan *et al.*, 2015). However, other healthcare workers providing care in the NICU can and should be encouraged to provide psychosocial support. Social workers and psychologists are tasked with screening for mental distress, counselling and educating parents and staff and encouraging appropriate parenting skills and bonding (Hynan *et al.*, 2015). By working within the principles of FCC, FCDC and trauma-informed care, nurses, neonatal therapists (occupational therapists, physiotherapists, speech and language therapists), child life specialists (CLSs) and faith-based leaders all play a role in providing psychosocial interventions (Altimier, 2013; Lookabaugh and Ballard, 2018; Loewenstein, Barroso and Phillips, 2019).

The role of a CLS within the NICU environment is multi-faceted. CLSs are equipped with knowledge and expertise on child development, non-pharmacological pain management strategies, the principles and importance of FCC and the provision of psychosocial support for parents and siblings (Romito *et al.*, 2021b). Further roles include providing parents and siblings with educational support and resources (Morrison and Gullón-Rivera, 2017). A CLS can assist with bereavement support and legacy activities within the NICU environment (Romito *et al.*, 2021b).

2.13 Current South African best practice guidelines in NICU

Best practice guidelines for South African NICUs have been suggested and published (Lubbe, 2010). These guidelines embrace the importance of the FCC philosophy to be implemented in all NICU facilities in South Africa. Further research conducted on the successful implementation and compliance with regard to these best practice principles in 25 private NICU facilities highlighted a 50% compliance rate of implementing FCC philosophies (Rheeder *et al.*, 2017). The highest compliance rate was attributed with feeding best policy guidelines and the lowest with environmental compliance (Rheeder *et al.*, 2017). Supporting these challenges of FCC implementation and compliance, Abukari and Schmollgruber (2023) highlighted the limited research within the African continent regarding FCC implementation, and the challenges of implementing FCC principles in NICUs in Africa African context. The challenges of implementation were attributed to the varying cultural, social and demographic elements found within the African NICU environments.

In the guidelines published , the FCC approach incorporates the need for parent support programmes however, no mention is made on specific mental health care workers such as psychologists or social workers to be included in the multi-disciplinary team in NICU (Lubbe, 2010). This is in contrast to the suggested inclusion of mental health care workers suggested previously (Hynan *et al.*, 2015; Treyvaud *et al.*, 2019). This study could support the need for these policies and guidelines to be implemented in South African NICUs and include added psycho-social support by giving a voice to the parents and highlighting this barrier.

2.14 Conclusion

There is no current governmental policy specifically pertaining to premature birth in the South African context and medical landscape, despite the burden of mortality and morbidity associated with preterm birth (Ramokolo, V. et al., 2019). The South African Maternal, Perinatal, and Neonatal Health Policy (2021) acknowledges the need to improve maternal, perinatal and neonatal health provision that is appropriate and accessible to the South African population (South African Department of Health, 2021). However, no mention is made in this document regarding care for premature babies in the NICU and strategies such as FCC to be standard care principles.

Understanding and exploring parents' lived experiences is essential to ensuring advocacy, policy planning and appropriate medical interventions within the NICU environment (Yu and Zhang, 2019; Adu-Bonsaffoh *et al.*, 2022).

The NICU environment continues to evolve and change. The introduction of FCC principles and practices within the NICU environment in 1970 highlight and facilitate the need to improve care for preterm infants and their parents (Gómez-Cantarino *et al.*, 2020). The introduction of FCC has ensured an improvement in the parental experience of the NICU and concomitantly created an environment promoting the babies' developmental outcomes (Gómez-Cantarino *et al.*, 2020).

The literature review highlights the evidence that the physical and psychosocial milieu of the NICU affects the preterm baby and parents individually as well as collectively by influencing the baby–parent dyad.

CHAPTER 3: METHODOLOGY

This chapter discusses the research methodology, including location, study design, inclusion criteria for subjects, data collecting procedures and data analysis.

3.1 Study Design

This research study followed a descriptive qualitative phenomenological study design to describe the lived experiences of parents regarding a particular phenomenon (Cuthbertson, Robb and Blair, 2020). The phenomenological approach was selected for this research as it not only informs on what parents experienced during the admission period in NICU, but also informs on how the phenomenon was experienced (Neubauer, Witkop and Varpio, 2019). In the health care research setting, a phenomelogical approach provides the ideal platform for health care workers to understand patient's experience of a particular phenomenon/ health related event. This in turn may facilitate changes in health care provision, informing quality and appropriate care interventions (Neubauer, Witkop and Varpio, 2019).

3.2 Study Setting

The study was undertaken in Johannesburg, South Africa. From the eleven interviews conducted, four Johannesburg-based neonatal facilities were identified as the admission units for the infants and ensuing parental experience. All four units provided private health care services , with parents relying on medical insurance to cover costs of the admission. All four of the units were able to provide full medical care, including mechanical ventilation if the babies required it. The units comprised of open bay spaces with a few private rooms. These private spaces are allocated to babies that require added infection control or due to medical fragility. The parents were not asked to specify if their baby was in the open bay areas or a private room. However, during the admission, the babies were moved at times between areas of higher nursing care in the NICU to areas allocated just prior to discharge with less nursing intervention. There was only one unit that parents specified a two-hour period during the day that visiting was not allowed. None of the hospitals provided any facilities for parents to stay overnight with their babies.

3.3 Population Sample

The study employed purposive sampling to obtain participants for the study based on particular characteristics and the research objective. Purposive sampling is often used in qualitative research (Lasiuk, Comeau and Newburn-Cook, 2013). Healthcare professionals working with premature infants post-discharge from the NICU assisted in identifying potential participants. The healthcare professionals included physiotherapists, occupational therapists and speech therapists. These healthcare professionals were chosen by the researcher as they worked in various private NICU settings and continued to work with the parents post discharge. They were therefore able to identify suitable parents that would be able to add richness to the research objectives (Lasiuk, Comeau and Newburn-Cook, 2013).

The researcher furnished information about the research to the healthcare professionals (Appendix 1) and subsequently the invited parents (Appendices 2 and 3). The potential participants were parents who had experienced the birth of a premature infant and the subsequent admission of the infant to a NICU within a private hospital facility in Johannesburg. Parents who met the inclusion criteria were invited to participate in the study. The primary researcher did not select the participants to avoid bias of any kind. Bias can occur through a prior understanding of participants' life world, individual biases and internalised values (Lundqvist, Weis and Sivberg, 2019).

Parents who met the research criteria were invited to participate in the individual interviews conducted between January 2023 and July 2023.

3.3.1 Inclusion criteria

Inclusion criteria were purposefully broad to ensure richness in the data obtained (Petty, Jarvis and Thomas, 2019).

Accordingly, the following inclusion criteria were specified:

- Infant gestational age younger than 37 weeks at birth
- Hospital admission of at least four weeks in a NICU
- Private hospital facility admission
- Mother and father or both parents cohabiting
- One parent or both parents could choose to be interviewed.

- Parent able to converse and understand English.
- Time post discharge: up to eight months

3.3.2 Exclusion criteria

- A pre-existing therapeutic relationship with the researcher in her capacity as a treating physiotherapist. This relationship could have led to bias on the part of the participant and researcher, affecting the interpretation and quality of the interview.

3.4 Data Collection and Procedures

Consequent to the introduction of the POPI Act, several procedures had to be followed before enrolling participants in the research project. Once parents had been identified by referring health professionals and they had given consent for sharing their contact information (Appendix 1), the researcher contacted the parents and introduced the research procedure to them. After consent was received, the researcher scheduled interviews with the parents. Of the eleven interviews, ten were conducted at the parents' residences at their convenience. The home environment offered privacy, convenience and familiarity, encouraging richness in the information the parents shared. One interview was conducted in a public space, as requested by the parent. The consent form stipulated that both parents were required to consent; however, one or both could choose whether to be interviewed. Of the 11 interviews conducted, eight were with mothers and three with fathers, of whom three were couples who had both agreed to participate. Whenever both parents were interviewed, they were interviewed separately but on the same day and at the same location. No specific time limits were allocated for the interviews. The participants were allowed to withdraw from the research project at any stage, with no consequence for them or their infants.

Following protocol, the interviews were conducted in person at the participating parent's residence or a location of their choice. Of the 11 interviews, ten were conducted at the parent's residence, with a single interview, per the parent's choice, conducted in a public space. All interviews occurred at the participants' convenience.

The interviews were conducted in English, using voice recordings and voice-to-text transcription technology. All identifying names or information was redacted in the transcripts to protect the parents' and infants' anonymity. Furthermore, each parent

was allocated a pseudonym. The researcher took notes during the interview, documenting specific emotional, behavioural or contextual cues that added to the value of the data and thematic analysis. These observations were taken down in a manner that did not disrupt the natural flow of the interview and the interaction between the participants and the researcher.

It was essential for the researcher to identify the possible emotional responses of the parents during the interviews (Draucker, Martsolf and Poole, 2009). A distress protocol (Appendix 4) was included by the researcher in case the parents required emotional support post-interview.

Upon completion of the interview, the participants completed a demographic questionnaire (see Appendix 6). The researcher compiled the questionnaire to obtain relevant information on the parent, the pregnancy and the NICU experience. After transcription, a copy was sent to the participants to verify the authenticity of the information contained in the questionnaire. This member checking adds to the validation process of the research outcomes (Birt *et al.*, 2016) .The transcripts were password-protected to safeguard all personal information. Parents were free to ask questions and clarify any possible concerns. After completing 11 interviews, data saturation was achieved, and no more interviews were conducted. Interviews were conducted between January 2023 and July 2024.

3.5 Data Collection Tools

The interview consisted of three semi-structured, open-ended questions and prompts as required (Appendix 5). The questions allowed the parent to explore their personal experiences of the pregnancy, the baby's delivery and NICU experience. The three questions and probes chosen for this research attempted to uncover personal information about the participants and their experience of their pregnancies and the NICU. In addition, the content of the interviews, and the field observations made during the interviews were noted. These observations are regarded as an integral aspect of the phenomenological approach (Frechette *et al.*, 2020).

The researcher created a biographical questionnaire (Appendix 6) to gain further information relevant to the research. This information included:

- Parent: age, gender, education, employment, pre-existing medical conditions
- Pregnancy information: planned pregnancy, assisted pregnancy, gravidity, multiple pregnancies
- Baby: gestational age
- NICU environment: travel distance, orientation to NICU, accommodation for infant and parent in NICU, visitation
- The interview guide

The study employed *OtterAi* to record and transcribe the interviews. *OtterAi* is a real-time, password-protected meeting notes and transcription platform ('Otter AI', 2021). The researcher edited and checked all transcripts for accuracy. In addition to using *OtterAi*, the interviews were recorded using a second password-protected device as a backup recording of the interviews.

3.6 Data Analysis and Interpretation

Following the six steps described by Braun and Clarke (2006), the study conducted a six-step inductive thematic analysis (Byrne, 2022) to generate codes and themes to analyse the data collected from the interviews. Figure 3.1 describes this process.

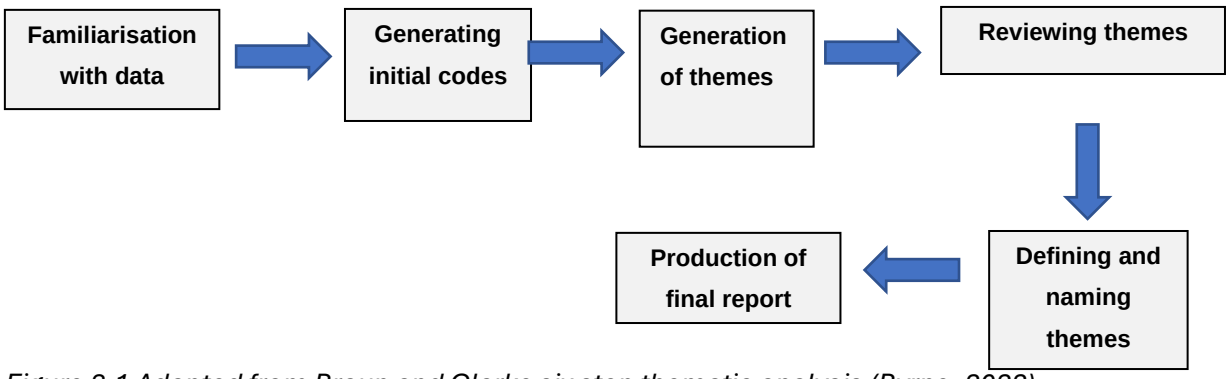


Figure 3.1 Adapted from Braun and Clarke six step thematic analysis (Byrne, 2022)

3.6.1 Familiarisation with data

Familiarisation with the data involved repeatedly reading and listening to the interview recordings, thus gaining insight and familiarity with the parental experiences of NICU admission. The knowledge and understanding of the nuances and context in which the interviews had been conducted further enriched familiarisation with the data.

3.6.2 Generating initial codes

The initial codes were created by reading through the transcripts repeatedly and identifying information relevant to the research questions. The researcher repeatedly reviewed these codes to provide a richness of information and accurately express the participants' experiences. The research supervisor performed a secondary analysis utilising software (*MAXQDA*). This was done to compare and triangulate the codes generated by the researcher.

3.6.3 Generating themes

Once the code identification had been completed, the relationships between the codes and their meaning were analysed, and subsequently, themes emerged.

3.6.4 Reviewing themes

The themes, categories and codes were reviewed to ensure their relevancy and appropriateness.

3.6.5 Defining and naming the themes

Once the themes and codes had been reviewed and accepted, the next phase commenced with selecting the quotes from the narratives that best describe the themes and codes.

3.6.6 Producing the report

This process of creating the report involved continuous analyses of the themes and codes, finally producing the finished document (Byrne, 2022).

3.7 Data Management

The POPI Act requires all personal information to be stored appropriately in password protected cloud services. All consent forms and demographic questionnaires were stored appropriately in the researcher's personal password-protected Google Drive platform.

The transcripts were downloaded immediately upon completion to the researcher's computer and subsequently to a protected cloud platform. The University's research regulations require the data to be stored for two to six years. All observation notes, transcribed interviews, analysed and thematic data were stored on a password-protected cloud platform.

