CAREGIVER EXPERIENCES OF ATTACHMENT AND BONDING PRACTICES IN NEONATAL INTENSIVE CARE UNITS IN GAUTENG SOUTH AFRICA.

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Acknowledgements

I would like to acknowledge my supervisors – Prof. Joanne Neille and Mrs Cynthia Sawasawa. Thank you for the time you have spent typing out comments, recommendations, and emails. I am so grateful for your assistance, guidance, and knowledge contributing to my dissertation.

I would like to further thank the faculty of humanities at the University of the Witwatersrand for their support and guidance throughout the last two years in terms of guiding policies and procedures in finishing this dissertation.

I am grateful for fellow post-graduate students for their moral support and continued encouragement as well as the fellowship that was felt between one another.

Thank you to my friends and family, I would not have been able to complete this without your support which sustained me through this dissertation. Your emotional support gave me the strength for all the early mornings and late evenings.

Thank you to all those who participated in the study and were willing to share their experiences with me to gain a deeper understanding on the subject. It was a privilege to hear all your stories and insights.

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JOHANNESBURG

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Abstract

Background: Infant attachment and bonding are crucial within the early post-natal period to ensure a secure and healthy relationship from which the infant can explore the world thereby allowing for the development of a variety of skills. Context and culture are known to influence attachment and bonding practices. Then considering the challenging Neonatal Intensive Care Unit environment it is crucial to explore how this environment might influence attachment and bonding with a specific focus on context and culture.

Objectives: This study aimed to describe the experiences of caregivers regarding attachment and bonding practices in the Neonatal Intensive Care Unit in central Gauteng, South Africa.

Methods: A qualitative design was used to explore caregiver experiences around attachment and bonding practices concerning context and culture in the Neonatal Intensive Care Unit. An advertisement was posted on online forums for caregivers in South Africa who have had infants admitted to the Neonatal Intensive Care Unit. Non-probability, purposive sampling and snowball sampling was used to collect data. Both in-person and remote semi-structured interviews took place and were used to collect data. Thematic analysis was used as data analysis.

Results: The following themes and subthemes were identified; the act of mothering in the NICU (with subthemes loneliness and disempowerment of caregivers, the emotional roller-coaster ride, and the need for psychological/emotional support), Culture in the NICU (with subthemes care in the NICU, the influence of culture and caring for a baby in the NICU, and limited information-giving practices in the NICU), and a Sense of missing out (with subthemes unexpected pre-term birth, feeling estranged, and the tension between society's image and the reality of having a baby in the NICU). While context and culture influence attachment practices amongst caregivers, in the case of an infant being admitted to the NICU, these practices do not take precedence, but rather the health of the infant.

Implications: Methodological recommendations include alternative sampling and data collection methods than online advertised snowball sampling that allow for a larger and more diverse sample size. Policy and practice recommendations for NICUs include improving accessibility to psychological support services and orientating information on the NICU for caregivers.

Keywords: Attachment, bonding, Neonatal Intensive Care Unit (NICU), South Africa, culture, and context.

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Glossary

TERM	DEFINITION
Alloparenting	Alloparenting refers to the care of the young by other members than the biological parents, this could refer to extended family, friends, other tribe members, siblings, and so on (Herlosky & Crittenden 2021; Van Aswegen et al., 2018).
Attachment	An infant is born with the instinctive behaviour to form a secure attachment with a caregiver so as to ensure future success in self-regulation and prediction of situations by modelling a secure-base formed with a caregiver (Bowlby & Ainsworth, 2013; Phuma-Ngaiyaye & Kalembo, 2016).
Attachment Theory	The main tenets of the attachment theory aim to explain how the caregiver-infant attachment is formed and the consequences it holds for future relationships (Ainsworth, 1974; Bowlby, 1969; Voges et al., 2019).
Bonding	Bonding on the other hand relates to the caregivers' in terms of responsiveness, sensitivity, feelings and emotions towards the infant (Holmes & Slade, 2017; Young, 2013).
Bronfenbrenner's Bio-ecological model	This hypothesis states that children do not develop in isolation, but rather that development is influenced by the microsystem, mesosystem, exosystem, macrosystem and the chronosystem (Navarro et al., 2022; Onwuegbuzie et al., 2013).
Caregiver	One who provides direct care to someone else, in the case of this research proposal to an infant (Chakona, 2020).
Context	The situation or setting in which a concept or individual exists that influences their perspective, whether geographical or socio-economical (Dahan et al., 2023).
Cross-cultural research	This highlights the importance of research across cultures and societies in order to compare data or hypothesis (Penn & Watermeyer, 2018).
Culture	A network of beliefs, values, and practices that are shared among a group of people to create a community or society that is social norms (Yap et al., 2019).
Family-centered care	Here the family should be integrated to be at the very core of information sharing, participation, and collaboration so as to ensure respect and dignity (Gómez-Cantarino et al., 2020).
Generational parenting	This describes when multiple generations care for the young such as siblings, parents, and grandparents (Herlosky & Crittenden 2021; Van Aswegen et al., 2018).
Neonatology	This is described as the hospital-based care for the newborn infant that is critically ill and is required to be admitted to the NICU (Webbe et al., 2020).
Neonatal Intensive Care Unit (NICU)	The working environment of healthcare workers such as doctors, nurses, and other developmental healthcare workers who provide vital specialized medical interventions to neonates (Matus et al., 2019; Naylor et al., 2020).

Chapter One: Introduction and Rationale

Attachment and bonding are the foundations for early infant development to form a secure bond from which to explore the world (Le Bas et al., 2020). Being able to safely explore the world with a positive and healthy caregiver relationship allows infants to develop holistically, whether it be psychological skills, social skills, cognitive skills, physical skills, or language-based skills to name a few (Bowlby & Ainsworth, 2013; Ettenberger et al., 2021). This deduction is drawn from the attachment theory which states that the caregiver-infant attachment that is formed early in life holds consequences for future relationships and socio-emotional development (Le Bas et al., 2020; Trombetta et al., 2021).

It is widely accepted that culture influences attachment and bonding between caregivers and infants in terms of bonding and attachment practices, maternal responsiveness, maternal sensitivity, and child-rearing practices to ensure a secure attachment is formed (Carter et al., 2015; Little & Derr, 2020; Vicedo, 2020). To ensure a secure attachment and therefore a secure base from which to explore the world the attachment theory largely relies on maternal sensitivity and parenting practices (Ainsworth, 1974; Bowlby, 1969). This may not be universal and may differ from one context to another.

In non-western cultures, such as Asian and African cultures, polyadic family structures are often the norm resulting in a well-socialized child that is calm and neutral (Keller, 2018). This has implications for the “Westernized” definition of responsiveness that is reiterated in attachment theory as responsiveness cannot be measured in the same manner across cultures (Keller, 2018; Zaidman-Mograbi et al., 2020). In many collectivist cultures, such as the Sub-Saharan African Cameroonian Nso tribe the mother is not always the primary caregiver, but rather generational parenting takes place (Keller, 2018; Zaidman-Mograbi et al., 2020).

New data are emerging giving us a better understanding of how bonding takes place in different contexts and thereby drawing a link between the influence of context and culture on attachment and bonding, illuminating how the attachment theory might not be universal in different ethnic contexts (Dawson et al., 2021). However, there is still a paucity of empirical knowledge related to how South African caregiving practices might differ from Euro-western caregiving practices given our unique cultural diversity.

When considering how multicultural South Africa is, it becomes evident that South Africa could give rich and dense findings related to context, culture, and attachment (Voges et al., 2019). It is therefore imperative that local cultural and contextually relevant bonding practices are explored in terms of the NICU environment in South Africa in both the public and private health sectors.

South Africa is classified as an upper-middle-income country (Weimann & Oni, 2019). However, due to social disparities and injustices such as socio-economic inequalities, gender and race differences, rich cultural diversity, high crime rates, and failing policies South Africa's healthcare system has multiple fallouts in service delivery (Buissinne et al., 2018) possibly similar fallouts to other low-middle income countries.

Considering the complexity of attachment and bonding one then needs to consider how the NICU environment might impact the attachment and bonding process. Further examining the various sequelae that are generally associated with NICU admission such as prolonged hospitalization which has financial, social, and emotional implications (Gibson, 2017; Buissinne et al., 2018). Furthermore, there are psychological and emotional effects on caregivers (Liu et al., 2022). Caregivers of infants in the NICU experience an elevated level of stress which may cause emotional and psychological trauma such as anxiety and depression which in turn may affect attachment and bonding (Byiringiro et al., 2021).

There is a paucity of research on the South African experience of caregivers (Buissinne, 2018; Buys, 2020). Little is known about how South African caregivers might experience the NICU environment concerning how it influences attachment and bonding practices. There is a further dearth of literature informing current practices and policies in NICUs relating to how healthcare workers can facilitate the unique bonding process in the complex NICU context while being culturally sensitive.

Rich and diverse data could emerge from South Africa, given the cultural, linguistic, and financial diversity this country holds as well as systemic issues faced in this upper-middle-income country such as reduced access to services. As caregivers in South Africa would then have a different experience in the NICU due to contextual differences, novel data may emerge from this population.

The act of bonding and attachment is essential to the vulnerable caregiver in the NICU. This heightened need for caregivers to be able to connect with their infant in a culturally, socially, and contextually appropriate manner becomes essential to the well-being of both the caregiver and the infant. It is therefore imperative to ensure that the NICU environment and NICU staff allow for attachment and bonding practices related to context and culture to occur within the NICU as far as possible given the medical safety of the infant.

Chapter Two: Literature Review

2.1 Attachment and bonding

The concept of the first 1000 days refers to the period from conception up until two years of age and how crucial this period is for the health and development of an infant (Darling et al., 2020). During this period an infant requires many contributions to develop in a healthy manner such as adequate nutrition, a healthy environment, and a safe and secure relationship with a caregiver (Kassier & Madlala, 2018). Attachment and bonding are the foundation for healthy relationships between caregivers and infants within the early post-natal period as attachment and bonding facilitate the above-mentioned contributions that influence the health of the infant (Kassier & Madlala, 2018; Madiba & Sengane, 2021).

Attachment and bonding are therefore fundamental for development throughout childhood as the first 1000 days largely influence the trajectory of an infant's development into early childhood (Kassier & Madlala, 2018; Madiba & Sengane, 2021). Failure to form a secure attachment to a caregiver early in life may lead to negative consequences later in life, such as difficulty forming secure relationships in adulthood, poor self-esteem, or poor self-reliance which hold negative consequences for cognitive and communication development (Ainsworth, 1974; Bowlby, 1969; Carter et al., 2020). While attachment and bonding are often used synonymously within the literature, the two are not the same (Ettenberger et al., 2021).

Attachment can be defined as an inherent, instinctive behaviour that an infant is born with so as to maintain a sense of security (Trombetta et al., 2021). Attachment is a working model for the infant in order to learn how to self-regulate as well as how to predict future situations by using the caregiver as a model (Holmes & Slade, 2017; Phuma-Ngaiyaye & Kalembo, 2016). For example, if an infant is startled they seek attachment to a caregiver so as to feel safe, once safe, infants can explore their environment and therefore improve developmental skills such as language and cognitive skills (Woodhouse et al., 2020). The caregiver, therefore, becomes a secure base from which to explore the environment and world (Karakaş & Dağlı, 2019).

Bonding, on the other hand, can be defined as a process driven by the caregiver that influences development within the early years of life (Ettenberger et al., 2021; Young, 2013). Bonding relates to caregiver responsiveness or sensitivity, caregiver feelings, and emotions towards the infant, it is, therefore, an affective state (Shreffler et al., 2021). Attachment describes how the infant inherently builds a relationship with a caregiver and bonding describes the emotions, and feelings of the caregiver towards the infant (Ettenberger et al., 2021).

The attachment and bonding process starts after birth and rapidly progresses to continue through life but is critical during the first 1000 days (Kassier & Madlala, 2018; Madiba & Sengane, 2021). This relationship grows in strength as more time is spent between the infant and the caregiver and is often promoted by skin-to-skin contact, speaking to the infant, and daily activities of care (Le Bas et al., 2020; Trombetta et al., 2021). However, for some parents, a portion of the first 1000 days are spent in the Neonatal Intensive Care Unit (NICU) leaving implications for their attachment and bonding journey with their infant as the "normal" route for attachment is now disrupted by the NICU admission.

Attachment styles may further relate to communication development. A secure and safe attachment involves a parent who is sensitive to the needs of the infant and responds to the infant in a reciprocal manner, thereby, initiating communication (Walsh et al., 2019). Many acts related to attachment and bonding also relate to early communication development such as reciprocal and sustained eye contact and responding to communicative intent (Guerrero, 2021). Children often learn through models, caregivers are therefore models for children in terms of communicative development (Walsh et al., 2019). Caregivers in their sensitivity and reciprocity and then either good or bad models for the development of their infant (Walsh et al., 2019).

As parenting style has an immense role in infant development and future competence it then becomes important to consider how contextual and cultural influences may impact parenting styles which in turn affects attachment and bonding (Cabrera, 2022). Parenting behaviour is intrinsically influenced by context and culture, for example, Asian American parents are viewed to be more authoritarian regarding academic achievement than American parents (Arafat et al., 2020). Another example is Kenyan parents who display more dominating and authoritarian parenting styles with an emphasis on physical punishment when compared to their Euro-Western counterparts (Arafat et al., 2020).

Literature on cross-cultural parenting is primarily based on white middle-class families in the West using Western standardized norms and parenting practices (Chen, 2019; Gregory et al., 2020; Lansford, 2022). Articles published in high-impact journals oftentimes are not fully representative of all cultures and cultural practices associated with attachment and bonding, such as an article published in a 2015 journal that represented less than 8% of the world's children (Lansford, 2022; Nielson et al., 2017). This excludes many cultures and contexts across the world that may have successful practices related to attachment and bonding that the current literature does not include.

Cultures may differ in terms of infant-rearing practices related to attachment and bonding in terms of expected behavioural norms (Kramer & Hamilton, 2019; Lansford et al., 2018). As well as taking socio-economic factors into account such as availability of resources or time. For example, a study that took 24 sub-Saharan African countries into account yielded that only 4% of Zimbabwean children were independently responsible for collecting water versus 44% from Niger (Graham et al., 2016) indicating that the level of independence that is expected from children, which influences caregiving practices, varies based on physical and environmental constraints. Understanding the cognitive beliefs that underpin certain caregiving behaviours indicates that these cultural differences are important, for example, in Senegal, parents traditionally avoid speaking to their infants as this could increase the likelihood of an evil spirit possessing the infant (Weber et al., 2017).

Current literature also largely excludes fathers and other caregivers such as grandparents (Lansford, 2022) which becomes important when considering the South African context and family structures found in South Africa. Finally, more context-dependent research is required globally to understand how context and culture might influence attachment and bonding practices, especially considering that the current literature on parenting does not represent all parents and their attachment and bonding practices (Cabrera, 2022).

2.2 Attachment theory and types of attachment

Attachment theory was founded by John Bowlby and Mary Ainsworth and broadly observed the emotional connection between a primary caregiver and an infant that is characterized by a sense of security allowing the infant to explore his or her environment from a dependable, secure base (Ainsworth, 1974; Bowlby, 1969). The main tenets of the attachment theory aim to explain how the caregiver-infant attachment is formed and the consequences it holds for future relationships (Ainsworth, 1974; Bowlby, 1969; Voges et al., 2019). The attachment theory informs attachment-related psychotherapy in child psychology and has therefore lays the groundwork for a child’s socio-emotional development within the first year of life (Thompson et al., 2022).

Attachment is most likely to form with a caregiver who is sensitive to the needs of the infant with caregiver sensitivity such as responding to attention-seeking cues from the infant promptly as well as emotional reciprocity (Dawson et al., 2021). Attachment-seeking behaviours may include behaviours to promote physical closeness or contact such as clinging, approaching, crying, smiling, or calling to ensure proximity to a caregiver and therefore improve chances for survival (Ainsworth et al., 1974).

The Strange Situation experiment led by Ainsworth described attachment patterns that were observed during the interaction between infants, their primary caregivers, and strangers (Ainsworth et al., 2015; McKenna, 2009). The following patterns were identified; secure attachment and insecure attachments, namely, ambivalent attachment, avoidant attachment, and disorganized attachment (Woodhouse et al., 2020). Ambivalent attachment characteristics include infants and young children whose attachment to the primary caregiver is not trusting, and therefore, suspicious (Voges et al., 2019). Great distress signs are shown when separated from a caregiver, but cannot be consoled even with the comfort of the primary caregiver (Bowlby & Ainsworth, 2013, Voges et al., 2019). Avoidant attachment, on the other hand, shows avoidance behaviours toward caregivers (Voges et al., 2019). Comfort is often not sought after by the infant and no preference is shown between strangers and primary caregivers (Bowlby & Ainsworth, 2013). Disorganized attachment styles show little to no clear patterns of attachment that can include resistance to contact and interactions as well as avoiding caregivers (Bowlby & Ainsworth, 2013, Voges et al., 2019).

Secure attachment characteristics involve an infant showing distress signs when separated from his or her primary caregiver and showing joy when the caregiver has returned (Bowlby & Ainsworth, 2013). Therefore, showing a preference for the primary caregiver, the infant seeks comfort from the caregiver (Bowlby & Ainsworth, 2013). There is reciprocity during secure attachment and initiated contact is happily returned (Bowlby & Ainsworth, 2013). Caregiver secure attachment is reflected by increased time spent with joint play while quickly and sensitively responding to the needs of the infant (Woodhouse et a., 2020).

Secure-based behaviour hypothesis postulates that infants require a secure attachment to a caregiver to allow them to first explore their unfamiliar environment with the safety and security that the caregiver represents and secondly, to maintain proximity with the caregiver (Ainsworth et al., 2015; Voges et al., 2019). This allows the infant to explore, learn, and develop more effectively as a responsive and sensitive caregiver would scaffold and co-construct with the infant while exploring the environment (Bowlby & Ainsworth, 2013; Śliwerski et al., 2020).

The premise of the Attachment theory is based on practices and principles of middle-class Western families with a dyadic relationship structure and middle to high socio-economic status (Mesman et al., 2018; Keller, 2018). This class only represents about 5% of the world's population, it is therefore not inclusively representative (Keller, 2018; Morelli & Henry, 2013). This creates a gap in current literature and a need for more contextually and culturally inclusive research on the topic of attachment and bonding.

2.3 The impact of the NICU on attachment and bonding practices

2.3.1 The NICU setting

Neonatology refers to hospital-based care, related to the care of infants, specifically those that are premature or ill and therefore admitted to the NICU (Webbe et al., 2020). Common illnesses or conditions treated in the NICU involve prematurity, low birth weight, intrauterine growth restrictions, congenital malformations (such as heart defects), sepsis, pulmonary conditions (for example, pneumonia), and birth asphyxia (Naef et al., 2020). The effectiveness of neonatal care is crucial when considering this period during one's lifespan specifically the first 1000 days which are crucial to development as it has long-term health impacts (Lissauer et al., 2020; Kassier & Madlala, 2018). The goal of the NICU is to reduce the mortality and morbidity of neonates (Webbe et al., 2020).

The NICU is a working environment of doctors, nurses, and other developmental healthcare workers who provide vital specialized medical interventions to neonates (Matus et al., 2019; Naylor et al., 2020). A holistic approach is subsequently necessary for the NICU so as to ensure the best care (Matus et al. 2019). The multi-disciplinary team (MDT) includes nurses, fetal medicine, obstetrics, genetics, neonatology, paediatric surgery, and specialists such as urology, ear nose and throat (ENT) specialists, neurosurgery, orthopaedics, and paediatrics may be involved (Lissauer et al., 2020). As well as allied members such as occupational therapists, physiotherapists, speech therapists, audiologists, and dieticians (Lissauer et al., 2020).

While healthcare workers are essential to the care of the neonate, caregivers should remain at the centre of the MDT (Matus et al., 2019). Caregivers should therefore also be involved in the decision-making process regarding the care of the neonate (Matus et al., 2019). Communication between healthcare workers and caregivers is essential to an effective NICU environment and therefore it is essential to the care of the neonate (Matus et al., 2019). Collaboration between MDT members is a key component of quality care being provided to the neonate and caregiver (Rhoda et al., 2018).