3.8 Ethical Considerations

This research adhered to all ethical guidelines, as set out by the Health Professions Council of South Africa (HPCSA) (HPCSA, 2008). The study protocol was approved by the University of the Witwatersrand Human Research Ethics Committee (Medical), and ethical clearance was granted (Ethical clearance number M211152) (Appendix 7). Following approval, the researcher commenced the interviews, adhering to the research methodology as set out in the protocol.

Participating parents were identified after discharge from the NICU by healthcare professionals known to the researcher. Under the POPI Act (Protection of Personal Information Act), health professionals are required to obtain consent from prospective participants to transfer contact information to the researcher (Appendix 2). Thereafter, the researcher obtained consent to be interviewed, including audio-recording and transcribing the interviews, directly from the parents (Appendix 3). Consent was required and obtained from both parents, irrespective of whether one or both parents agreed to be interviewed. The consent forms included information about the research and procedures.

All material obtained from the interviews was viewed as confidential, and the interview transcripts contained no identifying information (the names, professions, and names of hospital or staff). In addition to the interviews, a biographical questionnaire was administered to obtain information relevant to the research. All identifying information was excluded from the questionnaire to maintain anonymity. For research purposes, the parents were assigned a pseudonym for identifying purposes and anonymity.

Furthermore, the interview transcripts were returned to the participating parents via password-protected emails for their perusal and final confirmation of authenticity.

It is essential to adhere to the ethical principles of autonomy, beneficence, and justice when research involves people as the sample population (Orb, Eisenhauer and Wynaden, 2000).

Autonomy

Autonomy was considered and ensured by no prior therapeutic relationship existing between the researcher and the participants, ensuring an imbalance in power between

researcher and participant was not created. In addition, the participants involvement in the research was voluntary and predictable with information shared on consent, the research procedures and reason for research.

Beneficence

The principle of beneficence was maintained by ensuring participant anonymity and confidentiality with the use of pseudonyms and no identifying information regarding the respective NICUS and participants was revealed. By ensuring anonymity the researcher ensured no harm was done to the participants from the research.

Justice

The consideration of justice was demonstrated by the researcher acknowledging the possible vulnerability of the participants and not exploiting their vulnerability in the context of their NICU experience. A distress protocol was put in place in case of distress caused by the interview.

3.9 Rigour of Research

Research rigour was determined by validity, dependability, credibility, and transferability.

3.9.1 Validity

This research employed data triangulation (Carter *et al.*, 2014; Cope, 2014), which involved using multiple data sources to examine one phenomenon. Accordingly, the researcher used the interviews, observations and notes taken during the individual interviews for data collection.

3.9.2 Dependability

The study has described the research methodology in detail to allow for the research to be replicated by other researchers (Mabuza *et al.*, 2014).

3.9.3 Credibility

The credibility of the research has been demonstrated by the appropriate research methodology, adequate engagement on the research topic, and a continuous review of the transcripts and emerging themes with supervisors (Cope, 2014; Mabuza *et al.*, 2014).

3.9.4 Transferability

Transferability relies on “thick” descriptions, i.e., a detailed description of the study, participants and conclusions (Mabuza *et al.*, 2014).

3.10 Conclusion

This chapter discussed the methodology of the current research. The chapter highlighted the ethical considerations, the study location, subjects, procedures, data collection management, and tools. Chapter 4 discusses the results of the study.

CHAPTER 4: FINDINGS AND DISCUSSION

This chapter presents the study's results and the related discussions garnered from the biographical questionnaires and parent narratives. The results and discussion are presented systematically, with each theme presented separately in combination with the relevant discussion and references to current literature. The researcher selected categories , subcategories and verbatim quotes from the interviews to highlight the emerging themes. The quotes are written in bold italics. For brevity and clarity of reading and meaning, this chapter highlights only some of the quotes, and parts of the quotes might be omitted and are indicated by ellipses. A comprehensive list of quotes is included for further reference and reading, adding information to the categories and codes (see Appendix 8).

The phenomenological approach in qualitative research uses interviews as the main source of data collection (Bevan, 2014). The interview process allowed the participants to narrate their particular experiences of the NICU and how such experiences affected them. Typically, this method of research proposes the use of semi-structured, open-ended questions, and adequate time for the participants to explore and narrate their experiences (Bevan, 2014). The interview context also added richness to the narratives and influenced the emerging themes.

Researchers examining the phenomenon of the lived experiences of parents in the NICU have used a variety of timelines for conducting interviews, ranging from during the admission period, immediately post-discharge, and up to 18 months post-discharge (Tooten *et al.*, 2013; Steyn E, Poggenpoel M, Myburgh C., 2017; Yu, Zhang and Yuan, 2020; Adu-Bonsaffoh *et al.*, 2022; Witt *et al.*, 2022). None of these research articles indicated or discussed the specific reason for their choice of timing. The period conducting the interviews was originally set out in the methodology as up to eight months post-discharge; however, all interviews were completed within six months post-discharge. Frechette *et al*. (2020) do not suggest or indicate a specific time frame within which to conduct interviews (Frechette *et al.*, 2020). They suggest that the main aim and goal of phenomenological research "is to uncover layers of forgetfulness or hiddenness that are present in our everyday existence" (Frechette *et al.*, 2020).

4.1 Demographic Information of Participating Parents

A total of eight mothers and three fathers participated in the research study. Of the eleven interviews conducted, three were with married cohabiting couples. The study gathered information from the biographical questionnaire, adding context to the semi-structured interviews. The information focused on various individual demographic and pregnancy particulars and the NICU data. The upcoming paragraphs and tables contain the summarised information gathered. Table 4-1 presents information pertaining to individual parent demographic data.

Table 4-1 Parent Biographical data

Participant	Age	Marital Status	Education	Employed	Race
Julie	30	M	Tertiary: Master's	Yes	W
Bev	27	M	Tertiary	No	I
Sue	33	M	High school	Yes	W
Ben	33	M	College	Yes	W
Pam	20	M	Grade 9	No	W
Rob	29	M	Grade 10	Yes	W
Meg	29	M	Tertiary	Yes	I
Ruth	28	M	Tertiary	Yes	W
John	29	M	Tertiary	Yes	W
Carri	30	M	Tertiary	Yes	W
Kim	42	M	Tertiary	Yes	W

Names were changed for confidentiality purposes.

M = Married (Colours denote married couples.)

Race: W = White; I = Indian

There were no Black African participants in the parent cohort, despite attempts to recruit Black African parents.

4.2 Pregnancy Data

Table 4-2 Information related to the pregnancy

Participant	Singleton/multiples	GA (weeks)	Time in NICU (weeks)
Julie	T	33	6 (both babies)
Bev	S	29	9
Sue	S	27	11
Ben	S	27	11
Pam	S	26	12
Rob	S	26	12
Meg	T	31	7 (both babies)
Ruth	S	35	5
John	S	35	5
Carri	S	30	8
Kim	S	31	7

T- twins; S- singleton

The average duration of stay in the NICU was eight weeks. A trend indicating an inverse relationship between GA and NICU admission length was noted. The baby born at 35 weeks GA was admitted for five weeks, and the baby born at 26 weeks was admitted for 12 weeks. In the case of the two sets of twins, the babies were admitted for the same duration of days and discharged together.

4.3 NICU Environment

Table 4-3 highlights information regarding parental accommodation in the NICUS and the distance between home and the NICU.

Table 4-3 NICU Environment

Participant	NICU Orientation	Distance Travel to NICU (Km)	Hospital Accommodation (Parents)
Julie	No	15-30	No
Bev	No	0-15	No
Sue	No	15-30	No
Ben	No	15-30	No
Pam	No	30+	No
Rob	No	30+	No
Meg	No	30+	No
Ruth	No	30+	No
John	No	30+	No
Carri	No	15-30	No
Kim	No	0-15	No

Four different Johannesburg-based NICUs were identified as the admitting facilities. Six of the babies were admitted to one particular ICU, with the remaining four babies

admitted to the remaining three facilities. The distances required to travel from home to the NICU are highlighted and discussed in the theme discussion.

4.4 Research Findings

Following the process as set out by Braun and Clarke (2006), the study conducted a thematic analysis of the parental interviews (Virginia Braun and Victoria Clarke, 2006). Three themes emerged from the codes generated, with each theme developed with categories and subcategories. Table 4-4 summarises the themes as they emerged from the interviews.

Table 4-4 Summary of themes, categories and subcategories

Themes	Categories	Subcategories
Theme 1- Journey to NICU- Context of the pregnancy	1.1 Pregnancy experience	1.1.1 Planned/unplanned pregnancy 1.1.2 High risk pregnancy 1.1.3 Emotionally complex pregnancy 1.1.4 Managing multiple responsibilities 1.1.5 Support during pregnancy
	1.2 Delivery experience	1.2.1 Birth plan 1.2.2 Self-blame for premature delivery 1.2.3 Concern for baby 1.2.4 Concern for partner
Theme 2. Transition to parenthood in NICU-Parenting in an unnatural environment	2.1 Parenting experiences	2.1.1 The NICU environment 2.1.2 Positive experiences 2.1.3 Information sharing 2.1.4 Separation 2.1.5 Medical fragility 2.1.6 Managing multiple responsibilities 2.1.7 Cultural considerations
	2.2 Organisational challenges	2.2.1 Hospital failures and irritations 2.2.2 Internal architecture failures 2.2.3 Lack of accommodation
Theme 3 - Coping with the emotional journey during a prolonged admission	3.1 Psychosocial challenges in the NICU	3.1.1 Rollercoaster of emotions 3.1.2 Parent worries 3.1.3 Perseverance and positivity
	3.2 Seeking support	3.2.1 Religious support 3.2.2 Partner support 3.2.3 Peer support 3.2.4 Professional support

4.4.1 Theme 1: Journey to the NICU—Context of the pregnancy

Table 4-5 Theme 1

Themes	Categories	Subcategories
Theme 1- Journey to NICU- Context of the pregnancy	1.1 Pregnancy experience	1.1.1 Planned/unplanned pregnancy 1.1.2 High risk pregnancy 1.1.3 Emotionally complex pregnancy 1.1.4 Managing multiple responsibilities 1.1.5 Support during pregnancy
	1.2 Delivery experience	1.2.1 Birth plan 1.2.2 Self-blame for premature delivery 1.2.3 Concern for baby 1.2.4 Concern for partner

This theme emerged from parental descriptions of their pregnancy and the delivery of their preterm baby. The pregnancies were characterised by both medical and psychosocial challenges. The first theme was informed by two categories: pregnancy experience and delivery experience.

The first theme is aptly defined by John:

"I have to say the time before the NICU was more stressful." (John)

4.4.1.1 Category 1.1: The pregnancy experience

The first category described the pregnancy experience of the parents. Ben described a journey different to their much anticipated and wanted experience of their first pregnancy.

***"In terms of the pregnancy, I think, obviously there's excitement and joy in the beginning. But as everyone thinks it's all going to be sunshine and roses and rainbows which isn't."* (Ben)**

Two families experienced unplanned pregnancies that created an element of fear and apprehension during the pregnancy. Ruth experienced numerous preexisting medical conditions that dictated her need not to fall pregnant, whereas for Bev a small age gap between her first born and current pregnancy was one of the reasons for not planning a pregnancy.

"...every doctor visit, they were like you can't fall pregnant or anything…so, when it happened, it was all quite a surprise." (Ruth)

"And then I found out I was pregnant, and it took me by shock. And it took my whole family by shock, everyone was totally shocked how you going to manage whatever, with two small ones" (Bev).

Most pregnancies, except one, were fraught with medical complications. The complications varied from gestational diabetes and pre-eclampsia to the need for a hysterectomy due to placental complications. Kim described her medically challenged pregnancy as:

"So, my pregnancy was terrible. I had placenta previa, and then placenta accreta. And then I got gestational diabetes, so I was on bedrest from 24 weeks and then I was admitted at 28 weeks for bedrest in hospital." (Kim)

Not only did participants experience medical complications but they also experienced emotionally complex pregnancies. The emotional complexity of the pregnancies was created by a multitude of factors. Not only managing the fears for their unborn baby, but also managing their partner's difficult pregnancy.

Meg stated that "And we were stressed but like every scan because you've got this in the back of your head if something can go wrong."

Ben indicated that: "From a father's perspective or husband's perspective… the emotions that you must deal with and the up and down swings with your partner, it's tough to handle, let's just be honest with that. I think also with my wife, she didn't have a normal pregnancy as such, she had a lot more I don't want to say an emotional one."

Bev and John added that the challenges of managing additional responsibilities whilst simultaneously navigating the challenging pregnancy was difficult and made the pregnancy experience challenging.

"I had a baby, my first baby … I breastfeed till like maybe a few days before I gave birth the second one …I had a very difficult pregnancy."(Bev)

"Luckily, my, the company I work for… every time I have a scan or something, they would say that's fine- you can go." (John)

None of the parents indicated any formal emotional or psychosocial support and/or interventions during the pregnancy. The biographical questionnaire did not indicate parental religious beliefs or faith, however, from the interviews, it was found that there was a Jewish mother and a Muslim mother. One mother indicated finding her solace in religious beliefs and that it assisted her during her unplanned and difficult pregnancy- ultimately leading to acceptance.

"I believe my religion, everything's from God's so I was happy with it… I accepted that this is God's gift to me." (Bev)

Discussion category 1.1: The pregnancy experience

Pregnancy is an emotional and physiological journey that shapes and creates an emotional bond between parents and their unborn baby (Kim *et al.*, 2020). For the parents interviewed, this pregnancy journey was challenging for a variety of reasons.

Whether a pregnancy is planned and accepted influences parental psychological and emotional well-being regarding the pregnancy (Moreau *et al.*, 2022). Moreau *et al*. (2022) suggest four different constructs for describing a potential pregnancy: A pregnancy can be "planned/welcomed, unplanned/welcomed, planned/unwelcome

and unplanned/unwelcomed" (Moreau *et al.*, 2022). Unplanned pregnancies are associated with increased maternal stress and depression (Abajobir *et al.*, 2016); an unaccepted pregnancy is also associated with increased maternal distress (Moreau *et al.*, 2022). An unplanned pregnancy was highlighted by Bev. Although only one participant expressed her emotional distress when discovering her pregnancy, her distress was significant, and it influenced her narrative of her pregnancy and her fears for childbirth.