Furthermore, it is essential to consider that necessity for proper infection prevention control procedures within a NICU, however, the use of personal protective equipment (PPE) may place further strain upon relationship building between caregivers and their neonates within the NICU (Yance et al., 2023). The NICU environment, which is required to be sterile, enforces strict infection prevention control measures to ensure that the neonates admitted in the NICU who generally have weaker immune systems, or already compromised immune systems, and who are more prone to infections are kept safe (Yance et al., 2023). The use of certain PPE, such as gloves, aprons, and masks, may however limit a caregiver's ability to interact and therefore bond with their neonate (Yance et al., 2023). Research has specifically cited that not being allowed physical touch between a primary caregiver and a neonate placed strain on bonding (Yance et al., 2023).

2.3.2 Protective factors relating to attachment and bonding in the NICU

Support within the NICU can facilitate resilience within caregivers to support well-being and thereby their ability to securely attach and bond with their infant (Provenzi et al., 2015). Receiving support from family, friends, healthcare workers, and other caregivers can facilitate well-being and interactions with the neonate (Coertze, 2019). Healthcare workers in the NICU can aid in supporting caregivers with clear communication, and psycho-social support, allowing participation in caring for infants, and feeling understood (Waddington et al., 2021). Caregivers expressed that support can be shown in several ways outside of the NICU environment; transportation, care of other children, assistance in everyday routines, psycho-social support, and advice (Coertze, 2019).

It can be overwhelming for caregivers to receive an overload of information on the status of their neonate that is often filled with jargon and under or overstatements (Coertze, 2019; Labrie et al., 2021). If information is provided in a sensitive and effective manner this can aid in caregivers feeling in control and therefore acts as a facilitator in the well-being of caregivers (Labrie et al., 2021; Waddington et al., 2021). Caregivers who understood their infants' condition, prognosis, and current care often experienced more positive feelings in the NICU (Byiringiro et al., 2021).

Communication can be defined as an effective process between a sender and receiver where a message is reciprocally sent and understood (Kynoe et al., 2020; Labrie et al., 2021). Communication is dependent on the context and the methods used to communicate (Kynoe et al., 2020) for example, communication in the NICU is often characterized as being short due to time constraints. Communication between healthcare workers and caregivers can further aid in interactions between the infant and caregivers thereby reducing stress, assisting with attachment, and bonding, and becoming a locus for support in the NICU (Byiringiro et al., 2021). Caregivers reported feeling hopeful and more confident in the recovery of their infant when effective communication was received from healthcare workers and when a positive and caring attitude was had by healthcare workers (Byiringiro et al., 2021).

Effective communication firstly serves as a clinical goal between healthcare workers and caregivers so as to obtain informed consent, aid in decision making and foster collaboration (Labrie et al., 2021). Communication between healthcare workers and caregivers is central to how the NICU environment affects the experiences of both neonates and caregivers (Labrie et al., 2021). Caregivers who understood their neonates' condition, prognosis, and current care often experienced more positive feelings in the NICU (Byiringiro et al., 2021).

Recent research has shown that caregivers value information provided in the mother tongue (Labrie et al., 2021). That the information is clear and accurate and accessible to them timeously. The function of clear communication in the NICU broadly relates to building and maintaining relationships, the exchange of information, informed decision making and empowering caregivers (Labrie et al., 2021). Family-centred care models can encourage effective communication between healthcare workers and caregivers (Jordan, 2018). Giving caregivers access to information and education about the state of their neonates, empowers them to actively participate in the decision-making process, thereby following Family-centred guidelines (Labrie et al., 2021).

NICU staff often serve as role models to caregivers through supportive interactions such as aiding in the understanding the NICU environment and taking charge in the daily care of the infant (Citter & Ghanouni, 2021) which is integral to supporting the psycho-social well-being of caregivers. Nursing staff are the main carers of neonates and can therefore increase the participation of caregivers by assisting them in understanding infantile cues for caring and how to perform activities of daily living (Citter & Ghanouni, 2021).

2.3.3 Barriers to attachment and bonding in the NICU

Caregivers are often exhausted by the physical and emotional demands of the NICU (Liu et al., 2022). The NICU is an unknown and demanding environment with various mechanical equipment and machinery that are unknown to most caregivers, this can seem very foreign and frightening (Buissinne et al., 2018). The NICU is associated with the prolonged hospitalization of infants which causes further stress, trauma, and feelings of hopelessness for caregivers which can lead to negative consequences for attachment and bonding (Buissinne et al., 2018).

The medical condition and health of the neonate cause both stress and feelings of worry, frustration, anger, guilt, despair, and disappointment due to parental expectations not being met to parental expectations not being met this was often worsened by visually seeing the infant (Byiringiro et al., 2021). These negative feelings were worsened by visually seeing the infant as caregivers found this quite distressing (Byiringiro et al., 2021). Especially considering the anticipation that caregivers have of a normal, healthy, full-term infant and anticipation and expectations around that journey, which are now taken away due to the hospitalization of the infant, caregivers enter a psychologically unprepared state which elevates negative feelings (Leahy-Warren et al., 2020).

The prolonged hospitalization and NICU stay complicates the bonding process between caregivers and infants as normal caring opportunities are often limited (Coertze, 2019). As this relationship is interrupted the NICU environment has several measures in place to aim to facilitate this process which in turn facilitates caregiver well-being (Coertze, 2019). This includes physical contact and touching of the neonate, Kangaroo mother care (KMC), participation in the feeding of the neonate, increasing the number of times caregivers can spend in the NICU with their infants, and their involvement in the NICU to support attachment and bonding (Suitor, 2023).

The relationship between caregivers and healthcare workers may cause stress, emotional distress, poor communication, and a lack of support if the relationship is not positive (Coertze, 2019). Feelings of uncertainty can be created as nurses are the primary caregivers of infants in the NICU, leaving caregivers unsure about their position in caring for the neonate which consequently affects attachment and bonding (Givrad et al., 2021). This can cause a power struggle between staff and caregivers as well which in turn negatively affects the well-being of caregivers (Givrad et al., 2021). Caregivers have also internationally reported feeling as though they are in the way or feelings of being unwanted (Buissinne et al., 2018).

Self-esteem is a key element that is negatively affected by caregivers with infants in the NICU. Self-esteem in the first few weeks of hospitalization of the infant is greatly influenced by interactions with healthcare workers which affects a caregiver's ability to attach and bond with their infant (Bernardo et al., 2021). This once again places emphasis on the importance of positive and supportive interactions with healthcare workers (Givrad et al., 2021). Facilitating interactions includes allowing caregivers to interact with their infants by supporting participation and providing accurate counselling on the condition of the neonate (Bernardo et al., 2021).

Caregivers of infants in the NICU experience an elevated level of stress which may cause emotional and psychological trauma such as anxiety and depression which could have a negative impact on attachment and bonding (Byiringiro et al., 2021; Phuma-Ngaiyaye & Kalembo, 2016). Caregivers often experience various negative feelings apart from anxiety and depression such as frustration, hopelessness, guilt, and feelings of unpreparedness (Hall et al., 2020).

Quality healthcare should provide both an evidence-based clinical environment that allows for best clinical practice as well as a positive and healing environment for both caregivers and their infants (Byiringiro et al., 2021; Phuma-Ngaiyaye & Kalembo, 2016). This level of care cannot be given without exploring, recognizing, and implementing the experiences of NICU caregivers (Byiringiro et al., 2021). In supporting the psycho-social well-being of caregivers and the parent-infant relationship it becomes essential to provide caregivers with support in the NICU environment (Bukola et al., 2020; Phuma-Ngaiyaye & Kalembo, 2016).

Hope in the NICU environment may act as a protective factor for caregivers who find themselves in incredibly stressful environments by allowing them to cognitively engage with that environment to cope (Buissinne et al., 2018). Hope thereby increases the well-being of caregivers and decreases the impact of negative feelings as it reinforces positive experiences (Coertze, 2019).

Both intrinsic and extrinsic factors have been found to give hope to caregivers in the NICU. Intrinsic hope factors included being involved in the care of the neonate such as feeding and holding which allowed caregivers to visualize a version of reality in which the neonate was healthy (Buissinne et al., 2018). This allowed for time to bond with the infant thereby also improving attachment (Buissinne et al., 2018). Furthermore, supportive training, education, and communication from healthcare workers aided in developing hope (Buissinne et al., 2018). Extrinsic factors included symbols of hope found within and outside of the NICU to help caregivers cope with grief and loss (Buissinne et al., 2018).

Post-traumatic stress disorder (PTSD) is also common among caregivers who have gone through the trauma of having a neonate admitted to the NICU (Schecter et al., 2020). PTSD may occur due to a traumatic event with traumatic symptoms and characterize by mood alterations, negative mood, alterations in arousal, and reactivity (McKeown et al., 2023). The admission of a neonate to the NICU can cause stress, anxiety, depression, uncertainty, and trauma PTSD is a common disorder among caregivers (Schecter et al., 2020). Caregivers of NICU neonates who suffer from PTSD may face further challenges in attaching and bonding with their infants due to the mental health implications of PTSD (Sebnis et al., 2019).

2.4 The influence of context and culture on attachment and bonding

Culture can be defined as a network of beliefs, values, and practices that are shared among a group of people to create a community or society (Yap et al., 2019). This shared belief system is passed down from generation to generation and can therefore act as a secure base from which to explore the world as this community all share these ideals and values (Yap et al., 2019). This implies that individuals can not only create an attachment to a caregiver but also to a culture (Voges et al., 2019; Yap et al., 2019).

Culture shapes attitudes, belief systems, experiences, and thereby caregiving practices (Voges et al., 2019). Culture can further influence attachment and bonding practices amongst caregivers as it shapes a certain point of reference or worldview that influences child-rearing practices (Simpson & Belsky, 2016) and should be considered with centrality when discussing the issue of infant attachment. While most cultures engage in infant attachment and bonding, these interactions and bonds vary greatly based on ecological and cultural context (Little & Derr, 2020; Vicedo, 2020).

For example, in some Sub-Saharan communities (such as Cameroonian Nso tribes, Gambian families, rural Ethiopian communities, and communities in Kenya, Uganda, Zambia, and more), infants are socialized to a variety of caregivers in these contexts as generational parenting often takes place as well as the dividing of responsibilities across the community, whoever is able to care for the infant at that given time and place does so (Hanlon, 2018; Keller, 2018). Infants therefore seldom present with stranger anxiety as the contextual experience does not require stranger anxiety as an emotional regulation tool (Hanlon, 2018; Keller, 2018).

In biological terms alloparenting refers to the care of offspring or young by other members than the parents (Herlosky & Crittenden, 2021; Van Aswegen et al., 2018). Generational parenting focuses on the care of the young by multiple generations (Herlosky & Crittenden, 2021; Van Aswegen et al., 2018) for example, siblings, parents, and grandparents. Specifically highlighting the issue of the caregiver, in Western communities, it is common for a primary caregiver, the mother, that is responsive and consistent to the needs of the infant, while there is a lack of representation of non-westernized caregiving practices (Herlosky & Crittenden, 2021; Van Aswegen et al., 2018).

It is common in non-Western families, such as the Cameroonian Nso tribe, for the grandmother, mother, aunt, father, uncle, sibling, and more to share the caregiver responsibilities as they are available to do so (Otto, 2015). For example, the HIV pandemic in South Africa led to many children being orphaned and thereby an increase in child-led households (Cluver et al., 2018; Norman, 2011).

In other groups such as foragers, pastorals, and fisherman communities young children’s responses to visitors are often perceived to be neutral as they are socialized to be neutral, whether out of respect or multiple caregivers (Hanlon, 2018; Keller, 2018). If the Attachment Theory were to be applied in this situation, the children's responses would not be seen as appropriate, especially considering that the Attachment Theory implies stranger anxiety to be biological and therefore universal (Hanlon, 2018).

Research done with the Gusii tribe in Kenya (Bryant et al., 2012), is another well-cited African study when referencing attachment. In this community, mothers are often involved in a variety of tasks throughout the day and not exclusively in childrearing (Bryant et al., 2012). Older children are often involved in childrearing tasks while mothers have other responsibilities such as farming and food preparation (Voges et al., 2019). Mothers are primarily involved in the physical needs of the infant such as breastfeeding, but other caretaking responsibilities are divided between family and community members (Voges et al., 2019).

Another African example of context and culture that influences attachment and bonding practices is that of the agrarian communities in Mali. True, Pisani and Oumar (2001) described infant attachment in Mali with the Dogon ethnic community family structures here are ruled by cultural influences and typically involve polygamous and patrilineal households with multiple wives and many children. Children, therefore, experience a social environment with a variety of caregivers (True et al., 2001).

Minde et al. (2006) conducted a South African study in urban townships in Johannesburg. With much lower socio-economic conditions than most attachment studies conducted in Euro-Western areas and cultures this comparison between attachment styles is to be noted (Minde et al., 2006). It was found that almost two-thirds of participants showed secure attachments when compared to Western groups (Minde et al., 2006).

Considering the influence of context and culture on attachment and bonding, healthcare workers must understand these tenets to be sensitive and competent in the care of patients due to cultural differences sensitivity is required in terms of their respective norms and practices (Dawson et al., 2021). It is important to then explore the South African context due to its rich cultural and linguistic diversity (Penn & Watermeyer, 2018).

When considering culture, context, and the attachment theory, which is considered to be the most important theory for children's socioemotional development during the first years of life it is only ethical to consider the fact that the attachment theory has been mainly developed under Euro-Western philosophies around attachment, bonding, and child development (Thompson et al., 2022; Zaidman-Mograbi et al., 2020).

2.5 The NICU contextualized to the South African context

Having considered the current global literature around the NICU environment and attachment and bonding, it is essential to focus on South Africa and the unique climate it creates for the influence that context and culture have on attachment and bonding within the NICU. South Africa is classified as an upper-middle-income country (Buissinne et al., 2018). However, it often performs worse than other lower-income countries when scrutinizing the healthcare system (Buissinne et al., 2018). This is due to social disparities and injustices such as socio-economic inequalities, gender and race differences, rich cultural diversity, high crime rates, and failing policies (Buissinne et al., 2018). Furthermore, South Africa further faces a quadruple burden of disease; the HIV/AIDS pandemic and tuberculosis, maternal and child mortality, non-communicable diseases, and injury and violence (Young, 2016).

2.5.1 The South African Healthcare System

South Africa has a healthcare system that comprises a public and private sector. The private sector is largely funded through individual contributions to medical aid schemes or health insurance and serves around 16% of the population (Gordon et al., 2020). The public sector is three-tiered and state-funded and caters to the majority 71% of the population (Mhlanga & Garidzirai, 2020; Ndebele et al., 2021). With such a large portion of South Africans accessing public healthcare, thus placing stress on the public health sector the effects of South Africa's quadruple burden of disease, the HIV/AIDS pandemic and tuberculosis, maternal and child mortality, non-communicable diseases and injury & violence is worsened (Achoki et al., 2022).

The three tiers within the public sector include district, regional, and provincial tertiary service delivery levels (Ndebele et al., 2021). The district level provides support for community health centres with generalist services such as diagnostic, treatment, counselling, and rehabilitation services (Malakoane et al., 2020). Regional levels support district services with specialist referrals (Malakoane et al., 2020). The provincial tertiary level provides support to regional services with both general and specialist services such as neurosurgery, neurology, plastic surgery, and cardiology to name only a few (Malakoane et al., 2020). The NICU with specialized services is found at a tertiary level or higher and this level of care should uphold a certain standard of evidence-based care (Lloyd & de Witt, 2013). However, there are numerous reasons why this care standard is often comprised in the South African context.

The study by Mahwasane et al. (2020) found the following to be key areas related to compromised service delivery in NICUs in the public sector of South Africa; under-staffed NICUs (high patient-to-staff ratios), delayed referrals to MDT members, decreased number of NICU beds, poor resuscitation management (lack of equipment) and hospital-acquired infections accounted for numerous deaths in the hospital. Further difficulties include educational and linguistic barriers, poor access to healthcare due to financial and logistical reasons, cultural barriers, healthcare worker burnout, long waiting times, safety and security (Mahwasane et al., 2020).

The NICU is a foreign and stressful environment that in itself holds barriers to attachment and bonding such as physical separation (Mahwasane et al., 2020) one needs to consider which additional barriers might be faced in a country such as South Africa. For example, effective communication serves as a clinical goal between healthcare workers and caregivers to obtain informed consent, aid in decision-making, and foster collaboration between healthcare professionals and the caregivers (Labrie et al., 2021).

Recent research has shown that caregivers value information provided in the mother tongue (Labrie et al., 2021). Information or the lack thereof is often a barrier experienced in the NICU as information is rarely provided in the home language of caregivers and therefore a lot of the information may go lost in translation or be misunderstood (Buissinne et al., 2018). This is significant in the South African context when considering the rich linguistic diversity.

The cost of transport, language differences, language barriers, and unreliable access to mobile phones have been cited as common factors leading to insufficient communication between doctors, nurses, and caregivers (Mburu et al., 2019). Mburu et al (2019) noted that the experiences of caregivers should be at the centre of troubleshooting ways to improve communication in the NICU (Mburu et al., 2019).

A need for early communication service development is essential in a healthcare system that has moved toward preventative healthcare at the primary health level such as South Africa (Austin et al., 2019). Early Communication Service development is essential when considering the various sequelae that come with prematurity or a NICU admission (Austin et al., 2019). These sequelae include prolonged hospitalization which has financial, social, and emotional implications, there are psychological and emotional effects on caregivers, there are risks for the neonate to develop comorbidities and other illnesses affecting health negatively (Zhang et al., 2021).

2.6 Covid-19 pandemic implications in the South African context

The Covid-19 pandemic resulted in international stressors on healthcare systems and the services they provide (Erdei & Liu, 2020). As a global public health disaster, Covid-19 impacted access to service delivery disruptions due to the lockdown, disruptions in food parcel delivery, lower socioeconomic status, and an increase in gender-based violence trends that were all noted during the early lockdown period (Mbunge, 2020; Stiegler & Bouchard, 2020). In South Africa, the effects of the pandemic were felt and worsened by the large disparity in socioeconomic status among residents (Mbunge, 2020; Stiegler & Bouchard, 2020). Given that a portion of residents in South Africa live in informal settlements, as per the national census in 2022 8.1% of households reside in informal settlements (Statistics South Africa, 2022) with limited access to water and sanitation resulting in a higher probability of transmission of the Covid-19 virus.

South Africa’s healthcare system already faces challenges such as a lack of funding, resource constraints, increased burden of disease, and limitations in healthcare staff which were then exacerbated by the pressure the Covid-19 pandemic placed on healthcare (Coutts et al., 2022; Louw, 2021). For example, South Africa faced a shortage of personal protective equipment (PPE) which had implications for how well the healthcare system could respond to the pandemic (Mbunge, 2020).

Before the Covid-19 pandemic, the caregivers within the NICU were already a vulnerable population due to the high rates of negative emotional sequalae experienced in the NICU, which means the adverse effects of the Covid-19 pandemic could be felt more deeply (Vance et al., 2021). While neonates appeared to present with mild symptoms, the main form of transmission continued to be caregiver-neonate interactions post-natally (Erdei & Liu, 2020). Public health measures, such as lockdown, were therefore reinforced to minimise transmission and to improve the safety of neonates utilizing social distancing. This, however, held implications for the caregiver-neonate relationship and therefore for caregiver well-being due to visitation limitations (Coutts et al., 2022; Louw, 2021). This challenges family-centred care practices within the NICU as families now play a less active role in the management of the neonate (van Stralen & Mercer, 2021).

Social distancing between a caregiver and a neonate admitted in the NICU could make the already strained bonding process more difficult resulting in elevated feelings of stress and isolation (Vance et al., 2021). Restricted access to the NICU environment during the Covid-19 pandemic increased feelings such as worry, stress, isolation, distress, trauma, decreased bonding, and many more for caregivers (Coutts et al., 2022; Louw, 2021). While some studies have described the physical effects of Covid-19 such as restrictions on visiting, there is little qualitative data that addresses the experiences of parents in the NICU during the Covid-19 pandemic.

It is therefore imperative to also consider the short and long-term psychological effects that the Covid-19 pandemic may have on caregivers during their NICU stay (van Stralen & Mercer, 2021). Caregivers require support during these uncertain times to remain advocates for their neonates and to improve their self-confidence (van Stralen & Mercer, 2021).

2.7 Conceptual Frameworks

Conceptual models aid in the conceptualization of the literature review, the methodology as well as the analysis of the research. When considering the theoretical frameworks below possible integrations can be made for the inferences of policy, procedure, and education. The following Conceptual models will be explored; Family-centered care (Carter et al., 2021) and The Creating Opportunities for Parent Empowerment (COPE) program (Hart et al., 2019; Melnyk et al., 2006).