Two of the reasons cited by Bev for her unwelcome pregnancy are worthy of further discussion. The first reason was pre-existing interpersonal challenges with her husband, and the second was a previous NICU experience following a premature delivery. The literature confirms that an altered or difficult relationship with a partner can add a dimension of stress to the pregnancy experience in varying degrees (Alves, Cecatti and Souza, 2021). Furthermore, a previous experience of having a preterm baby leaves an indelible mark on the mother. Such an experience affects the mother's perceptions of the risk involved with another pregnancy and possible subsequent preterm delivery, leaving her with added emotional distress (O'Brien, Quenby and Lavender, 2010). The fear of a possible negative outcome of the pregnancy sets up a pregnancy during which the mother remembers the past while trying to navigate the current pregnancy and manage future expectations for a healthy baby (O'Brien, Quenby and Lavender, 2010).

The high-risk characterisation of the pregnancies further contributed to making them challenging. Rodrigues *et al*. (2016) suggest that purely labelling a pregnancy as high-risk will elicit an emotional and stress response in the mother. Due to the actual or potential threat of harm to either or both the mother and baby, high-risk pregnancies are traumatic and psychologically stressful for both parents (Jackson, Ternestedt and Schollin, 2003; Rodrigues *et al.*, 2016; Bodunde *et al.*, 2023).

As relates to the fathers interviewed, their experiences of the high-risk pregnancy were confounded by not only supporting their wives emotionally and physically but also navigating added responsibilities externally, maintaining daily routines and financial stability during the pregnancy, all in the face of concern about their partner and unborn baby. These factors all combined set up a pregnancy experience fraught with emotional distress. These findings are consistent with a metanalysis of fathers' experience of high-risk pregnancies by (Jackson, Ternestedt and Schollin, 2003). Fathers experience

signs and symptoms of PTSD and depression because of the overwhelming mental and physical reserves they need to dedicate during a high-risk pregnancy.

Of note was the absence of psychosocial support offered to or accessed by the parents, with only one parent expressing religion as her source of support during her unplanned and initially unaccepted pregnancy. Despite her overall anxiety about the unplanned pregnancy, Bev could use and engage religion and faith as a coping mechanism. The literature is limited on the use of religion as a coping mechanism in high-risk pregnancies. Vitorino *et al*. (2017) suggest that engaging religious and spiritual beliefs can be paradoxical; parents can use it positively to reinforce their coping or negatively, increasing their sense of failure and inability (Vitorino *et al.*, 2018).

The inferences made from this category are the daily struggles parents experienced during the high-risk pregnancy and its psychosocial ramifications.

4.4.1.2 Category 1.2: The delivery experience

The second category of Theme 1 focused on the delivery, the disappointment of not reaching a full-term pregnancy, and the emotional challenges facing both parents in light of the premature arrival of their baby:

"And everything went not according to plan but according to doctor's plan." (Rob)

"The fact that you expect this dream of normal, full term 40 weeks …but with us it wasn't any of that." (Ben)

All the babies were delivered by caesarean section (C-section). This was not necessarily anticipated nor desired by the parents as the method of delivery. However, medical circumstances and complications dictated the trajectory of the delivery and birth.

"Your baby is going to die if you don't deliver right now. And within like 10 minutes, they had a theatre ready for another C section." (Bev)

Self-blame for the premature arrival of the baby and baby fragility was expressed by several of the mothers interviewed. This self-blame encompassed several feelings of guilt at the inability to sustain the pregnancy and deliver a healthy baby.

"And so, I basically wasn't feeding him anymore. He was supposed to be around 1.2 kilos and he came out at 770 grams. "(Sue)

The feelings of relief following the successful delivery of their baby was tempered by the knowledge of the immediate medical dangers and fragility of the newborn baby requiring NICU admission.

"Once baby came out it's a sense of relief, but now the focus is to try and keep them alive because he was so premature at 27 weeks. "(Ben).

For the fathers in particular, the delivery and the perceived responsibility for both their partner and the baby were overwhelming.

"And then you know waiting for my wife to come out, sitting there for 40 minutes plus waiting, is she Okay, is she not okay, if she's not alive? So, all of that does work on your on your brains a bit." (Ben)

Discussion category 1.2: The delivery experience

A preterm delivery occurs within a confounding, emotionally charged context. Loewenstein, Barroso and Phillips (2019) describe the emotional distress following the shattering of parental hopes of a healthy full-term baby and discharge home. The American Psychiatric Association suggests that the parental experience of a premature birth can be considered a definable traumatic event, with all the consequential ramifications of feelings of helplessness and fear (Lasiuk, Comeau and Newburn-Cook, 2013). Thus, Theme 1 highlights possible preexisting levels of parental stress even before their journey in the NICU begins.

For the fathers, in particular, the delivery and the perceived responsibility for both their partner and the baby were overwhelming, whereas the element of self-blame and guilt about the early arrival and medical fragility of the newborn premature baby was evident with the mothers.

Several of the mothers expressed self-blame for the unsuccessful full-term pregnancy; the mother, in particular, carries the self-developed role of responsibility for the safe arrival of the newborn baby. Lasiuk, Comeau and Newburn-Cook (2013), note that irrespective of the health status of the pregnancy, mothers, in particular, always hope for a full-term delivery, despite experiencing a medically challenging pregnancy and being aware of the possibility of a preterm delivery. Failure in this results in guilt and self-blame (Lundqvist, Weis and Sivberg, 2019).

The self-blame took the form of the mothers feeling incompetent to create a healthy internal environment for their baby and their perceived role in causing the preterm delivery. The literature defines this as behavioural self-blame, whereby an individual's perceptions of their actions result in negative consequences (Raz, Rubinstein and Shadach, 2023). Self-blame and guilt might have been used as a coping mechanism for the mothers during the stressful high-risk pregnancy and delivery. The use of self-blame as a means of asserting a measure of control over an unpredictable environment is highlighted in the literature (Gilbert, 1998).

The mode and timing of the delivery were mentioned as some of the uncontrolled elements of the pregnancy, specifically, the delivery. All ten of the babies were born by C-section because of medical complications and not necessarily the initial choice of the parents. Notably, C-sections, whether or not an emergency, are found to be associated with increased maternal distress within the context of preterm delivery (Adu-Bonsaffoh *et al.*, 2022). Emergency C-sections heighten the risk of PTSD and create a negative experience of the delivery for both mothers and fathers (Döblin ***et al.***, 2023).

Ben succinctly identified the fathers' dual challenges of worrying about their partners undergoing surgery and the arrival of their premature babies. Although the literature identifying the impact of high-risk pregnancy on fathers is limited, it indeed confirms Ben's concerns to be relevant and common among fathers (Jackson, Erasmus and Mabanga, 2023). Lasiuk, Comeau and Newburn-Cook (2013) describe fathers' "additional anguish when they had to choose between remaining with their partners or following their infant to the NICU" (Lasiuk, Comeau and Newburn-Cook, 2013:4).

Conclusion of Theme 1

Theme 1 broadly described the pregnancy journey leading up to the admission of the preterm baby to the NICU. The gamut of emotional and physical stressors both mothers and fathers experienced during the pregnancy created parental emotional vulnerability even before the admission of their premature baby to the NICU. The emotional vulnerability of mothers with high -risk pregnancies has been shown in the research (Kingston, Tough and Whitfield, 2012; Goetz *et al.*, 2020; Williamson *et al.*, 2023). The need for psychological support and appropriate referrals is important in high risk pregnancies (Roomaney, Andipatin and Naidoo, 2014) . In their review of the

literature Williamson et al., 2023 , highlight the need for appropriate support during the high- risk pregnancies but do not suggest specific healthcare workers that should be responsible for this intervention. They also comment on the importance of family and friend support.

There was no mention in any of the interviews of any psychosocial interventions suggested to or utilised by the parents, despite their medically complex pregnancies and high risk of preterm delivery. The quality of obstetric care should be measured by the holistic management of pregnant women, ensuring appropriate and necessary culturally sensitive medical, social and psychological interventions (Alves, Cecatti and Souza, 2021). It has been suggested that in lower resourced countries, routine screening for psychosocial risk factors could be beneficial in improving obstetric outcomes (Austin, 2014). In South Africa currently no policies regarding this exist.

4.4.2 Theme 2: Transition to parenthood in NICU - Parenting in an unnatural environment.

Table 4-6 Theme 2

Themes	Categories	Subcategories
Theme 2. Transition to parenthood in NICU-Parenting in an unnatural environment	2.1 Parenting experiences	2.1.1 The NICU environment 2.1.2 Positive experiences 2.1.3 Information sharing 2.1.4 Separation 2.1.5 Medical fragility 2.1.6 Managing multiple responsibilities 2.1.7 Cultural considerations
	2.2 Organisational challenges	2.2.1 Hospital failures and irritations 2.2.2 Internal architecture failures 2.2.3 Lack of accommodation

The quote best describing this theme emerged from Carri's description of her perceptions of her NICU journey:

"The people that have never been in a NICU experience, have no idea what actually goes on, it's a different world—it's crazy what goes on there… If you haven't ever been in there, you have no idea." (Carri)

Two categories informed this theme: Parenting experiences and Organisational challenges.

4.4.2.1 Category 2.1: Parenting experiences

This category describes the parenting experiences inside the NICU and the fundamental factors that shaped and influenced the transition to parenthood in the unnatural environment of the NICU.

The two quotes below illustrate this category, aptly highlighting the juxtaposition of the NICU experience:

"***And I remember the first time I walked in …they put a sign outside the NICU saying 'Welcome to Premmiville' and I told my husband I wish you could change the sign to 'Welcome to hell', because this is hell for me." (Bev)***

"When I think of my NICU, when I think of the NICU, I get warm fuzzies, which is very unusual because most have PTSD." (Kim)

The study identified seven subcategories that helped deconstruct the positive and negative elements of the parenting experience in the NICU that when combined to create the lived experiences of parents in a NICU.

The NICU environment contributed to the parents' levels of psychosocial distress and their ability to parent in such a challenging environment. These quotes point to the overall parental perception of the NICU and the effects of the numerous sounds and presence of life-saving medical equipment:

"You realise it's such a normal environment for the doctors, and it's such a normal environment for the nursing staff, but it is the most abnormal environment and experience you would ever have in your life." (Julie)

"And with all this going on, you still got all these sensors and alarms going off and you don't know what desaturation is and what it should be at and what the resting rate should be… I became so obsessed with it that the moment anything went a little bit funny, you start almost hyperventilating…so, for my side that was quite taxing as such, and they were tough days." (Sue)

Notwithstanding their negative perceptions of the NICU environment, the parents remembered and narrated numerous positive experiences during the admission. Overall, such positive events occurred once parents could experience physical proximity to their baby, observe developmental milestones and master the medical equipment and daily routines. Over and above these elements, the parents' feelings of

trust and respect for the medical staff engendered a positive environment and experiences:

"I can't remember anything else besides the new milestones that you reach, you know like getting to put clothes on her for the first time and that kind of thing. Yes, when she's off the tube and fully on the bottle, when I go to actually breastfeed her the first time." (Carri)

"What stood out for me was the first time I saw his face…Oh my God, that's my child. Like I'm seeing my child for the first time. Like I saw him. But for the first time, I actually saw his features. Yeah. And like, she let us take photos of him and stuff, and they would always let me touch him." (Sue)

Five parents expressed their admiration for and trust in the doctors and the nursing staff:

***"It's a different kind of nursing staff to your general nursing staff. They, they've got a special soul to them. They really do."* (Kim)**

Parenting in the NICU was influenced by the unnatural NICU environment as the backdrop to the transition into parenthood. The parents expressed the physical separation from their baby as one of the negative experiences during their time in the NICU:

"I don't wish that on anybody to leave your child and come home without your baby. And you wake up in the middle of the night and you wonder if your child is okay. Because they're not with you." (Bev)

At no time during the high-risk pregnancy or admission to the NICU did the parents receive official orientation to the NICU, and information sharing between staff and parents was perceived as limited and insufficient. Only two parents had previous NICU experience with older siblings. One couple described their orientation within the NICU, whereby they were only shown where their baby would be admitted, and one mom described her orientation as consisting of how to wash her hands:

"You know, and I think they've got the knowledge, but they're not sharing it, because it's such a normal environment for them. So, whatever is happening is

logic for them. But it's the most illogical thing for you. I think that's what it was.'' (Julie)

There were two distinct challenges in dealing with the medical fragility of their baby—unexpected changes in medical status and the medical procedures their baby endured:

"Doctor phoned and she said listen, I think you really need to come to the hospital because Baby 2 just crashed." (Julie)

"It's better waiting outside then seeing them doing whatever they need to do. That was like the worst experience I would say actually from everything." (John)

Parents also commented on managing multiple responsibilities. For the fathers, juggling work responsibilities, family responsibilities and trying to be present for significant milestones in the NICU proved challenging:

"Trying to balance to go see your child and hospital and then still trying to run a normal household you know feeding dogs looking after mommy making sure that the washing is done." (John)

Other instances regarding the difficulty of handling multiple responsibilities revolved around parenting twins in the NICU. Julie described the challenges of feeding two babies when her husband wasn't able to be with her in the NICU:

"Think it was just difficult to have Brad as well. I think it was really tough on him and he wants to be with us. But when you go to the hospital, he obviously can't go into the unit. So then one of us had to stay outside with him [***referring to sibling***] ***and then that's challenging then is that you cannot help feed and now obviously now if you have two babies, you know you want to be a little more hands on." (Julie)***

The parents referred to cultural differences influencing care routines during the admission, particularly relating to the use of specific creams during bathing and expressing milk in public. The second incident had more far-reaching consequences for both the mother and the father:

"And unfortunately, from a white culture you['re] ***very reserved and I know African cultures, they don't care they just whip it out and they don't care. And so from our side that was a bit annoying towards the end." (Ben)***

Discussion Category 2.1: Parenting experiences

The first category of the theme illustrated and explored the transition to parenthood in the unnatural environment of the NICU. A range of context-specific events related to the NICU environment, and the medical fragility of their premature baby shaped the transition. Five central parental challenges emerged, underpinning the negative experiences in the NICU: the NICU physical environment, lack of information sharing, physical separation, managing their baby's medical fragility and managing additional personal and familial responsibilities. Regarding positive experiences, the parents valued the experience of proximity to their babies, participating in care routines and positive interactions with their babies and developing trust in the medical staff.

The literature cites the NICU environment, specifically the sounds and presence of the medical equipment, as substantial elements creating barriers to parenting, thereby affecting attachment and increasing stress (Williams *et al.*, 2018; Caporali *et al.*, 2020; Givrad, Hartzell and Scala, 2021).

The parents identified information sharing and orientation would have assisted them to cope better and help them navigate the unfamiliar environment. The parents were not issued with any written information regarding the NICU environment and procedures in any of the four NICUs in this study. The literature suggests that appropriate information sharing, particularly regarding medical care, procedures and NICU equipment, plays a two-fold role in reducing stress and changing the parental experience, either positively or negatively (Williams *et al.*, 2018).

Throughout their narratives, the parents described the physical separation from their premature babies during the NICU admission. There were different reasons for the separation, with category one assigning the separation to the presence of the lifesaving equipment and the baby's medical fragility. The physical separation is known to affect the parent–baby dyad as well as opportunities to perform and accomplish the parental identity (Treherne *et al.*, 2017; Petty, Jarvis and Thomas, 2019). In contrast, the parents enjoyed times of closeness, participation in care routines and being present at momentous developmental and care milestones. The literature is rich with research exploring the importance of parents' participation in care routines in the NICU as a way to facilitate the transition to parenthood (Provenzi and Santoro, 2015; Kutahyalioglu *et al.*, 2023).

For the parents, holding, feeding and bathing their baby were symbolic on multiple levels, creating moments of positivity, physical connection, autonomy and trust. A

mutual trust developed between the parents and staff that facilitated increased parental involvement in care routines. This element of mutual trust is described by Treherne *et al*. (2017).

Further to the idea of creating moments of physical closeness, the first time the parents were able to see their baby's face, first exposure to KMC, first smiles, and choosing clothing and dressing their baby for the first time were all moments of positive physical closeness. The timing of these interactions was significant, not only the interaction itself. Baylis *et al*. (2014) infer the importance of such first-time events. Optimising and encouraging first-time events as early on as possible, within medical constraints, ensures the necessary transition of the parents to the central role players in the care of their baby instead of just team members (Baylis *et al.*, 2014). Jackson *et al*. (2003:124) suggest this concept and comment that within the context of care routines, parents need to feel that they are not "just borrowing the child" from the nurses but rather are its central caregivers.

In the current narrative and interviews, the fathers expressed their challenge of physically managing the multiple responsibilities of work in conjunction with finding time to visit the baby in the NICU. Some researchers find that for some fathers, work creates an element of distraction from the challenges of the NICU experience and is welcomed by them, whereas others agreed with the challenge of managing the multiple responsibilities of NICU and work (Ireland *et al.*, 2016; Lundqvist, Weis and Sivberg, 2019; Petty, Jarvis and Thomas, 2019).

The added responsibility of managing the care routines for their twins in NICU posed an additional responsibility for the mothers that they could not always manage, particularly when the father was not available to assist. A search of the literature found no discourse regarding this factor and the implications of having twins on achieving the parental role in the NICU, thus highlighting the need for further research. In addition, the presence of siblings and the challenges of managing time to be available to both the newborn and the sibling contributed to the added responsibilities. One of the difficulties for siblings after the unexpected birth of a sibling, particularly a baby requiring admission to the NICU, relates to their difficulties with a perceived and actual increased separation from their parents (Beavis, 2007). Navigating this challenge

creates both a physical and emotional challenge for the parents when trying to adapt to parenting in the NICU.

The final element creating a challenge to parenting in the unnatural environment of the NICU was the perceived cultural differences between the parents and staff. Despite attempts, no black African parents participated in the current research, which might have influenced the lack of cultural richness and experiences. Previous research exploring the lived experiences of South African parents in a single private NICU setting did not highlight any cultural elements; however, the demographics of the cohorts in those studies were not specified (Steyn, Poggenpoel and Myburgh, 2017). The general implications of cultural differences, not a particular incident in isolation, were the possible differences in perceptions within and during the NICU admission regarding care routines, the baby's health status, and parenting styles and roles (Caporali *et al.*, 2020).

4.4.2.1 Category 2.2: Organisational challenges

The second category of Theme 2 is informed by hospital failures and irritations. Certain organistional and infrastructural aspects of either or both the hospital and NICU proved lacking and annoying for the parents.

Ben describes his frustration with inadequate facilities and spaces in the hospital as well as the insensitivity of the nursing staff:

"So now you got to find and ask the unit manager where she can pump, and she said go and pump at home. I live half an hour away; I'm not going to drive home half an hour for my wife to pump and drive all the way back. There was [a] ***day she sat in the toilet and pumped and to me I'm like that's not sanitary." (Ben)***

Three subcategories best characterised the parents' frustrations and irritations as hospital failures: frustrations with staff, the unsuitable internal infrastructure of the NICU and a lack of accommodation.

For Sue and Ben, the experience in the NICU was marred by perceptions of staff incompetence. The incident occurred when their baby choked during a feed. This incident left both parents feeling distrustful of the staff and themselves in their ability to care for their baby:

"And then this nurse swaddled (sic) ***in stinking of cigarettes. And I was like ohh, you having a cigarette while my child was dying?***

"Towards the end some of the hospital staff** [**they**] **started becoming … unwilling to assist and be accommodating in the sense that we felt uncomfortable sitting in the NICU." (Ben)

Besides the lack of appropriate facilities for expressing milk, other frustrations emerged regarding the NICU facilities. A simple complaint from Kim referenced the inadequate seating for mothers who had undergone surgery:

"One thing I would say is that the chairs in the NICU are really uncomfortable for mothers recovering from caesers and operations… and there were no cushions." (Kim)

This subcategory was informed by the complete absence of overnight accommodation provided for the parents during the NICU admission. The distances the parents travelled varied from fewer than 15 km to the NICU to more than 50km each way. The ramifications were twofold; hence, the researcher selected the two quotes below:

"I would spend a few hours and then I would come home and then drive back, so I was probably back and forth three or four times a day. THAT was very hectic and then we'll go again at night when my husband got home from work and then spend quite a lot of time there at night…and then probably only getting home around 11–12 o'clock at night. So that was a hard time the back and forth." (Carri)

The inability to remain with her son affected Kim's perceptions of the NICU experience and her parenting role:

"I felt like it was a bit like a petting zoo. Like I was coming every day to see my child and then leave my child." (Kim)

Discussion 2.2: Organisational challenges

Certain organistional and infrastructural aspects of either or both the hospital and NICU proved frustrating for the parents. This category of Theme 2 was informed by parental perceptions of incompetent staff, the inconsiderate internal infrastructure of the NICU environment and the absence of accommodation for the parents. Willaims *et al*. (2018) concur that the NICU environment is multi-dimensional, incorporating not only physical elements (equipment, lights and sounds) but also the actual infrastructure and interactions between the staff and parents (Williams *et al.*, 2018).

The perceptions of staff being inept regarding their care ability and responsibilities affected the trust between parents and staff. The quality of relationships, particularly the relationship established between the parents and the NICU staff, is vital to creating a positive environment of information sharing, learning and support so essential for the parents (Steyn, Poggenpoel and Myburgh, 2017).

The infrastructural challenges the parents described included the absence of appropriate room for expressing milk and uncomfortable seating in the NICU for the mothers. The implication of these organisational failures was reduced privacy and discomfort during the time parents spent in the NICU. Flacking ***et al***. (2012) emphasise that the comfort of the furniture affects the quality of the time parents spend there and the facilitation of physical closeness to the baby. Furthermore, the structural NICU environment affects parental satisfaction with the NICU experience (Williams *et al.*, 2018).

Visitation was only restricted during shift changes and designated quiet times during the day. However, due to the lack of accommodation at any of the NICU facilities in this study, the unavoidable separation at night reinforced the physical separation that parents experienced in the NICU. Worldwide, the trend has shifted from open bay NICU settings to single-family rooms, thereby ensuring privacy and physical closeness by providing full-time parental presence (Flacking *et al.*, 2012).

The second implication of the absence of accommodation was the distance parents were required to travel to the respective NICUs, precipitating separation from their baby (limited visitation) and monetary and time concerns. Several parents had to travel substantial distances to the NICU. The literature highlights the typical compromise between admission to a closer NICU facility and seeking a facility of excellence and higher levels of care (Villeneuve *et al.*, 2018). Three reasons the parents noted regarding the great distances between home and the NICU were the lack of an appropriate NICU facility close to home and the need for specialised care for the premature baby and the mother.

Conclusion theme 2

Parenting in the NICU is influenced by a multitude of factors affecting the acquisition of the parenting role. This finding is echoed by Kutahyalioglu ***et al***. (2023) in their research, identifying that the physical environment of the NICU influences not only the quality of the care provided but also the parents' involvement and presence in the NICU

(Kutahyalioglu *et al.*, 2023). The two themes universally highlighted in the literature regarding the parental experience in NICU include the challenges of adopting the parental role in the NICU as well as the psychosocial distress experienced by parents in the NICU (Al Maghaireh *et al.*, 2016; Steyn, Poggenpoel and Myburgh, 2017; Trumello *et al.*, 2018; Lundqvist, Weis and Sivberg, 2019; Namusoke *et al.*, 2021; Adu-Bonsaffoh *et al.*, 2022.)

Theme 2 discussed the first element, and the second is addressed in Theme 3.

4.4.3 Theme three - Coping with the emotional journey during a prolonged admission

Table 4-7 Theme 3

Themes	Categories	Subcategories
Theme 3 - Coping with the emotional journey during a prolonged admission	3.1 Psychosocial challenges in t	3.1.1 Rollercoaster of emotions 3.1.2 Parent worries 3.1.3 Perseverance and positivity
	3.2 Seeking support	3.2.1 Religious support 3.2.2 Partner support 3.2.3 Peer support 3.2.4 Professional support

Theme 3 of the thematic analysis highlights the emotional response, worries and coping strategies the parents employed during the NICU admission. The study selected one quote to represent this theme:

"…and the other mommies in the ICU because goodness gracious , you need to talk to someone who's going through the same thing as you because if you've not been through it, nobody can understand what it's like." (Julie)

Two categories informed this theme: Psychosocial challenges in the NICU and Seeking support.

4.4.3.1 Category 3.1: Psychosocial challenges in the NICU

Parents experienced significant difficulties during the baby's stay in the NICU.

"It's a really taxing tolling emotional journey." (Sue)

"I mean, obviously it's heartbreaking to go through." (Carrie)

Parents talked about various significant psycho- social experiences during the NICU admission. Julie summed this up by saying that:

"But it was just such a rollercoaster." (Julie)

"And obviously if something happens, like it just goes well and then there is a setback. Then it goes well again, so it's kind of it's an emotional rollercoaster." (Ruth)

The rollercoaster nature of the admission contained elements of both positivity and negativity during the NICU experience. Not only Ruth described a positive experience in the NICU:

"Actually, it wasn't that bad." (Ruth)

"It just was I had great service from the hospital, and everything went smooth and fine." (Rob)

Ben was particularly expressive of the fears he and his wife Sue had concerning their preterm baby:

"I'll never forget the doctor said we're going to have to give him steroids. And one of the side effects of steroids was cerebral palsy. So now as a parent, you put in (sic) ***a rock and a hard place. Whether you take him off oxygen, without giving steroids in the hope that he's strong enough to be able to do it and, or do you administer steroids in the hope that he doesn't get cerebral palsy?'' (Ben)***

Sue expressed that it was hard for her husband to spend time in the NICU due to the emotional toll that it took on him

"It's not the same dad that walked in. Yeah, when he first walked in there, he couldn't even spend ten seconds. And there he had, like, look at him, heard the machine beep and he would run out. So, then it built to like, 30 seconds, then [***a***] ***built to a minute. Then it was five minutes. Then it was an hour.'' (Sue)***

Discussion: Category 3.1: Psychosocial challenges in the NICU

All the parents vividly communicated their psychological and emotional journey during the NICU admission. They expressed and described emotions like worry, depression, vulnerability, fear, shock, disappointment, frustration, and guilt.

Previous systematic reviews of parental experiences in the NICU find emotional distress as one of two significant consequences post-admission to a NICU (Al Maghaireh *et al.*, 2016). Across a spectrum of countries, independent of their socioeconomic status, emotional distress features as a prominent experience during NICU admission (Abuidhail *et al.*, 2017; Steyn, Poggenpoel and Myburgh C., 2017; Lundqvist, Weis and Sivberg, 2019; Hemle Jerntorp, Sivberg and Lundqvist, 2021).

Comparing the findings from this exploration of the NICU experience reveals similarities with the available literature. Describing the psychological journey of the NICU experience as a rollercoaster of emotions is not a concept unique to this research but has indeed been described in previous research (Provenzi and Santoro, 2015; Loewenstein, Barroso and Phillips, 2019; Petty, Jarvis and Thomas, 2019).

In unpacking the mothers' and fathers' emotions, different emotions connected to specific stressors and events in the NICU emerged. Fear, shock and worry were often associated with the medical fragility of the baby, its appearance, and the possible short- and long-term consequences of prematurity. These emotions are similarly substantiated in the research (Steyn ,Poggenpoel, and Myburgh, 2017; Loewenstein, Barroso and Phillips, 2019; Caporali *et al.*, 2020). Regarding the vulnerability related to the unknown and unpredictable NICU environment, Lawton's environmental press theory affirms that "the more vulnerable a person is, the more sensitive he or she is to the environment" (Johnson and Abraham, 2020). Johnson and Abraham (2020) further suggest this theory could apply to parents' experiencing the NICU environment.