2.7.1 Family-centered care (FCC):

Family participation within the NICU is crucial to the healthy relationship between caregiver and infant, as well as for the well-being of the caregiver and the infant (Carter et al., 2021). Humanization is at the very core of family-centred care because it integrates the family into the care of the infant which empowers the family to achieve humanized care for the infant (Gómez-Cantarino et al., 2020). Family-centered care is based on the following pillars: respect and dignity, information sharing, family participation, and family collaboration (Oude Maatman et al., 2020).

While we now recognize the crucial role of parents in the care of their infants, it was not always the case (Kokorelias et al., 2019). Around the time of World War II healthcare started disengaging from the hard behavioural approaches that had guided healthcare up to that point (Reid et al., 2021). During this period many children were separated from their parents and this became a focus point for psychologists in determining the impact of parent-infant separation on mental well-being (Reid et al., 2021). The work of John Bowlby and James Roberston was crucial to the development of and acceptance of FCC (Reid et al., 2021). Neonatal FCC was introduced about six decades ago and its implementation has been varied due to variations in its understanding but comes down to dignity and respect, communication, information sharing, partnership, and collaboration (Kokorelias et al., 2019).

Family-centered care has been found to have various benefits for the infant admitted to the NICU including reducing the length of hospitalization, reducing the presence of neurobehavioral difficulties (for example, executive function and integration), pain relief, improved weight gain, aiding in bonding with caregivers (and therefore increasing the possibility of breastfeeding), and finally reducing stress levels of caregivers (Fonesca et al., 2020; Oude Maatman et al., 2020).

Family-centered care allows caregivers to play an active role within the NICU, such as taking part in activities of daily living and being involved in the decision-making process thereby improving attachment and bonding and empowering caregivers (Fonesca et al., 2020). By empowering caregivers in the above-mentioned ways family-centered care alleviates feelings of anxiety and helplessness and allows for a feeling of safely controlling a very stressful situation thereby improving emotional well-being (Carter et al., 2021).

While FCC has many benefits as discussed above, the practical application thereof is often a critiqued difficulty in current literature due to the diversity of acute care contexts around the world in terms of culture, access to resources, and staffing (Abukari & Schmollgruber, 2023). There is especially limited research on FCC in African contexts where the social and cultural climate is vastly different than in Western countries (Abukari & Schmollgruber, 2023). Especially when considering the core concepts of FCC and how then to apply those to diverse cultural contexts (Abukari & Schmollgruber, 2023). For example, looking at the inclusiveness of family presence and participation in acute care settings; where typically the mother and father are allowed in the NICU, what of other crucial family members such as grandparents who often do a lot of child-rearing in African countries?

FCC was implemented in the methodology of this study by guiding the development of questions asked during semi-structured interview sessions as well as guiding the results and discussion sections. The FCC framework which highlights the role of sharing information and collaborating assisted in structuring results from this study as these pillars are crucial to acknowledge in the diverse social and cultural context of South Africa. When then considering FCC and this study which is exploring how the NICU affects attachment and bonding practices between caregivers and infants these pillars that FCC upholds become important. FCC may further aid this study in making recommendations regarding NICU policies and procedures to facilitate attachment and bonding and the influence the culture and context may have on it. Family-centered care may further aid in describing barriers and facilitators experienced by caregivers in the NICU.

2.7.2 The Creating Opportunities for Parent Empowerment (COPE) program:

It is well established in literature that preterm delivery birth and subsequent NICU admission has psychosocial implications wherein a caregiver's expectations of a "normal" pregnancy and birth with a healthy infant are not realized (Melnyk et al., 2006). The COPE program is used to conceptualize how individuals manage and cope with stressors (Melnyk et al., 2008). Originating from Leventhal and Johnson's self-regulation theory (Melnyk et al., 2006).

The model of self-regulation from Leventhal and Johnson describes the process of perceiving, interpreting, and responding to illness or illness-related information (Leventhal et al., 2003). This model aids in describing how individuals respond to and cope with stress relating to health which is a fundamental process in coping with stress (Leventhal et al., 2003). Understanding the beliefs that underpin how individuals will respond to illness or health-related information gives us insight into health-seeking behaviour (Hagger & Orbell, 2022). Beliefs either motivate an individual to seek treatment or deter them from it (Hagger & Orbell, 2022) which is important when considering this study and how caregiver's beliefs around their infant's health will advise how to react and cope with stress.

Knowing what to expect when dealing with a stressful event enables an individual to cope with the stressor through increased understanding, predictability, and confidence by creating cognitive schemas for the event (Hart et al., 2019; Melnyk et al., 2008). When this is then extrapolated to caregivers of hospitalized children and premature infants who undergo extreme stress, anxiety, and possibly depression the need for a framework to support their ability to cope with stress becomes necessary (Treyvaud et al., 2019).

The COPE program is underpinned by the self-regulation theory that states that cognitive beliefs are influenced by educational interventions (in other words, concrete or tangible information) thereby aiding in the emotional adjustment of coping with stress (Melnyk et al., 2008). When caregivers with infants admitted into the NICU were provided with concrete information it resulted in less parental, stress, anxiety, and depression (the emotional outcome of coping) and promoted positive parent-infant interaction (the functional outcome of coping) (Treyvaud et al., 2019).

The COPE program consists of two types of educational information; firstly information around the child's behaviour that teaches caregivers about typical emotions and behavioural responses that the child may display (for example, how possibly small and ill looking premature infants generally look) and secondly education around the parental role on how to interact with their child and support their development thereby addressing how to parent their child in the NICU (Melnyk et al., 2008).

Current literature on the COPE program indicates that there is little evidence available on the effectiveness of intervention-based programs such as COPE and therefore more practical research is necessary in the NICU (Treyvaud et al., 2019). For example, the COPE program often times incorporates screening caregivers for psychological stress, when would the best time be to screen parents and following on that, when would the best time be to provide intervention (Treyvaud et al., 2019).

The COPE program therefore improves caregiver beliefs about what to expect in their infant in the NICU thereby empowering them to care for their infant (Chertok et al., 2014). For example, caregivers oftentimes have a certain belief about what an infant looks like, a pre-term or medically ill infant looks drastically different with machines and pipes connected to them (Treyvaud et al., 2019). Here the preceding belief around what their infant should look like possibly results in psychological stress as it is disconcerting to see their infant in such a way. Once they receive education on how medically ill or preterm infants look like, this might stabilize their psychological status a bit. This reduces stress, decreases anxiety and depression surrounding the NICU experience, and promotes more positive mother-infant interaction (Treyvaud et al., 2019). COPE is a theory-driven, reproducible intervention program that can be easily translated and adjusted into clinical settings so as to improve outcomes in NICU's (Treyvaud et al., 2019).

The COPE program is therefore beneficial in this study as it gives the researcher a unique point of view when analysing data. Knowing that the population this study is targeting, caregivers of NICU infants, and that they often experience anxiety, depression, and stress in the NICU considering how the NICU can be adapted to reduce these symptoms is key to finding recommendations for this study and in analysing data.

2.8 Conclusion

The aforementioned information highlights the importance of attachment and bonding between an infant and a caregiver within the early post-natal period so as the ensure the survival of the infant as well as to create an environment conducive to healthy development (Holmes & Slade, 2017; Phuma-Ngaiyaye & Kalembo, 2016). When considering the NICU environment and the barriers it holds, this process of attachment and bonding is often disrupted which could lead to negative consequences for both the caregiver and infant as well as the social, emotional, cognitive, and communicative development of the infant (Coertze, 2019).

Consequences of the NICU environment to the well-being of caregivers include negative attitudes, feelings of stress, emotional distress, poor communication, and a lack of support (Coertze, 2019). Information or the lack thereof is often a barrier experienced in the NICU and ties in with communication, Waddington et al. (2021) and is rarely provided in the home language of caregivers therefore a lot of the information may go lost in translation or be misunderstood (Buissinne et al., 2018).

This dearth of literature on how context and culture might affect attachment and bonding in NICUs in South Africa is little, but significant in the South African context when considering the rich linguistic diversity. Furthermore, the NICU environment is stressful, placing caregivers at risk for negative sequelae such as anxiety and depression if the necessary support structures are not in place (Buissinne et al., 2018; Coertze, 2019). Caregivers have also internationally reported feeling as though they are in the way or feelings of being unwanted (Buissinne et al., 2018).

The South African context, as per the above, is a rich environment when it comes to attachment research as there is a large gap in current literature, it is culturally and linguistically diverse, and it allows for a very different economic climate than Westernized countries when considering that is a middle-income country and economically deprived (Dawson et al., 2021).

In conclusion, the attachment theory which is used as a basis for the development of social and emotional skills and postulates that a secure attachment and bonding process with an infant links to global development, but also specifically to communication development (Walsh et al., 2019). However, the concept that bonding is innate to certain contexts and cultures thereby influencing maternal sensitivity, socialization, and caregiver responsiveness (Keller, 2018) needs to be explored in more detail in current literature. The proposed research, therefore, aims to explore the concept of how the NICU might affect attachment and bonding practices with the understanding that context and culture influence bonding practices.

Chapter Three: Methodology:

3.1 Research question:

How does the NICU affect attachment and bonding practices between caregivers and infants in both the public and private sectors in Gauteng, South Africa?

3.2 Aim:

To describe caregiver experiences relating to cultural and contextual attachment and bonding practices in the NICU in Gauteng, South Africa in both the public and private sectors.

3.3 Objectives:

1) To determine how the NICU facilitates attachment and bonding practices pertaining to cultural and contextual influences.
2) To determine how the NICU impedes attachment and bonding practices pertaining to cultural and contextual influences.
3) To describe how caregiver well-being is affected by the NICU and how it relates to attachment and bonding within the NICU.
4) To describe how caregivers perceive their culture to influence attachment and bonding.
5) To identify how attachment and bonding practices can be facilitated in the NICU in the future.

3.4 Research Design:

A qualitative phenomenological design was used to explore caregiver experiences around attachment and bonding practices in the NICU in Gauteng, South Africa. Qualitative research can be described as the collection of non-numerical data that is then analysed using a qualitative paradigm and techniques so as to understand opinions, experiences, or concepts (Braun & Clarke, 2019).