Feelings of guilt continued to plague the parents in the NICU, creating a continuum from the pregnancy, delivery, and subsequent admission. Thus, mothers and fathers identified two stressors that specifically perpetuated their feelings of guilt: their inability to protect their babies from harm and, at times, needing to be away from the NICU and thus not visiting their babies. Although not always directly related to these stressors, guilt features prominently in research exploring the emotional distress of parents in the NICU (Roque *et al.*, 2017; Steyn, Poggenpoel and Myburgh C., 2017; Loewenstein, Barroso and Phillips, 2019).

Depression was specifically cited by only one of the parents; several factors, particular to this mother and her husband, could have precipitated this depression. Their baby was born at the youngest GA and had the longest admission period; they lived the farthest distance from the NICU (>50 km) and expressed in their interview the limited

finances to go and visit regularly. Roque *et al*. describe several of these factors as markers for the development of depression in the NICU (Roque *et al.*, 2017). Citing these specific barriers, black Hispanic and Ghanaian mothers experienced emotional distress during admission to a NICU (Adu-Bonsaffoh *et al.*, 2022; Witt *et al.*, 2022).

By countering their distressing and negative emotions, the parents could ultimately continue to see positivity in the NICU. This juxtaposition of emotions can be seen as one of the coping mechanisms the parents accessed. The emergence of both positive and negative emotions is not unique to this research, as Petty *et al*. (2019) note in their assessment of the available literature. Lowenstein, Barroso and Phillips (2019) describe the concept of "emotion-focused coping", whereby parents can utilise feelings of hope and optimism to balance the negative and distressing emotions felt during the admission (Loewenstein, Barroso and Phillips, 2019).

4.4.3.1 Category 3.2: Seeking support

The second category of Theme 3 was informed by the following quote:

"And eventually you find your team, your rhythm, and the bad days you do get emotional, you do get overwhelmed … but for me personally the good days carried me through the tough days and the bad days." (Ben)

In adjusting to the abnormal environment of the NICU, the ramifications of prematurity and the psychosocial consequences, parents need to try managing their daily physical and emotional needs by developing coping mechanisms. Four codes emerged from the interviews: religious support, partner support, professional support and peer support.

Bev's trust and belief in God gave her comfort in knowing that she could cope with any obstacles or challenges coming her way:

"So, thank God, I think God knew what I couldn't handle." (Bev)

It was apparent that both the mothers and fathers needed and benefitted from spousal support. Parents were able to help each other on an emotional and physical level:

"But we pushed each other to still go irrespective of what we were going through or what stresses and pressures we had from a personal level and then, you know, from a relationship level supporting each other still is, was, massive. That was massive. Yeah, I can't stretch the fact on it." (Ben)

"So, I was coping better when my husband was there and yeah, if he wasn't there, then I was like sitting and crying and not coping and just feeling like I'm a bad mother." (Ruth)

Overwhelmingly, parents expressed the benefits of peer support during their NICU admission. The support was mostly informal, not in an organised group setting or environment. Specifically for the mothers who had twins in NICU, finding commonality with other moms with twins was both beneficial and important:

"I think meeting parents … that was sort of a nice experience and having people that are going through the same thing with you helps because almost everyone else doesn't really understand." (Kim)

"We both twin mommies we were there the same amount of time. You go through that emotion, but at least you can support each other."(Julie)

The two quotes chosen highlight the varied levels of emotional support offered and received in the NICUs. The parents quoted were admitted to different NICU facilities, stressing the varying support offered. The support offered by the nurses seems to point to more situational support rather than structured regular professional interventions. The support Sue received was limited to nursing support and none from trained mental health professionals:

"One thing I'd add was that was that in terms of emotional support, there wasn't any." (Kim)

"When you'd have your emotional breakdown, there was always a nurse hugging you and telling you it was OK." (Sue)

Discussion Category 3.2: Seeking support

To cope with and manage the emotional rollercoaster experience of the NICU, parents sought support from different sources. Loewenstein, Barroso and Phillips (2019) describe this as "problem-focused coping", whereby "coping is pragmatic and objective" and aimed at finding a specific solution (Loewenstein, Barroso and Phillips, 2019:344). The parents sought support from their partners, their NICU peers and the nursing staff. The analysis of the parental narratives foregrounded the overall impression that despite the parents' overall negative perception of the NICU environment (as discussed in Theme 2), they often perceived their actual experience

in the NICU more positively. This could be due to the effect of the support and the coping strategies that they had implemented individually and as couples.

Only one parent attributed coping to her beliefs, religion and trust in a higher power. This was not asked specifically but rather offered spontaneously by the mother. This contrasts with research by Sih, Bimerew and Modeste (2019) in Cape Town, where prayer and faith formed the most common coping strategy for mothers. The difference in the location of the study and the use of a government facility could have influenced the results; however, the research article does not highlight or discuss the demographics of the sample (Sih, Bimerew and Modeste, 2019). The significance of religious support is the element of protection it offers against stress in the NICU (Heydarpour, Keshavarz and Bakhtiari, 2017).

The professional support from the nurses and NICU peers was informal and unstructured. The unit manager provided weekly support sessions at one of the NICUs; however, this was not consistent. Significantly, the parents did not describe or mention any formal availability of support from professionals such as psychologists, psychiatrists, social workers or from any structured groups with peers. This situation applied to all the NICU environments in this study and is contrary to research suggesting the importance of the presence of these professionals in the NICU, together with the best practice of a multilayered approach to support in the NICU (Hynan *et al.*, 2015; Treyvaud *et al.*, 2019).

In the absence of additional support provided in the NICU, drawing on the strength and support from their partners formed one of the cornerstones of the coping mechanisms for some of the parents, as expressed by both mothers and fathers. This support occurred in the form of shared emotional support and sharing of care responsibilities.

Conclusion of Theme 3

The study noted the juxtaposition that the parents perceived the NICU environment negatively yet described their NICU experience positively. The words the parents used to express their overall perceptions of the NICU environment included “crazy”, “chaos”, and “abnormal” although they described their overall experience in NICU positively. Their coping mechanisms and the support they received, albeit very limited on a formal level, might be underlying factors in these differences between their perception and experience of the environment.

CHAPTER 5 : CONCLUSION AND RECOMMENDATIONS

The preceding chapter presented the research findings with references to the thematic analysis and the current literature. Chapter 5 presents the conclusions of the research in relation to the research objectives, the implications for practice, suggestions for future research, and the limitations of the study.

5.1 Research objectives

The study aimed to explore parental experiences during the admission of their preterm baby to the NICU. The researcher set out two objectives for this research report. Each is discussed separately in the context of the identified themes.

- To explore parental experiences during the NICU admission of their preterm baby.

The primary objective of the research was to explore the phenomenon of the NICU experience, as described by the parents. All three themes contributed to this objective, providing a rich narrative of the parental experiences. Theme 1 gave insight into the high-risk pregnancy and delivery of the preterm baby leading up to the admission to NICU and the parental emotional distress on admission. Theme 3 highlighted the psychosocial challenges during the admission period. The combination of these themes aptly describes the gamut of emotions and the emotional build-up that preceded the admission, portraying parents already vulnerable due to one traumatic event leading to another.

Theme 2 further provided insight and met the objective of describing the challenges to acquiring the parental role in an unnatural parenting environment, the NICU. Despite four different NICU environments, the experience did not differ significantly regarding these challenges. This commonality highlights that parental experiences were similar and did not necessarily depend on a particular NICU context.

- To compare the emerging themes with existing research findings from other countries.

This research highlights and discusses the two most common themes that emerged from the literature. Theme 3 describes the challenges of the emotional distress parents experience during the admission period in a NICU; Theme 2 describes the difficulties

in the process of achieving the parental role when parenting a premature baby in the NICU.

5.2 Limitations and Strengths

This research added to the current understanding of parents' lived experiences during the admission of their preterm babies to a private NICU in Johannesburg. Previous research was limited to a single private NICU facility in Johannesburg. The implications of four different facilities highlighted the universal experience despite the specific setting. However, the findings of this research cannot necessarily reflect all private NICU settings in South Africa.

Despite attempts through purposeful sampling, the study's cohort of parents did not reflect the diversity of the South African population accessing private healthcare in Johannesburg, South Africa. Only white and Indian parents were interviewed; no black African or coloured parents enrolled as part of the cohort. Therefore, this research did not explore or highlight the possible influences of cultural beliefs and practices of other race groups, constituting a limitation of this study. In addition, the focus of selecting the study setting within the private sector health care, and not the public sector, further limited the diversity of the parents interviews.

Furthermore, in the demographic questionnaire, the study gathered limited information regarding specific religious affiliations and socioeconomic factors. Such information could have added another layer of significance to the parental experiences and challenges.

The literature on past research is limited, particularly pertaining to parents of twins or multiples and their lived experiences in a NICU. Identifying differences and similarities would further improve service provision and delivery of FCC in the NICU setting.

5.3 Recommendations for Future Research

The South African medical landscape contains both private and governmental NICU facilities; therefore, further research is required to highlight the differences and similarities of parental experiences within different medical contexts. Access to the different medical facilities is predominantly based on differences in socioeconomic status, which might impact parental experience.

Furthermore, the context of family structures (twin/multiple pregnancies and older siblings) might affect parental experiences. Single-parent households could introduce a variety of different factors impacting parental experiences. Cultural influences on parental roles in the family and society should be researched regarding their impact on parental experiences.

This research did not have the objective to differentiate between the experiences of fathers and mothers; however, this aspect should be identified with the South African context and NICU environments.

Considering the described limited psychosocial support offered, further research is required to identify the nature of the psychosocial support professionals that would be most relevant to the South African context, accounting for the diverse cultural, racial and religious affiliations in South African society.

5.4 Implications for Future Practice

Despite this research only introducing the experiences in four private sector NICU environments in Johannesburg, the absence of formal, standardised professional and structured psychological interventions both during high-risk pregnancies and admissions to the NICU was significant. None of the eleven narratives mentioned support beyond the informal support offered by medical doctors, nurses and other parents in the NICU. This situation exists despite international recommendations for psychosocial support by trained professionals embedded in the NICU environment along with structured peer support, which is an integral element of FCC delivery in the NICU. There remains a need for South African NICU facilities to create context-based, appropriate best-practice standards in psychosocial support provision to parents in the NICU. FCC best practice guidelines have been suggested , however within these guidelines, there is mentioned only informal parent supports groups as being essential. There is no mention of other structured support from mental health practitioners (Lubbe, 2010). As part of best practices, introducing child life specialists into the South African medical landscape could assist in providing a level of psychosocial care that would be appropriate for and beneficial to the parents.

Further mitigating the stress associated with NICU admission, and fundamental to the principles of FCC, is the need to share appropriate information with the parents. Information sharing and orientation in the NICU environments must be established as

a basic requirement for all NICU facilities in an appropriate format that is acceptable to parents.

The emotional and financial impact resulting from long distances to travel between home and the NICU highlights the need for appropriate accommodation for parents at hospitals. Furthermore, the internal architecture of NICU environments should be viewed and recognised as an integral element of providing quality service and care to both the babies and parents admitted to a NICU facility in South Africa.

5.5 Final Reflexive Thoughts

All medical professionals working in the NICU environment should aim to offer holistic care to both parents and their babies, encompassing appropriate medical and psychosocial interventions. As a physiotherapist, gaining insight into providing parents with psychosocial support has paved the way to broadening my philosophy of treatment and embracing the tenets of FCC

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APPENDICES

Appendix1: Healthcare Professional Information Sheet

Information for referring healthcare practitioners

Study title: *The lived experiences of South African parents during the prolonged hospitalisation of their premature baby*

Dear Colleagues

My name is Linda Goldberg, I am a physiotherapist with an interest in paediatrics, currently working in private practice. I am completing a Master of Science in Medicine programme at the University of the Witwatersrand. The Master's programme is in Child Life Therapy and Psychosocial Care. My research study focuses on parental experiences of the admission of their preterm baby into neonatal intensive care.

As healthcare practitioners working with this population group, I would like your assistance in identifying parents who would be eligible for my study. The inclusion criteria include all parents with infants born at fewer than 37 weeks gestation and admitted to a NICU for a period of four weeks or more. The participants will be asked to participate in an interview with the researcher and must be willing to discuss their experience of NICU admission. The interview will last 30–45 min, in their home or a location decided upon by both parties. The interview will take place four weeks post-discharge of their baby from the hospital. The parents will need to be proficient in English. It is essential that the parents understand participation is voluntary and will in no way interfere with your medical relationship with the parents and their infant.

Due to the strict laws regarding the transfer of information between parties, as specified by the POPI Act, the parent will be asked to sign a consent form, allowing you as the healthcare professional to transfer their personal contact information to the researcher. This will precede the researcher being allowed to contact the participants directly to get their consent and set up an interview time. Parental confidentiality will be maintained at all times, and no identifying information (parent, infant or hospital) will be published. Each parent will be anonymised and coded. The interview will be recorded and transcribed and, thereafter, thematically analysed to identify common themes. The parents will have access to the transcribed interview for perusal. The

information will be stored in a password-protected cloud-based programme, as required by the POPI Act, to ensure no transfer of personal information. A summary of the research outcomes will be available to the healthcare practitioner and participating parents.

Due to the nature of the information shared during the interview, there is the possibility of the parent/s becoming distressed. A distress protocol has been put in place with the correct procedures for the researcher to follow and names of professional councillors/therapists that will be available to offer the parent counselling. The cost of one session will be covered by the therapist as part of the research if required. Therapists that have been included in the distress protocol are Tanya Rubin (social worker), 0826001989 and Joanne Zagnoev (clinical psychologist), 0844567959.

This research will provide the multi-disciplinary team working with premature infants and their families, insight into parental experiences. It will also provide information regarding similarities and differences to international research. This knowledge may help us to deliver holistic family-centred care.