A phenomenological approach further aided in understanding the reality of being human and reacting to internal and external influences therefore addressing the relationship between the participant and their context (Johnson et al., 2020). Phenomenology refers to exploring the lived experiences pertaining to an event, subsequently, the aim is to collect rich and meaningful data in a flexible manner (Miller et al., 2018).

Following the aims and objectives of the study, a qualitative approach was most beneficial as abstract experiences that are unique to each individual were described. A qualitative research design aided in understanding social phenomena, such as experiences, as it does not assume one version of reality, but rather that there are many versions and realities to a problem statement (Johnson et al., 2020). A qualitative design also states that data or results cannot exist outside of context (Braun & Clarke, 2019). As qualitative data tends to be flexible it can result in rich and meaningful findings collected (Braun & Clarke, 2019; Jamali, 2018).

3.4.1 Researcher Positionality and Reflexivity:

The positionality of the researcher refers to the worldviews of the researcher and the stance they take in applying this internal worldview to understanding and interpreting the research (Dodgson, 2019). Positionality further refers to social and political views shaped by the researcher's worldview and how this might affect their research (Holmes, 2020). A qualitative approach recognizes the fact that the researcher does not present without bias as they bring their own subjectivity such as their views, beliefs, values, perspectives, and assumptions (Braun & Clarke, 2019).

While this may seem to be a weakness it is rather a strength to acknowledge the researcher and their bias so as to actively prepare for it (Braun & Clarke, 2013). Rather than devising a hypothesis, the study aimed to gain an in-depth understanding of the lived experiences of caregivers in the NICU environment and how this in turn affected the influence of culture and context on attachment and bonding.

The positionality of the researcher was constantly considered with the use of reflexivity. The positionality of the researcher in the context of the research study is a white female Speech Therapist and Audiologist living in South Africa who is Afrikaans and English and educated at a tertiary level with a Bachelor's degree. The researcher further worked under supervision in NICUs in the public sector during her final year of studies. The researcher has now been working in the public sector in acute care settings for three years. The researcher has further also worked in the private sector in paediatrics for a year as well.

Reflexivity refers to the self-awareness of researchers in acknowledging themselves and the preconceived ideas and notions that they might bring into their research (Holmes, 2020).

Researchers then need to understand how these preconceived ideas or notions might influence their research and how they understand and interpret it (Dodgson, 2019). The researcher had experience in working with preterm infants and their caregivers in a NICU setting as a student which was the motivation for conducting research in this specific area. This however meant that the researcher had certain preconceived ideas about this population and their experiences.

The researcher observed how the NICU deprived some caregivers of the bonding experience with the infant. While this was the motivation behind the study, the researcher was aware that each experience that she was aiming to document was going to be unique to that caregiver and not to carry her ideals into the analysis of the data. Being reflexive during the research process aided the researcher in constantly critically examining interpretations and decisions being made and why these interpretations and decisions are being made (Dodgson, 2019).

The researcher examined her positionality during the course of her research by asking critical questions relating to how her worldview might affect the way in which she understands and interprets the research and results. The following questions were asked in the format of a reflexive journal; *"Who am I? What am I experiencing in the course of my research? How did the facts or events of my life shape my perceptions and ideas about my research?".*

A reflexive journal was kept during the data collection and analysis process that documented when and how the research process played out, as well as reflexive ideas and biases that were realized. The researcher noted the difficulty faced in the initial recruitment process as limited willingness to participate was found from advertising the study. The researcher acknowledges the homogeneity of the sample and therefore the caution to be taken when analysing this data. The researcher is aware that her unique positionality, especially as a speech-language therapist and audiologist, as the one conducting the interview, and as the researcher of the topics results in a power dynamic which could skew or influence the willingness of participants to share certain experiences.

The researcher was further aware that the first few participants she interviewed were from a similar demographic background as herself, these were the participants whom she asked to please spread awareness of the study. Thereby possibly causing that the participants contacted thereafter might be from a similar background as well. The researcher was able to reflect upon the interviews conducted and the information that was shared by participants. Keeping a journal further allowed the researcher to also keep a detailed account of what happened and when it happened which assisted in writing up the data.

3.5 Participants:

3.5.1 Access to participants

An advertisement was posted on online caregiver South African-based forums on Facebook so as to recruit participants, see Appendix A. Primary caregivers who had infants admitted to the NICU following birth were invited to participate in the study in the advertisement, as per Appendix A. The study aimed to include primary caregivers, however, all participants gathered in this study were the biological parent of the neonate.

Table 1.

Inclusion and exclusion criteria for participation in the research study.

Inclusion criteria	Exclusion criteria
Participants were required to be of 18 years or older in order to provide informed consent to participate in the study.	Participants younger than the age of 18.
Infants who were admitted to the NICU directly after birth were eligible.	Infants who were discharged and then admitted to the NICU will not be eligible as attachment and bonding will have taken place outside of the NICU.
So as to minimise potential distress, infants who were discharged more than 6 months prior to the interview were eligible.	So as to minimize potential distress, infants who were discharged less than 6 months prior to the interview were not eligible and must have survived as questions posed in interviews may be possibly distressing.
Participants were required to have had an infant admitted to the NICU within the last 4 years. The time frame was instated so as to ensure participants are able to give data specific to the NICU and therefore can still remember the specifics around the time of NICU admission as well as refer to current NICU practices in South Africa thereby utilizing shorter-term memory. This timeframe was further added to allow for the experiences of caregivers in the NICU during the Covid-19 pandemic to be included.	Infants who were admitted to the NICU more than 4 years prior to the interview were not eligible so as to ensure participants are able to give data specific to the NICU and therefore can still remember the specifics around the time of NICU admission as well as refer to current NICU practices in South Africa.
Participants of a variety of cultural and linguistic backgrounds were eligible to participate.	None.

Participants who had access to a smartphone or laptop/computer desired remote interviews were included in the study.	Participants who didn't have access to a smartphone or laptop/computer or desired remote interviews were either asked to do in-person interviews or were excluded in the study.
Participants who requested in-person interviews and that stayed within the following areas in central Gauteng, South Africa will be eligible; the City of Joburg, Tshwane, and Ekurhuleni districts.	Geographical restraints limited participants to central Gauteng namely; the City of Joburg, Tshwane, and Ekurhuleni districts. This was done for participants who preferred in-person interviews so as to ensure traveling feasibility for the researcher and the participants.
Participants who's infants survived throughout their NICU stay were eligible.	Participants who's infants passed away in the NICU were excluded from the proposed study. The reason for this exclusion is to minimize possible harm and distress. As attachment and bonding might not have been feasible given the amount of time participants spent with their infant these participants will be excluded.

3.5.2 Sampling procedure

The study used non-probability, purposive sampling to collect data. Non-probability sampling refers to a method of sampling where the researcher selects participants based on subjective judgment (Etikan & Bala, 2017). Purposive sampling is a sub-category of non-probability sampling where data is selectively chosen (Campbell et al., 2020). It is a less stringent method where participants are not selected randomly and where not all participants have an equal chance of being sampled (Etikan & Bala, 2017). This method of selection is usually carried out using observations and the theoretical or clinical expertise of the researcher (Etikan & Bala, 2017).

Sampling involved an advertisement that was posted on online caregiver forums on Facebook in South Africa so as to recruit participants. Primary caregivers who have had infants admitted to the NICU following birth were invited, as per Appendix A. The advertisement contained details about the aims of the study, whom the study was targeting, the inclusion and exclusion criteria, and how to contact the researcher to request further information or query an aspect of the research they might have been uncertain about. Relevant permission letters were submitted to the Facebook Forums, please refer to Appendix B through F.

The study aimed to include mothers and alternative primary caregivers so as to include a variety of cultural applications such as alloparenting and multi-generational parenting. The participant recruitment process started on the 8th of May 2023 once ethical clearance had been received by the University of the Witwatersrand Human Research Committee (Non-Medical) with protocol number: H23/02/14 (see Appendix G). Data collection involved advertising the study details on the following Facebook groups between the following periods 8 May 2023 to the 4th of September 2023.

The following groups were advertised on successfully during this period.

- Children with disabilities of South Africa,
- South African Mothers and Fathers of Disabled Children,
- The Mom Community Gauteng,
- Joburg Jewish Mommies,
- Mom and Baby South Africa,
- Mamahood South Africa,
- Johannesburg, South Africa,
- The Northcliff Community Facebook group,
- The Johannesburg South Community Facebook group,
- The Bedfordview/Bruma/Edenvale/Modderfontein Community Facebook group,
- The Linden Community Facebook groups.

When participants showed interest, either by contacting the researcher using email or telephonically on the details provided in the advert or by interacting with the post itself an information letter was sent to them (Appendix H). Telephonic information sessions were made available at no cost to the participants if they required further information or clarification. This was further used as an opportunity to discuss logistics around the semi-structured interview in terms of whether it would be online or in-person and where.

Many of the forums on Facebook either did not allow for the advertisement of the study or only allowed for the advert to be published once. The groups that did allow for multiple publications were used for advertising at least thrice in the above-mentioned period. Despite advertising numerous times on the above-mentioned Facebook forums very little participation was seen amongst caregivers with only three interviews conducted. Snowball sampling was then added to the sampling strategy to recruit more participants.

Snowball sampling refers to a type of convenience sampling where the researcher reaches out to a group of individuals who fit the criteria of the said study and asks those individuals to recommend the study to other individuals who fit the criteria (Parker & Geddes, 2019). While this approach allows for flexibility, it is criticized for the researcher's selection bias. The researcher, during reflexivity exercises, noted the possible bias of the study due to the snowball sampling used.

The researcher contacted caregivers who had participated in the study to share the information with eligible caregivers should they be willing to. A participant volunteered to post it on a WhatsApp group with NICU mothers on it. The details of the study were shared on a WhatsApp group for NICU mothers by a previous participant. As the researcher contacted individuals that she knew as part of snowball sampling the reach of the study may be limited by reaching those of a similar demographic as the researcher.

3.5.3 Sample size

Sample size, while not the focus of qualitative research, needs to be considered. When consulting global research, qualitative research generally aims to include 5-50 participants (Hennink & Kaiser, 2022). This varies depending on the variety of data that is received (Dworkin, 2012). When no new data is emerging, the data collection process stops (Hennink & Kaiser, 2022). Considering the feasibility of this study, a sample size of 10-20 participants was aimed for. However, due to significant challenges in recruiting a total of 14 participants were gathered.