This study has been approved by the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg ("Committee"). A principal function of this Committee is to safeguard the rights and dignity of all human subjects who agree to participate in a research project and the integrity of the research. If you have any concerns, please contact the Chairperson of this Committee, Professor Clement Penny on 011 717 2301 or on Clement.Penny@wits.ac.za. The Committee Secretariat can be contacted on 011 717 2700/1234 and Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za.

Thanking you for your time and consideration in this matter. I can be contacted directly on 082 519 1447, lindahazelgoldberg@gamil.com. My supervisor is Dr Janine van der Linde, who may be contacted on 011 717 3713 or Janine.vanderLinde@wits.ac.za

Kind Regards



Linda Goldberg M.Sc Med Child Development Wits; B. Sc Physiotherapy Wits

Appendix 2: Sharing of Information Consent Form

Consent form for referring health professionals and parent information

Date:

Dear parents

Thank you for your consideration regarding participation in the research project undertaken by Linda Goldberg.

Linda Goldberg is a physiotherapist with an interest in paediatrics working in private practice and currently completing a Master's in Medicine programme at the University of the Witwatersrand. The programme is in Child Life Therapy and Psychosocial Care. The research study focuses on parental experience of the admission of their preterm baby into neonatal intensive care. Linda Goldberg may be contacted directly for further information on the study on 082 519 1447, lindahazelgoldberg@gmail.com.

As a parent/s of an infant born at fewer than 37 weeks gestation, with admission into NICU for at least four weeks, you are eligible to participate in this study. Participants will be required to participate in an interview discussing their experience of the NICU admission. This study serves to explore parental experiences, which will offer information on providing holistic care in the NICU environment. The information obtained will assist the researcher in identifying differences and similarities from international research.

The interview will last maximum 60 minutes, in the comfort of your home or a location decided upon by both parties. The interview will take place four weeks post discharge of your baby from hospital. Proficiency in English will be essential. It is imperative that parents understand that participation is voluntary and will in no way will interfere with the medical relationship with the referring medical practitioner. Withdrawal from the research project at any stage is possible with no consequences to the parent or infant.

Due to the strict laws regarding the transfer of information between parties, as specified by the POPI Act, the parent/s will be required to sign a consent form allowing the healthcare professional to transfer the parents' contact information to the researcher. This will precede the researcher being allowed to contact the participants directly to

get their consent and set up an interview time. Parental confidentiality will be maintained at all times, and no identifying information (parental, infant or hospital information) will be published. Each parent will be anonymised and coded. The interview will be recorded and transcribed and, thereafter, thematically analysed to identify common themes. A copy of the transcript of the interview will be made available to the parent/s to ensure the accuracy of the transcribed information. The information will be stored in a password-protected, cloud-based programme, as required by the POPI Act, to ensure no transfer of personal information. The research outcomes will be available to the healthcare practitioner and participating parents.

Due to the nature of the information shared during the interview, there is the possibility of the parent/s showing signs of distress during or after the interview. A distress protocol has been put in place with the correct procedures for the researcher to follow and names of professional councillors/therapists that will be available to offer the parent counselling. One session will be covered by the therapist as part of the research if required. Therapists that have been included for the distress protocol are Tanya Rubin (social worker), 082 600 1989 and Joanne Zagnoev (clinical psychologist), 084 456 7959.

If you would like to participate and give consent to your name and contact details to be forwarded to the researcher, please sign the consent form below.

Informed consent

Parent 1

I, *(name of participant)* _____ hereby voluntarily grant my permission to the healthcare provider to provide Linda Goldberg, the researcher of the study, my name and contact details.

☐ The nature of the research study and privacy measures have been explained to me and I understand them.

☐ I understand my right to choose whether to participate in the research and that the information furnished will be handled confidentially following all POPI Act requirements.

Signed: _____ Date: _____

Witness: _____ Date: _____

Researcher: _____ Date: _____

Parent 2

I, *(name of participant)* _____ hereby voluntarily grant my permission to the healthcare provider to provide Linda Goldberg, the researcher of the study, my name and contact details.

☐ The nature of the research study and privacy measures have been explained to me and I understand them.

☐ I understand my right to choose whether to participate in the research and that the information furnished will be handled confidentially following all POPI Act requirements.

Signed: _____ Date: _____

Witness: _____ Date: _____

Researcher: _____ Date: _____

Appendix 3: Parent Consent Form and Information

Parental information and consent form for participation in study

Study title: *The lived experiences of South African parents during the prolonged hospitalisation of their premature infant*

DATE:

Dear Parents

My name is Linda Goldberg, I am a physiotherapist with a special interest in paediatrics currently working in private practice. I am completing a Master's in Medicine programme at the University of the Witwatersrand in the Department of Physiotherapy. The Master's programme is in Child Life Therapy and Psychosocial care. My research study focuses on parental experience of the admission of their preterm baby into neonatal intensive care and I would like to invite you to participate in my study. Thank you for considering participation in my research project. You have previously signed consent with your treating healthcare professional for me to obtain your contact details. Whether or not you agree to take part in the study will have no bearing on your and your baby's right to continuing healthcare.

The research involves a once-off interview, duration of 30–45 minutes, in the privacy of your home or a location chosen by parents and researcher as suitable. The interview will take place post-discharge (up to 12 months post-discharge) of your baby from the hospital. With your permission, the interview will be recorded, transcribed and anonymised to protect your information and privacy. Each parent/participant will be given an identification code, and no personal or identifying information will be used. No names of parents, babies, doctors or institutions will be used. A copy of the transcript will be made available for your perusal to ensure the accuracy of the transcribed data. All transcriptions and recordings will be stored in an approved password-protected cloud platform. All private information will be treated within the legal requirements of the Privacy of Personal Information Act (POPI Act). This means that all private information will not be shared in any manner or with any third parties. The completed findings from the research will be made available to you. Participation is voluntary, and consent can be withdrawn at any stage. There is neither cost nor payment involved in participating in the study.

Due to the nature of the information shared in the interview, the researcher is aware that the interview may be a stressful event, and a distress protocol has been put in place. As part of the distress protocol, the researcher will cover the cost for any parent who requires it, of one session with a registered counsellor/therapist to assist the parent/parents with the distress. Therapists that have been included in the distress protocol are Tanya Rubin (social worker), 082 600 1989 and Joanne Zagnoev (clinical psychologist), 084 456 7959.

I will be pleased to provide you with a summary of the study results on request, at no cost.

This study has been approved by the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg ("Committee"). A principal function of this Committee is to safeguard the rights and dignity of all human subjects who agree to participate in a research project and the integrity of the research. If you have any concerns about the way the study is being conducted, please contact the Chairperson of this Committee, Professor Clement Penny, who may be contacted on telephone number 011 717 2301, or by e-mail on Clement.Penny@wits.ac.za. The telephone numbers for the Committee Secretariat are 011 717 2700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za.

Please feel free to ask me any questions you may have regarding the research, I am available to discuss any concerns you may have. I can be contacted by email lindhazelgoldberg@gmail.com alternatively on 082 519 1447. My supervisor is Dr Janine van der Linde, who may be contacted on 011 717 3713 or Janine.vanderLinde@wits.ac.za

If you agree to take part in the study, I will ask you to sign a consent sheet to participate and to being recorded. Thanking you for reading this information sheet.

Kind Regards



Linda Goldberg

M.Sc Med Child Health and Neurodevelopment (University of the Witwatersrand)
B.Sc Physiotherapy (University of Witwatersrand)

Informed Consent

Parent 1

1.1 I, *(name of participant)* _____ hereby voluntarily grant my permission for participation in the research as explained to me by Linda Goldberg The nature, objective and privacy measures have been explained to me and I understand them.

1.2 I understand my right to choose whether to participate in the research and that the information furnished will be handled confidentially. I am aware that the results of the investigation may be used for the purposes of publication.

☐ I agree to the audio recording of the interview.

Signed: _____ Date: _____

Witness: _____ Date: _____

Researcher: _____ Date: _____

Parent 2

1.1 I, *(name of participant)* _____ hereby voluntarily grant my permission for participation in the research as explained to me by Linda Goldberg The nature, objective and privacy measures have been explained to me and I understand them.

1.2 I understand my right to choose whether to participate in the research and that the information furnished will be handled confidentially. I am aware that the results of the investigation may be used for the purposes of publication.

☐ I agree to the audio recording of the interview.

Signed: _____ Date: _____

Witness: _____ Date: _____

Researcher: _____ Date: _____

Parental consent to audio-recording of interview

Date:

Dear parent/s,

Thank you for agreeing to be interviewed as part of the research project: The lived experiences of South African parents during their preterm infant's admission in NICU.

The interview will be recorded, and a transcript produced from the recording. The transcript will be sent to you to verify and correct any factual errors. The transcript will then be analysed by the principal researcher, Linda Goldberg. Access to the recorded interview and transcript will be limited to the researcher and the supervisor and co-supervisor only. Interview content and direct quotes obtained from the interview will be anonymised, with no names of parent, baby or institution mentioned. No information from the interview that could identify the parent will be used in the research. Once the research is complete, the actual recording will be destroyed, and the transcript stored in password protected online storage format for a time period specified by the University of the Witwatersrand. If the parent chooses to withdraw from the study both the recording and the transcript will be destroyed in an approved manner .

Consent to audio-recording of the interview

Parent 1

1.1 I, *(name of participant)* _____ hereby voluntarily grant my permission for the interview undertaken, as part of the research, to be recorded by the researcher, Linda Goldberg.

1.2 I understand my right to choose whether to participate in the research and that the information furnished will be handled confidentially. I am aware that the results of the investigation may be used for the purposes of publication.

Signed: _____ Date: _____

Witness: _____ Date: _____

Researcher: _____ Date: _____

Parent 2

1.1 I, *(name of participant)* _____ hereby voluntarily grant my permission for the interview undertaken, as part of the research, to be recorded by the researcher, Linda Goldberg.

1.2 I understand my right to choose whether to participate in the research and that the information furnished will be handled confidentially. I am aware that the results of the investigation may be used for the purposes of publication.

1.3 I agree to the audio recording of the interview.

Signed: _____ Date: _____

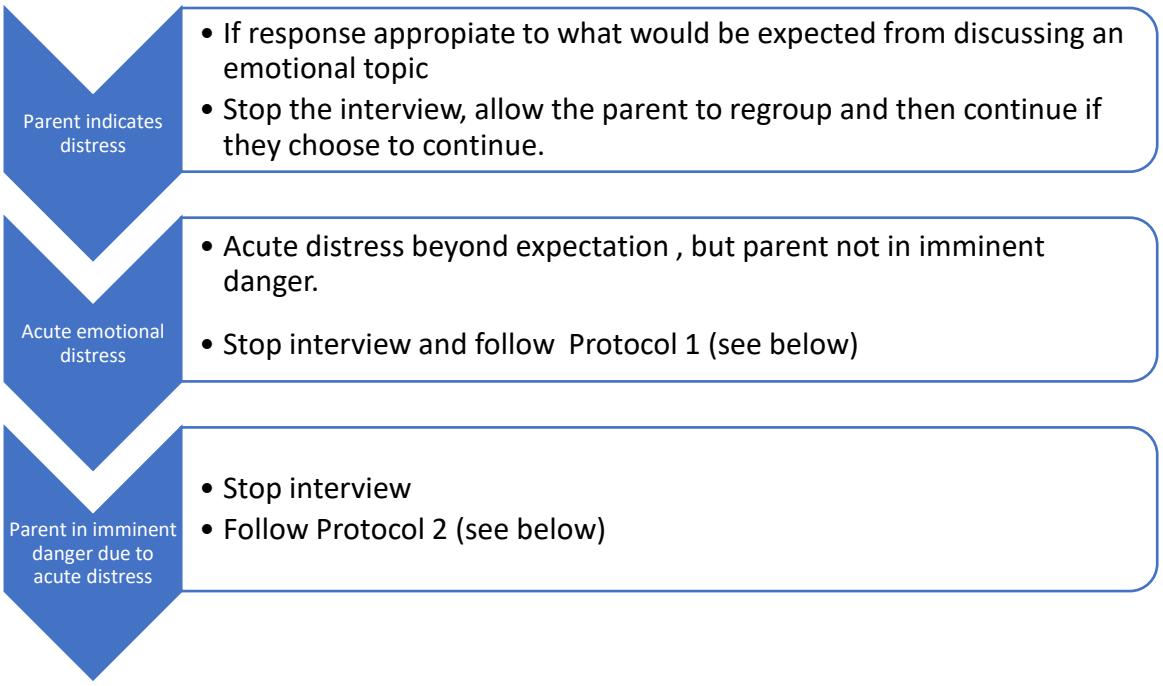
Witness: _____ Date: _____

Researcher: _____ Date: _____

Appendix 4: Distress Protocol

Distress Protocol

Modified from Drucker, Martsolf and Pool, 2009.



Signs of distress

crying, flashbacks, incoherent speech

Protocol

1. Encourage parent to contact their treating mental health professional. If they do not have a mental health professional, the number of two health professionals will be given to the parent. Tanya Rubin 082 600 1989; Nicole Canin 083 381 7803
2. Follow up with parent to ascertain if this has been done.
3. Alternatively, with permission from the parent, the researcher can contact the appropriate health professional to set up an appointment.
4. Follow up with parent/health professional.
5. The researcher will pay for one session with the health professional.

Appendix 5: Interview Questions

Parent Questionnaire Protocol

Parent name- _____

Parent pseudonym: _____

Thank you for joining the study. There are three questions to this interview, and it will probably take about 40 minutes to finish the interview.

There are no right or wrong answers. I am trying to gain as much information about the admission period, as you experienced it. I would like both of you to answer each question and feel free to stop me if you have any questions that need to be clarified.

Location of interview

General Insights from the interview

Question 1.

Thank you for joining my research project, this is a busy time for you with a new baby. I would like to start off with you telling me about yourself and your family.

Contextual notes from parent

Probe: Describe your immediate and extended family unit to me?

Question 2

Let us start at the beginning, could you please describe the pregnancy and birth experience?

Contextual notes parent

Probe: Can we discuss your expectations of the pregnancy? And the delivery?

Question 3

Can we now go on to exploring the admission period?

Contextual notes parent

Probe: Were there any specific memories/experiences that stand out to you as significant?

Probe: Can you describe the challenges that you faced as a parent

Appendix 6: Biographical questionnaire

Parent pseudonym:

Parent Information

Age of parent: _____

Gender:☐M ☐ F ☐ OTHER

Occupation: _____

Highest level of Education: _____

Are you employed? ☐Y ☐N

Type of employment?

_____

Pregnancy Information (answer if applicable):

First pregnancy? ☐Y ☐N

Planned pregnancy: ☐Y ☐N

Assisted pregnancy?☒Y ☐N

Surrogacy?☐Y ☐N

Was this a multiple pregnancy? ☐Y ☐N

Pre -existing maternal chronic medical conditions prior to pregnancy? ☐Y ☐N

If yes, please specify: _____

Medical conditions during pregnancy? ☐Y ☐N

If yes, please specify:

_____

Was your baby born during Covid lockdown periods? ☐Y ☐N

Please add in any other information you may feel is relevant to pregnancy: _____

_____

NICU environment

Proximity of the NICU to home: ☐ 0–15 km ☐15–30 ☐ More than 30

Was visiting allowed only during specific hours?☐Y ☐N

Were visiting hours restricted due to Covid? ☐Y ☐N

NICU accommodation

Infant was in own room ☐Y ☐N

Accommodation available for parents to sleep over ☐Y ☐N

Did you receive any written information booklets? ☐Y ☐N

Did you receive specific orientation to the NICU? ☐Y ☐N

If yes, please describe what information was given to you_____

_____

_____

Appendix 7: Ethical Clearance

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

R49 Ms L Goldberg

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
CLEARANCE CERTIFICATE NO. M211152

NAME: (Principal Investigator)	Ms L Goldberg
DEPARTMENT:	School of Therapeutic Sciences Department of Physiotherapy Medical School University
PROJECT TITLE:	*The lived experiences of South African parents during the prolonged hospitalisation of their premature infant*
DATE CONSIDERED:	2021/11/26
DECISION:	Approved unconditionally
CONDITIONS:	
NOTE:	If contact information regarding student study participants is required, please contact the Registrar's office - <Nicoleen.Potgieter@wits.ac.za>
SUPERVISOR:	Dr J van der Linde
APPROVED BY:	Dr CB Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	2022/03/30

This Clearance Certificate is valid for 5 years from the date of approval. An extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office secretariat on the 3rd floor, Phillip Tobias Building, Parktown, University of the Witwatersrand, Johannesburg.

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 submit details to the Committee. **I agree to submit a yearly progress report**. When a funder requires annual re-certification, the application date will be one year after the date when the study was initially reviewed. In this case, the study was initially reviewed in **November** and therefore reports and re-certification will be due in the month of **November** each year. Unreported changes to the study may invalidate the clearance given by the HREC (Medical).

Signature of Principal Investigator

Date

Appendix 8: Comprehensive list of quotes

Theme one

" So, we decided right, let's try for another one" (Julie).

Unplanned pregnancy

"And then I found out I was pregnant, and it took me by shock. And it took my whole family by shock, everyone was totally shocked how you going to manage whatever, with two small ones" (Bev).

"…every doctor visit, they were like you can't fall pregnant or anything. …So, when it happened, it was all quite a surprise" (Ruth).

"We didn't mind like falling pregnant or anything, but we also didn't expect it" (John).

"So, we were both quite shocked at that time" (John).

"And then one became two. I guess a surprise" (Julie).

Medical complications

"I actually I did have gestational diabetes, I forgot to say that. So that was also like, quite a pain" (Julie).

"And when I found out I was pregnant, , two weeks later I started bleeding… At 26-27 weeks, I was admitted, because I started bleeding again" (Meg).

"So, my pregnancy was terrible. I had placenta previa, and then placenta accreta. And then I got gestational diabetes, so I was on bedrest from 24 weeks and then I was admitted at 28 weeks for bedrest in hospital" (Kim).

"And then obviously, when she was diagnosed with high blood pressure and preeclampsia that was a different ballgame to manage… and from there the fright started coming a bit more prominent" (Ben).

"So gosh, I had a bit of bleed at 13 weeks because one of the placentas was just really low. And I was obviously being too wild with Brad (older sibling) and playing with him so , I had a small bleed, that was at 13 weeks"(Julie).

"And I have quite big babies unfortunately for me, because they that's probably why they came earlier" (Julie).

“I don’t know if I want to be mad about my pregnancy, but I am not the biggest person, and having twins, and like logically it felt like logically that I probably wouldn’t have carried further”(Julie).

“And so, I basically wasn't feeding him anymore. He was supposed to be around 1.2 kilos and he came out at 770 grams” (Sue).

“And I said to her you can't blame yourself for anything. You didn't cause preeclampsia. It's a natural thing that happens with not just yourself but a lot of other moms out there” (Ben).

Emotional challenges

“In terms of the pregnancy, I think, obviously there's excitement and joy in the beginning. But as everyone thinks it's all going to be sunshine and roses and rainbows which isn't.” (Ben).

“From a father's perspective or husband's perspective… the emotions that you have to deal with and the up and down swings with your partner, it's tough to handle let's just be honest with that. I think also with my wife, she didn't have a normal pregnancy as such, she had a lot more I don't want to say an emotional one” (Ben).

“And we were stressed but like every scan because you've got this in the back of your head if something can go wrong” (Meg).

“…two weeks later I started bleeding, so there was a lot of fear in the pregnancy” (Meg).

“The doctors were stressed during the whole pregnancy” (Ruth).

“I have to say the time before the NICU was more stressful” (John).

“And she told me… I may have another premature baby. And I cried and cried and cried” (Bev).

“I cannot ever go back to that NICU. My mental health would not allow. I never ever want to see that place ever again till the day I die” (Bev).

“I had a very difficult pregnancy emotionally. I was going through some problems in my marriage and my family. And so, I was very stressed out the pregnancy” (Bev).

Managing multiple responsibilities

“Luckily, my, the company I work for… every time I have a scan or something, they would say that's fine- you can go” (John).

“I had a baby, my first baby … I breastfeed till like maybe a few days before I gave birth the second one …I had a very difficult pregnancy” (Bev).

Support

“I believe my religion, everything's from God's so I was happy with it… I accepted that this is God's gift to me” (Bev).

“and the support we got from family not even just immediate family, even like grandparents and aunts and like everyone was so excited because on my side and my wife side it’s like the first grandchild and so on, so everyone was like very, very excited and so we got support the whole time like, with everything” (John).

Unplanned delivery

“Whatever we had to do, we had to do so even though I mean I would have preferred not to have a Caesar it is what it is babies come first” (Julie).

“your baby is going to die if you don’t deliver right now. And within like 10 minutes, they had a theatre ready for another C section” (Bev).

“and everything went not according to plan but according to doctors plan” (Rob).

Emotional challenges at delivery

“I started getting panic attacks. And so eventually they couldn't allow me to be awake. So, they need to make me sleep” (Bev).

“Delivery was also like quite a trauma” (Kim).

“She was afraid because she hasn't been in for a big operation as such, so that fear kicked in” (Ben).

“A lot to take in. Especially for myself. I don't do hospitals as such, so I don't do blood, needles, guts glory, not even I can't even watch Grey's Anatomy. That's how pathetic I am” (Ben).

“and then you know waiting for my wife to come out sitting there for 14 minutes plus waiting , is she Okay, is she not okay, if she's not alive? So, all of that does work on your on your brains a bit” (Ben).

“once baby came out its a sense of relief, but now the focus is to try and keep them alive because he was so premature at 27 weeks” (Ben).

“and you flooded with emotion because you've just gone through this uphill of your wife's going to theatre you know, they are pulling your son out , now you start thinking life and death” (Ben).

“Well, the delivery, I was not quite myself because it was a huge shock and I didn't feel myself, but I managed well” (Rob).

“Well, a once in a lifetime experience basically that can’t..... I think like all your emotions and everything on the inside was just like, all excited and yeah, knowing that literally from that moment you not just responsible for yourself any more basically” (John).

Theme 2

NICU Environment

“You realize it's such a normal environment for the doctors, and it's such a normal environment for the nursing staff, but it is the most abnormal environment and experience you would ever have in your life” (Julie).

“it is so normal to them, for us, it's like, such chaos” (Julie).

“All I felt was just can we get out of here…I know that my babies are there, but I mean, I need to leave this environment” (Meg).

“The people that have never been in a NICU experience, have no idea what actually goes on, it’s a different world- it’s crazy what goes on there…. If you haven’t ever been in there, you have no idea” (Carri).

“*And then the second time I went back. And I remember the first time I walked in to see my second son they put a sign outside the NICU saying welcome to Premmiville, and I told my husband I wish you could change the sign to Welcome to hell, because this is hell for me’ (Bev).*

“In the beginning, you obviously new parents don't know what to expect what’s coming” (Ben).

“And like I say there is no one to relate to. There's no reference point, reference guide.… And I actually said to my wife, you should look at writing a book just as small or even just a blog or something like that” (Ben).

“I'm a health care worker. No, but I didn't even know these things. You know, I mean, I'm sort of having to wing it and nobody's giving you like guidance and I think that was the most frustrating thing” (Julie).

“But in the meantime, nobody tells you basic things” (Julie).

“You know, and I think they've got the knowledge, but they're not sharing it, because it's such a normal environment for them. So, whatever is happening is logic for them. But it's the most illogical thing for you. I think that's what it was” (Julie).

“I knew a lot about the NICU. So, whenever I was there, I would check up on his feeds ,his oxygen levels, what is his oxygen sitting at? …I knew a lot. I knew how the pump works, over how many hours he is getting his feed” (Bev).

Positive experiences

“All in all, the NICU experience was amazing” (Sue).

“I would say but most of it was actually good experiences” (John).

“And I must say he was very well looked after where he was, they were looking after him very well. I can’t complain about anything” (Pam).

“So, it was quite an easy experience that I don't even know if that's the right way to put it” (Carri).

“*We were there during World Prematurity Day, which I think was quite a nice experience. They had; they did like a whole event for the parents, little bags. So that was quite a nice experience” (Carri).*

“I felt very at home there” (Kim).

“In seven and a half weeks I had a bad experience with one nurse. And that's about that… overall, that was it was a positive very positive experience” (Kim).

“The second time I came in and asked the nurse can I bath him? And they left me with the oxygen and all the tubes and everything to sort out myself, which I did” (Meg).

“They would let us hold the syringe with his milk. So little things like that, they would get us involved” (*Sue).*

“…at that moment, knowing it’s your first skin to skin with your son” (Ben).

“My first kangaroo moment with him, the KMC, they helped me, but they would encourage it all the time to do it every day …. and I'll be like yes!” (Sue).

“*I was there when he started sucking his thumb and started smiling at the nurses” (Pam).*

“So that was something good for me to see ok you sucking this bottle for the first time I was there, he was sucking his thumb. I was there. And every time we recorded every first move, he made, we've got on the phone” (Pam).

“I can’t remember anything else besides the new milestones that you reach, you know like getting to put clothes on her for the first time and that kind of thing. Yes, when she's off the tube and fully on the bottle, when I go to actually breastfeed her first the first time. Those kinds of things are exciting” (Carri).

“What stood out for me was the first time I saw his face…Oh my God, that's my child. Like I'm seeing my child for the first time. Like I saw him. But for the first time, I actually saw his features. Yeah. And like, she let us take photos of him and stuff, and they would always let me touch him” (Sue).

“What stands out I just felt held there. You know, I felt like I could, I could phone anytime and ask how the baby was doing, and they'd find, they'd find the nurse and ask, and they told me” (Kim).

“But also, to mention that the COVID restrictions have been lifted with my second one which made a world of difference, I could now do skin to skin I could go, I could come home, see to my first one has something to eat and go back. So, it wasn't as miserable as the first time” (Bev).

“What I enjoyed about that is it obviously if you as a mommy also have a good bond with them as they look out for your baby. So, if your baby starts crying, and there isn't anybody there, then make sure that the baby gets held and settled. And that type of thing. So that was nice” (Julie).

“The nurses are top notch” (Sue).

“They really are chosen for their job” (Sue)

“Not everyone can have this empathy they have…They were just super helpful” (Sue).

“It's a different kind of nursing staff to your general nursing staff. They, they've got a special soul to them. They really do” (Kim).

“But you know the paeds are so amazing. They like just to pick up subtle differences in they realized something was wrong” (Julie).

“But yeah, so the doctor was very, very helpful like she really like was helpful she communicates to us, like, send messages” (John).

“I think we were really lucky with the doctors we had, the nurses, I think they do their best for you. And they try and make it as easy as possible” (Kim).

“Well, it stands out for me is when you go to other places, while other hospitals, it's you don't get that comfort that those people at the hospital gave us every time we went in, like greeted us. Good afternoon. How are you?” (Pam).

“They were very, very kind, very good” (Kim).

Negative and traumatic experiences

“…because it's better waiting outside then seeing them doing whatever they need to do. That was like the worst experience I would say actually from everything”(John)

“And then shame, every time they struggled to find like a vein and so then because every time, we used to like to touch his hand or and then he would pull away because its sore, so that was shame, that was not nice” (John).

“So, like, I also hated to see my baby when prodded and poked the whole day” (Bev).

“ And with all the pipes and all of that connected to him wasn't very, very lekker actually” (Rob).

“you go in there and after they assure you everything's fine and this and that and, but you see all these babies was I don't know exactly the amount but there was quite plenty like 30 babies or something” (John).

“it's not nice seeing your baby there lying” (Ruth).

“So, you walk in and all of a sudden purple lights are on and he has this this little mask on and you're like, What the hell's going on?” (Ben).

"Although the only thing that was quite bad to me was in the beginning, the time that you miss because I mean he's lying there, and you can’t hold them, and you can't see him and that was quite traumatizing” (Ruth).

“ You want to at least hold him basically and at least let him know you are there, but you can't really do much because you can't even really touch him or anything. So that was the worst thing basically” (Ruth).

“But I think the biggest thing is not being with him not being able to be with him the whole time. That that's a bit of a....that was not nice” (Ruth).