Data collection took place from 8 May 2023 to the 4th of September 2023. The study used non-probability, purposive sampling to collect data. However, due to limited reach snowball sampling was added as a strategy. Fourteen interviews were finally conducted. Five participants were recruited from Facebook groups where adverts were posted online. Nine participants were recruited from a WhatsApp group for caregivers who have had an infant in the NICU. Saturation was obtained after 14 interviews were conducted.

3.5.4 Participant demographics

Once the research participants had been recruited, consent was obtained through a consent form (Appendix I) after information had been provided on the particulars of the study via an information sheet (Appendix H). Pseudonyms are used for participants in this study. The pseudonyms were initially chosen by the participant at the beginning of the interview, however, for uniformity they were then changed by the researcher. This strategy allows participants to choose their own pseudonyms and is an opportunity to establish rapport as well (Lahman et al., 2023). The following demographics were obtained from the fourteen interview participants.

Table 2.

Demographics of participants.

Number	Participant	Age	Home Language	Gender	Ethnicity	Relationship to infant	Language in which interview conducted	Employment	Whether public or private services were accessed
1	June	29	English	Female	White	Mother	English	Unknown	Private
2	Lily	25	Setswana	Female	Black	Mother	English	Employed	Public
3	Rose	23	English	Female	White	Mother	English	Unemployed	Unknown
4	Bonny	31	Afrikaans	Female	White	Mother	Afrikaans	Employed	Private
5	Kate	21	Arabic	Female	Indian	Mother	English	Unknown	Private
6	Ally	35	Mandarin	Female	Asian	Mother	English	Unknown	Private
7	Pink	34	Afrikaans	Female	White	Mother	Afrikaans	Employed	Private
8	Mary	32	Afrikaans	Female	White	Mother	Afrikaans	Unemployed	Private
9	Christelle	28	English	Female	White	Mother	English	Employed	Private
10	Jack	30	English	Male	White	Father	English	Employed	Private
11	Daisy	34	English	Female	White	Mother	English	Unemployed	Unknown
12	Zani	41	Afrikaans	Female	White	Mother	Afrikaans	Unknown	Private
13	Loretta	41	English	Female	White	Mother	English	Employed	Private
14	Nicky	38	Afrikaans	Female	White	Mother	Afrikaans	Unknown	Private

As per table 2, many of the participants were white (twelve out of the fourteen participants), while thirteen out of fourteen participants were female. This homogeneity of the sample of participants might reflect upon the sampling strategy used, namely snowball sampling. While participants are relatively homogenous in terms of race, gender, and relationship to infant their experiences were vastly different from one another, yielding rich findings.

It might be notable to consider the employment status of participants during the NICU admission of their infant because if caregivers were employed their ability to access the NICU might be vastly different due to work commitments, especially in the case of an unexpected preterm delivery, than if they are not employed during the time of the NICU admission. This area was not directly probed during the interviews, therefore, many are unknown. Of the fourteen participants, six disclosed that they were employed at the time of the NICU admission. Three participants disclosed they were unemployed at the time. The remaining five participants did not disclose their employment status to the researcher.

All participants were sourced from Gauteng, however, the level of care accessed differed among them. Whether public or private healthcare services were offered influenced the experience of caregivers in terms of the resources available, interactions with staff, staff constraints, and accessing NICUs as well as other healthcare services. Eleven out of the fourteen participants accessed private healthcare services and one participant accessed public healthcare services, the other two did not disclose. This once again also reflects upon the homogeneity of the sample.

The two interviews that were done in person took place at the homes of the participants, who were located in the Gauteng area. The researcher travelled to the participants homes for the interview, which allowed for a convenient process for those caregivers. This location was discussed and agreed upon by both the researcher and the participant.

Each participant's experience in the NICU was further influenced by the level of prematurity of their infant and then how long the infant was admitted to the NICU for. Please see below table 3.

Table 3.

Level of prematurity and corresponding length of NICU stay.

Participant #	Pseudonym for the participant	Level of prematurity	Level of prematurity	Length of stay in NICU
1	June	Born at 28 weeks	Extremely preterm	2 months.
2	Lily	Born at 26 weeks	Extremely preterm	4.5 months.
3	Rose	Born at 30 weeks	Very preterm	2 months.
4	Bonny	Born at 36 weeks	Moderate to late preterm	10 days.
5	Kate	Born at 25 weeks	Extremely preterm	3.5 months.
6	Ally	Born at 35 weeks	Moderate to late preterm	Unknown
7	Pink	Born at 30 weeks	Very preterm	2 months
8	Mary	Born at 34 weeks	Moderate to late preterm	20 days
9	Christelle	Born at 38 weeks	Full term	1 months
10	Jack	Born at 38 weeks	Full term	32 days
11	Daisy	Born at 31 weeks	Very preterm	Unknown
12	Zani	Born at 36 weeks	Moderate to late preterm	6 days.
13	Loretta	Born at 32 weeks	Very preterm	4 months.
14	Nicky	Born at 39 weeks	Full term	2 days.

According to the World Health Organization preterm can be defined as infants born before 37 weeks' gestation, but based on gestational age infants are extremely preterm if born before 28 weeks, very preterm if born between 28 and 32 weeks, and moderate to late preterm if born between 32 to 37 weeks (World Health Organization, 2023). Of the 14 participants, three infants were born extremely premature, four were born very prematurely, four were born moderate to late preterm, and three were born at full term. The level of prematurity directly corresponded with length of NICU admission, the more preterm the infant was, the longer the NICU admission was. The average length of NICU admission was 53.3 days.

3.6. Method of data collection:

Data were collected via interviews either in person or remotely. Remote interviews had video on to accommodate rapport between the researcher and the participant. To allow for confidentiality, only audio was recorded. Audio only was recorded on a third-party digital voice recording device while the interview was being conducted live.

Participants chose which platform the interview should take place. Many of the participants (10 out of 14) preferred a WhatsApp video call due to the ease of use and accessibility. Participants always voluntarily shared their contact details with the researcher. Two out of the 14 interviews were conducted in person. One interview was conducted on Zoom and the last interview was conducted on Microsoft Teams. The above indicates that the ease of the interview was quite important for participants as their participation in the study oftentimes had to fit in with working and caring for others.

Semi-structured interviews were held as they allowed for a process of reflection that brings about openness and honesty in their reflection on the event (Creswell & Creswell, 2017; Roulston & Choi, 2018). An understanding of each participant's perspective can be gained with the use of several questions pertaining to the aim and objectives of the study to put forward discourse with the research participant (Roulston & Choi, 2018). The interview setting allowed the researcher to gain an in-depth understanding of the broader social and cultural context of each participant as well as internal influences (Braun & Clarke, 2013).

Open-ended questions were developed from gaps identified in current literature as well as the aims and objectives of the study (Appendix J). Open-ended questions related to the responses of caregivers in the NICU regarding culture and attachment. This process was then followed by follow-up questions probed by the researcher as the discourse evolved so as to gain further insight into their experiences. Allowing for a section of the interview that is not structured allowed for a truer reflection as each participant’s journey may have differed and themes that cannot necessarily be hypothesized prior to the interview may have arisen (Roulston & Choi, 2018).

3.6.1 Process for data collection and research site

Participants were reimbursed for the data used for the interview, where necessary. No participants wished to be reimbursed for remote interview data costs. For in-person interviews held the researcher was traveling to participants so there was no need for transport reimbursements.

3.6.2 Data collection instruments

Self-developed instruments were used during the semi-structured interview, (Appendix J) for the semi-structured interview questions as previously discussed.

3.6.3 Data management

The semi-structured interviews were audio recorded by a third-party device on a password-protected computer as an audio file and was immediately stored under a pseudonym. After each interview, the recording was backed up on the computer so as to be accessed at a later stage. No identifying information was used in the storage process thereby, upholding confidentiality and anonymity as far as possible. The recording was stored under the pseudonyms chosen by each participant.

The transcription process started after the interview was conducted. It took place on Microsoft Word. For English interviews, the researcher manually transcribed each verbatim interview by listening to the recording multiple times. For interviews conducted in Afrikaans the researcher transcribed the interviews herself as she is an Afrikaans first language speaker. For Afrikaans interviews, the researcher directly translated the audio recording to English on Microsoft Word by listening to the recording multiple times and transcribing it verbatim. As the researcher is fully fluent in both languages she was able to directly translate from Afrikaans to English.

3.6.4 Pilot study:

A pilot study was conducted prior to going ahead with semi-structured interview questions. A pilot study is done to ensure the efficacy of the data collection being done as well as to pilot whether any further accommodations or changes are necessary thereby improving the quality of the research (Malmqvist et al., 2019). A pilot study acts as guidance for the way forward during data collection (Aziz & Khan, 2020; Malmqvist et al., 2019). A pilot study allowed the researcher to ensure that the proposed questions were appropriate and addressed areas that needed to be addressed. It further allowed the researcher to familiarize herself with the interview process and gain confidence in establishing a rapport with participants.

A pilot study was conducted with the first participant that was recruited, the semi-structured interview questions were used to guide the interview. During the pilot study, the researcher noted certain areas that needed to be probed into further, however, the semi-structured questions were not changed as these areas may differ from patient to patient and more detail would be requested by the research in a participant-specific manner. The pilot study allowed the researcher to create rapport online as it was done on a WhatsApp video call. No significant difficulties were noted during the pilot study, a rapport was established with ease, and in-depth descriptions were given by the participants. No changes were made to the semi-structured interview questions. The pilot study was further counted as interview one as there were no significant changes that needed to be made.

3.7 Data Analysis

Thematic analysis was used for the analysis of data. Thematic analysis refers to arranging the narratives of participants into themes or core concepts (Braun & Clarke, 2013). This allows for an in-depth exploration of the experiences of participants (Armat et al., 2018; Braun & Clarke, 2019). An inductive approach was applied to this study. Inductive analysis is described as moving from detailed or specific observations to generalizations and conclusions (Armat et al., 2018).

Interviews were transcribed by the researcher and aimed to identify patterns and themes leading to generalized conclusions. This is important for the proposed study as in-depth knowledge of caregivers' reality during their time in the NICU is cardinal to understanding their lived experiences. The thematic analysis further aided the study in meeting the aims and objectives set.