“I don't wish that on anybody to leave your child and come home without your baby. And you wake up in the middle of the night and you wonder if your child is okay. Because they're not with you” (Bev).

“I felt like it was a bit like a petting zoo. Like I was coming every day to see my child and then leave my child” (Kim).

“And then this nurse swaddled in stinking of cigarettes. And I was like oh, you having a cigarette while my child was dying?... yeah it was just like that , gave us trauma. So ,my husband and I pulled back that we didn't want to feed the baby after that. We didn't wanna do much with the baby” (Sue).

“towards the end some of the hospital staff they started becoming… unwilling to assist and be accommodating in the sense that we felt uncomfortable sitting in the NICU” (Ben).

“But why do I have to fight like this? I have enough shit on my plate, dealing with my wife, the NICU and my son who's in the NICU” (Ben).

<u>Managing multiple responsibilities in NICU</u>

“I know for me on a personal level, at least and being a husband and a dad level, it's It was a tough balancing act because you're trying to deal with work pressures. I'm fortunate that I can work from home, so that was a blessing in disguise” (Ben).

“Dealing with work pressures, then still going to go see baby and you want to make an effort and go visit him and see him” (Ben).

“Trying to balance to go see your child and hospital and then still trying to run a normal household you know feeding dogs looking after mommy making sure that the washing is done” (John).

"*Every day I showed up I never missed one day of his NICU experience. Unfortunately, my husband had to because he was working" (Sue).*

"It does get overwhelming when you have a mother-in-law in your ear, you should be doing this you should be doing that you like but I'm the parent and I don't want to do that. I don't want to go this way you and it's just to manage dealing with different personalities and people" (Ben).

" I think it was just difficult to have my first son as well. I think it was really tough on him and he wants to be with us. But when you go to hospital, he obviously can't go into the unit. So then one of us had to stay outside with him and then that's challenging" (Julie).

Cultural experiences

"And unfortunately, from a from a white culture you very reserved and I know African cultures, hey don't care they just whip it out and they don't care. And the so from our side that was a bit annoying towards the end"(Ben).

"So, there's also cultural differences, right? So, if we are bathing the baby and we use the body wash, the nurse would say no, you must use the aqueous cream and have it all over the body and then wash it . Because guess what, it's up to us. I'm not disagreeing, but there is a cultural difference" (Meg).

Hospital failures and irritations

"I think the hospitals are understaffed" (Julie).

"So, I would check everything out, I often found mistakes and a complained a lot. I think they were very happy when I went home, I would complain a lot" (Bev).

"…so, the end of our experience was not good. We had a lot of complaints to the hospital" (Sue).

"Ended up having nurses, that they didn't know what they were doing, didn't care" (Sue).

"So, like if I, if the one nurse wanted me to bath , and the other one left me to do it by myself, then you get another nurse who's now trying to micromanage and control everything" (Meg).

"…somehow her teat was swapped, and it was obviously harder for her to suck on that teat than the other teat and then they gave her the teat she was using, and she was fine" (Carri).

"She sat on her on her phone which is not allowed in NICU, a nurse is not allowed to be on a phone in NICU. For sanitizing reasons because it's a germ spreader. She sat on her phone then she sat screaming to the other nurses around and whatever and there was nothing about quiet time" (Kim).

“And I think that was the hardest thing for me. Because they rotate nurses, which nurse is going to be there. Am I going to be welcomed? Are they going to be more like warmer towards me or just I'm doing my business don't come and trouble me” (Meg).

“And my wife has to express. So, there wasn't a dedicated room as such, where now she's sitting in a room where there's three other sets of parents and yes, you have a curtain, but the nurses come in and they throw the curtain open. Why is the curtain closed? And you're like, No, my wife was busy pumping. You don't want half the world to see her breasts and stuff like that” (Ben).

“So now you got to find an ask the unit manager where she can pump, and she said go and pump at home. I live half an hour away I'm not going to drive home half an hour for my wife to pump and drive all the way back. There was day she sat in the toilet and pumped and to me I'm like that's not sanitary” (Ben).

“Okay, and then also expressing milk... but where do I go? So, the first time when they asked me if I want to express milk?...and I'm like, sure no problem. So, they closed the curtains, and I could pump but I realized every few minutes, or every, like 15 minutes...are you done?...are you done? so we can open up?...so, then I felt no, like they’re not comfortable with me doing that” (Meg).

“There was a bit of a financial impact, obviously, I think was most NICU parents, like the driving up and down the whole time and eating there and everything and yeah, that was I think a big challenge” (Ruth).

“The one thing that was getting scary at the end was the travelling. Because you go there and sit there the whole day, you can’t do much, so that was the one thing that was getting a little bit hectic” (John).

“I would spend a few hours and then I would come home and then drive back, so I was probably back and forth three or four times a day. THAT was very hectic and then we'll go again at night when my husband got home from work and then spend quite a lot of time there at night…and then probably only getting home around 11-12 o'clock at night…so that was a hard time the back and forth” (Carri).

“ So, we kind of ended up because we stay far, we ended up staying there, sitting in the car eating our peanut butter sandwiches. So that was not nice” (Ruth).

“So, for the first two weeks, I stayed with my sister in Sunninghill , because I couldn't drive after the C section. So, to come up and down.... It was closer. Then it’s also difficult to stay with somebody else, I've had a c section, I am in so much of pain” (Meg).

“Her husband is there and as Muslims we had to cover so now it's my brother-in-law. So, I have to pump milk or I the needed the toilet really bad. So, you have to put everything on just go to the toilet or just to bath…so, it became very difficult so then I was like, I can't handle this” (Meg).

“One thing I would say is that the chairs in the NICU are really uncomfortable for mothers recovering from caesers and operations… and there were no cushions” (Kim).

Theme three

Roller coaster of emotions

“But it was just such a roller coaster” (Julie).

“…it was a roller coaster, definite roller coaster” (Ben).

“… like it just goes well and then there is a setback. Then it goes well again, so it's kind of it's an emotional roller coaster” (Ruth).

“Sometimes you see mother sobbing their eyes out, sometimes the mothers are absolutely perfect you know. So, like on some days you can tell I'm absolutely fine. And then some days you like am I ever gonna get out of here? Like is there an end point?” (Kim).

“they were tough days” (Ben).

“You think once the baby is in the NICU it's smooth sailing. And it's not it's a tough sea to sail” (Ben).

“It's a really taxing tolling emotional journey” (Sue).

“It's heartbreaking to go through” (Carri).

“After the delivery I started getting depression because I haven't seen him in three days and because we were living in x and he was that side (far distance between home and hospital), it was difficult for me, so I picked up depression” (Pam).

“…in the sense that you don't know what you're walking into for that day” (Sue).

“I think you know, all in all, like I say you don't know what you in for the day” (Ben).

“In the beginning, you obviously new parents don't know what to expect what’s coming” (Ben).

“I think that was one of the hardest parts for me adjusting every time we go to the NICU, what am I going to expect?” (Meg).

“…that physical holding, I was still too afraid and that fear and seeing him and because he's so small. You think he's so fragile and you might just sneeze and you break a bone” (Ben).

“I was too afraid to hold him” (Ben).

“the longer our babies stay the greater the risk of something else. And I'm now freaking out” (Julie).

“You become afraid in the sense that you hope your child doesn't go bad , that he recovers from his infection” (Ben).

“…things that you see and are exposed …you also become afraid” (Ben).

“At time it was a little bit terrifying…stressful obviously in NICU” (John).

“He's going for operation that made me very scared” (Pam).

“We were so reliant on the machines too. When they turned off the machines, our doctor, the one day just opted to turn the machine off. He was fine, he was breathing. He was stable. He had been stable for a few days. I told her I couldn't physically deal with the machine being turned off. So ,I said I couldn't deal with him, and the machine being turned off” (Sue).

“…you think 770 grams you know 33 centimetres tiny, tiny baby. So you are, at least for me, my senses were a bit more heightened” (Ben).

“it was just it was quite a shock to see. And especially being that small, a child can be that small” (Rob).

“You go in, you look at this baby and you like, what the hell do I do with it? Because he's so little” (Sue).

” …the fact that you expect this dream of normal, full term 40 weeks…but with us it wasn't any of that” (Ben).

“…she just broke down completely and she's like, I feel useless. There's nothing I can do” (Ben).

“We stayed in the same place for so long., she was in NICU for a very long time, 56 days…I think that also affected us, we saw so many babies coming into ICU, progressing to high care and then going home” (Carri).

“So, we stayed extra week in ICU for no reason…so, I want the babies out” (Julie).

“And because I think as a mom… you're the one that has to be there all the time. You are the one that the doctors are pushing pressure all the time. The nurses are saying you must KMC him, you must feed him, you must hold him at the end that you bath time, you do everything” (Sue).

“But I kept thinking if only he was in my tummy. He would not have to be prodded or poked” (Bev).

“There are days you just like I don't feel like sitting for half an hour in the car driving through then sitting there another four or five, six hours and driving all the way back” (Ben).

Parent worries

“So, so like those decisions- and myself and my wife sat the one night and we like what the bloody hell do we do? Do you make the decision to give the steroid knowing that it could potentially give cerebral palsy, or do you hold off a bit and hope he pushes himself to come through it?” (Ben)

“Now you start worrying about blindness and the doctors warn you about having too much oxygen can cause blindness. So now you start thinking to keep him alive you need the oxygen, but you then start thinking will he be blind” (Ben).

“But also, you start worrying about the blindness because he was so premature because he was so underweight” (Ben).

“I'll never forget the doctor said we're going to have to give him steroids. And one of the side effects of steroids was cerebral palsy. So now as a parent, you put in a rock and a hard place. Whether you take him off oxygen, without giving steroids in the hope that he's strong enough to be able to do it and, or do you administer steroids? In the hope that he doesn't get cerebral palsy” (Ben).

“You worry because underlying you want a perfectly healthy baby” (Ben).

“And I'm like oh my word, is the Klebsiella spreading but in the meantime, it wasn’t Klebsiella but different bacteria just a normal, not as pathogenic not as hectic” (Julie).

“Three babies down from ours, another mom’s baby got RSV in ICU, and the longer our babies stay the greater the risk of something else. And I'm now freaking out…we’ve already had a hospital acquired infection” (Julie).

“You worry , and apart from now just being a NICU parent, you now got to worry about buying prem clothes, prem nappies, prem dummies. I never knew prem dummies existed...so, when you look at the prem dummy compared to a normal size them you start to realise what sort of situation you're thrown into” (Ben).

“You do still worry and have trauma going back there. So, you question, if we have another child, will we be having the same experience, or we might have a completely different experience” (Ben).

Feelings of hope

“You wait every single day every week. You wait every single day every week. You're hoping that you're gonna get all clear” (Ben).

“…every time you like hope he's fine…okay, hope it's going to be okay over the night” (Ruth).

“You hope that your baby comes out alive and you hope your baby doesn't get sick” (Bev).

Support

“…and eventually you find your team, your rhythm, and the bad days you do get emotional, you do get overwhelmed … but for me personally the good days carried me through the tough days and the bad days” (Ben).

“But then, I guess I believe it was my test in life to make me stronger” (Bev).

“So, thank God, I think God knew what I couldn't handle” (Bev).

“And it was like amazing because it wasn't all on me anymore. It was us we were doing this together” (Sue).

“And it was just better when he started getting involved” (Sue).

“But at least my husband was there because I only have two hands” (Meg).

“And my wife especially as well, big support filler, just to talk to you because you've got someone there who understands what you're doing. You understand what she's going through, you know, and if I said to my wife I don't want to go in today and she says we have to and there were days when she said she didn't want to. I said we have to you have to go unfortunately because I think what got him through was us going every day” (Ben).

“But we pushed each other to still go irrespective of what we were going through or what stresses and pressures we had from a personal level and then you know from a relationship level supporting each other still was massive. That was massive. Yeah, I can't stretch the fact on it” (Ben).

“So, I was coping better when my husband was there and yeah, if he wasn't there, then I was like sitting and crying and not coping and just feeling like I'm a bad mother” (Ruth).

“We were blessed that my mom her mom came out from overseas, so she was with us for six weeks. And then she went back and came back for another five weeks. It's amazing because she's there for her daughter supporting her daughter” (Ben).

“One thing I'd add was that was that in terms of emotional support, there wasn't any” (Kim).

“When you'd have your emotional breakdown, there was always a nurse hugging you and telling you it was OK” (Sue).

“Every Wednesday, the unit manager would do an hour with the mommies. And that was nice… but it's also such a bad time December and January, you know, they didn't have the support sessions they usually had” (Julie).

“Once a week there was this general group thing done by the nurse, one of the nurses in the NICU. And personally, I don't want to sit in the group and talk about my own feelings and I don't want to hear that other people's stories to be honest ” (Kim).

“I don't really want to talk to a nurse” (Kim).

“*And I felt like if there was someone who was coming around and just checking on a mom and saying, are you okay?” (Kim).*

“…my wife said we should both go for therapy just to work through this” (Ben).

“And the other mommies in the ICU because goodness gracious , you need to talk to someone who's going through the same thing as you because if you've not been through it, nobody can understand what it's like. And having to deal with you know, everything together and everyone's setbacks together and everyone's wins together. Yeah, it's as bad as it sounds, there is always somebody a little bit worse off” (Julie).

“I think meeting parents - I made one good friend . So that was sort of a nice experience and having people that are going through the same thing with you helps because almost everyone else doesn't really understand” (Kim).

Appendix 9: Change of Title

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

06 January 2023
Person No: 8900415W
TAA

Mrs LM Goldberg
26 Chilton Road
Kew
2090
South Africa

Dear Mrs Linda Goldberg

Master of Science in Medicine: Change of title of research

I am pleased to inform you that the following change in the title of your Research Report for the degree of **Master of Science in Medicine** has been approved:

From:	**The lived experiences of South African parents during the prolonged admission of their premature baby**
To:	**The lived experiences of South African parents during the prolonged hospitalisation of their premature baby**

Yours sincerely

Mrs Sandra Benn
Faculty Registrar
Faculty of Health Sciences