The experience of caregivers is subjective due to their individual circumstances and thematic analysis allowed for data to be analysed in the context of the participants (Kiger & Varpio, 2020). The transcription process initially took place in order to start organizing data (Braun & Clarke, 2019; Kiger & Varpio, 2020). The process of data transcription further allowed the researcher to become familiar with the data in order to start organizing the data into themes.

Data were then organized into themes, and coherent patterns arising in the data (Braun & Clarke, 2019). These themes generally reveal novel and key patterns that relate to the research question. Firstly, a vertical analysis was done where each interview was analysed using thematic analysis and identifying key-themes per interview. Then a horizontal analysis was done where key-themes were identified across all interviews.

The six stages of thematic analysis described by Braun and Clarke (2019) will be used. The following six stages were used for data analysis:

1. Data Familiarization – this involved reading the transcriptions and identifying patterns in the data.
2. Generating initial codes – in the second phase, characteristics of the data set (codes) were identified and noted.
3. Searching for themes- this phase entailed the above codes being organized into umbrella headings which then created themes.
4. Reviewing themes- thereafter, these themes were reviewed so as to ensure all themes were relevant with enough substantiating data.
5. Defining and naming themes- themes were named and defined according to the aspect of the data that the theme represented.
6. Producing the report – this final stage involved collating the said themes in a written report.

3.8 Rigor and Trustworthiness

Rigor and trustworthiness is used in qualitative data to ensure a certain level of quality to the data and to reduce bias and subjectivity as far as possible (Hayre, 2021). Considering the researcher-participant relationship and the potential of subjectivity due to the worldviews, ideologies, and beliefs that the researcher might bring into the research design, data collection, and data analysis it is important to explore how to shed light on the data in a true and just manner (Hayre, 2021). Rigor in qualitative research can be defined as quality insurance that the data being collected and analysed is accurate and true (Cypress, 2017; Hayre, 2021). Rigor thereby ensures that the data can be trusted and used (Cypress, 2017).

Rigor and trustworthiness are crucial when designing the research study and analysing results so as to confirm the quality of the data and therefore whether or not the data can be trusted and used (Cypress, 2017). Rigor refers to the quality of the data and if it is justifiable or meaningful (Johnson et al., 2020). Rigor in qualitative research focuses on whether or not the methodology, data collection, and data analysis is appropriate in describing the data and answering the research question (Johnson et al., 2020). Trustworthiness describes consistency and visibility in the design and analysis of data (Cypress, 2017; Johnson et al., 2020). An open and mindful approach is used to consider the limitation of the research findings, for example, researcher bias (Cypress, 2017; Johnson et al., 2020). Trustworthiness describes the quality of the research and if the research findings are truthful and can therefore be trusted to be authentic (Cypress, 2017). Trustworthiness describes 4 criteria namely; credibility, transferability, dependability, and confirmability (Cypress, 2017).

Rigor and trustworthiness were established through thorough reflexivity from the researcher and member checking that was done prior to each interview that was conducted. The dependability of the research was further ensured by the use of a pilot study to screen for any issues in the data collection process. There was further prolonged engagement with the data with the researcher with a detailed process of familiarising herself with the data and going over the data multiple times before identifying and creating themes.

3.8.1 Credibility

Credibility involves the research design in terms of the question, data, and method and whether they align with one another. It further involves ensuring that each step in the data analysis is properly accounted for (Kyngäs, 2020). The study upheld credibility by carefully documenting the research design in detail and ensuring that the research question aligns with the design chosen. The data analysis process was further described in detail while constantly reflecting on the preconceptions and experiences that the researcher might have brought to the research. This was done with a reflexivity journal.

Credibility can be further improved when exploring research participants and the appropriateness of the inclusion/exclusion criteria, sample size, and population (Kyngäs, 2020). Data saturation should also be considered when describing credibility, therefore, the study aimed to collect data until a level of saturation was achieved thereby ensuring that the sample size was appropriate. Data saturation for this study was determined firstly when no more novel themes were arising from the interviews and secondly was influenced by the marked difficulty in recruiting participants within a period with time constraints.

Familiarity is another concept to explore when considering credibility, this refers to the researcher being very familiar with the research topic (Kyngäs, 2020). This was ensured by an extensive literature review of the research question. This familiarity was further substantiated by understanding the motivation for conducting the research and therefore preconceived ideas around the research topic that the researcher should be able to identify. Finally, the strengths and limitations of the study will be discussed.

3.8.2 Transferability

Transferability in qualitative research refers to the way in which results are described which could allow for the generalization of key aspects of data across contexts and therefore the applicability of the findings to other contexts (Schloemer & Schröder-Bäck, 2018).

Transferability was achieved during the planning stages by describing sampling techniques, inclusion/exclusion criteria, population, and the sampling procedure in detail. Transferability was further ensured with thick descriptions of the data, and robust and detailed phenomenological descriptions of data which allowed for the generalization of data across contexts where applicable.

3.8.3 Dependability

Dependability refers to evaluating the quality of the data under multiple conditions, thereby achieving consistency in the research design, data collection, and data analysis (Kyngäs, 2020). The study strengthened dependability with the use of constant reflection and reflexivity. Reflexivity refers to self-awareness from the researcher in acknowledging themselves and the preconceived ideas and notions that they might bring into their research (Holmes, 2020). Being reflexive during the research process aided the researcher in constantly critically examining interpretations and decisions being made and why these interpretations and decisions were being made (Dodgson, 2019). The researcher examined her positionality during the course of her research. Independent coding and recoding of data took place during data analysis to ensure the credibility of conclusions made.

3.8.4 Confirmability

Confirmability refers to the verification of data, how is the findings of the study supported by the data collected, to aim to reduce researcher bias as far as possible so as to give the truest reflection of the narratives of the participants (Schloemer & Schröder-Bäck, 2018). Therefore the data and the analysis of the data should be shaped more by the participants (data collected) than by the researcher and their bias (Schloemer & Schröder-Bäck, 2018). A reflexivity journal was kept the entire process detailing memos and field notes.

3.9 Ethical considerations

Ethical clearance was received by the University of the Witwatersrand Human Research Committee (Non-Medical) with protocol number: H23/02/14 (see Appendix G). During research ethical dilemmas often arise to protect the data/participants, especially so, qualitative research as there are extensive interactions between the researcher and participants (Sanjari et al., 2014). Ethical considerations are therefore used to uphold moral and ethical standpoints during the research (Sanjari et al., 2014). Researchers have an immense responsibility to protect participants as data are interpreted subjectively (Sanjari et al., 2014).

3.9.1 Autonomy: informed consent and voluntary participation

Autonomy refers to the rights of the participants in terms of privacy, liberty, freedom of will, and self-governance (Arifin, 2018; Kyngäs, 2020). Participants are therefore free to make their own decisions and act on them (Arifin, 2018; Kyngäs, 2020). Two key aspects of autonomy include informed consent and voluntary participation. Valid informed consent allows a participant to autonomously decide whether participating in the research aligns with their own values, beliefs, and interests (Kyngäs, 2020).

The study therefore included comprehensive participant information sheets that included the aim of the study, study methods, potential benefits and risks, data confidentiality, and voluntary nature of participation prior to the research as well as remote or in-person information sessions. Participant information sheets were supplemented with verbal explanations when necessary.

Consent from each participant was obtained through an online consent form on the day of the interview sent via email. Please refer to (Appendix I) for the consent form. If a signed consent form was not possible for the participant, verbal consent was obtained on the audio recording of the interview. Participants were asked to sign consent prior to the interview for participation in the study as well as to be audio recorded (Appendix I). Written consent was obtained with a signed consent form prior to the interview, 12 of the 14 participants were able to sign a consent form. For the other two interviews verbal consent was audio recorded as the participant was unable to sign a consent form electronically or print it out and scan the signed copy back to the researcher.

3.9.2 Anonymity and confidentiality

Anonymity and confidentiality are crucial when planning and implementing research so as to uphold the privacy of participants (Kyngäs, 2020). Participants have the right to be free from intrusion and interference (Kyngäs, 2020). As participants choose to share personal information they trust that the information will be kept confidential and that only predefined individuals will have access to their information (Arifin, 2018; Kyngäs, 2020).

Anonymity and confidentiality were ensured by not revealing any identifying information related to data collection, analysis, or final research report. Participants were given pseudonyms of their own choosing. Privacy during the interviews was managed carefully and conducted individually by ensuring that the researcher was alone in a room with a closed door during online interviews. Data management aimed to uphold anonymity and confidentiality as no identifying information was stored on the data.

3.9.3 Beneficence and non-maleficence

Beneficence aims to protect participants from any harm or stress caused by the proposed study and therefore promote well-being (Kyngäs, 2020). Non-maleficence refers to the researcher's ethical obligation to minimize harm or risk (Kyngäs, 2020). Beneficence and non-maleficence refer to promoting the welfare of all patients with regards to health, psychological, social, emotional, finances, and time and reducing any harm or distress (Kyngäs, 2020).

As this study broached a sensitive topic during interviews with the risk of emotional distress being caused. A distress protocol (Appendix L) is therefore available to identify and refer participants where necessary. Free counselling services were available to participants who experienced emotional distress at Emthonjeni Centre on the East campus of the University of the Witwatersrand. Counselling services were available in person and remotely depending on the needs of the participants. The above information was available on the participant information sheet, however, no participants required a referral to Emthonjeni Centre.

3.9.4 Justice

Justice refers to the equal treatment of all participants in a fair manner (Kyngäs, 2020). Fairness refers to key aspects namely; liberty and equality, therefore, each participant should be given an equal chance (Kyngäs, 2020). Each participant eligible for the research project should be given a fair chance as well as the opportunity to withdraw at any given point (Kyngäs, 2020). This principle was upheld by the fair selection of participants, freedom to withdraw, fair distribution of results, and the reimbursement of data/airtime when necessary to allow all participants would be able to participate.

The principle of distributive justice will further be upheld in terms of data analysis and the dissemination of the findings. The final research report will be available to all participants as well as in the Speech therapy Department at the University of the Witwatersrand. The data will be written up as a research report and possibly as a paper to which professionals will have access. The researcher has the contact details (via email) of the participants and will send a shortened version of the research report via email to distribute the findings.

Chapter Four: Results

This chapter will describe the themes and sub-themes identified during the data analysis of interviews conducted with participants. The following three themes were identified: the act of mothering in the NICU, culture in the NICU, and a sense of missing out.

Table 4.

Themes and sub-themes were identified during the analysis of results.

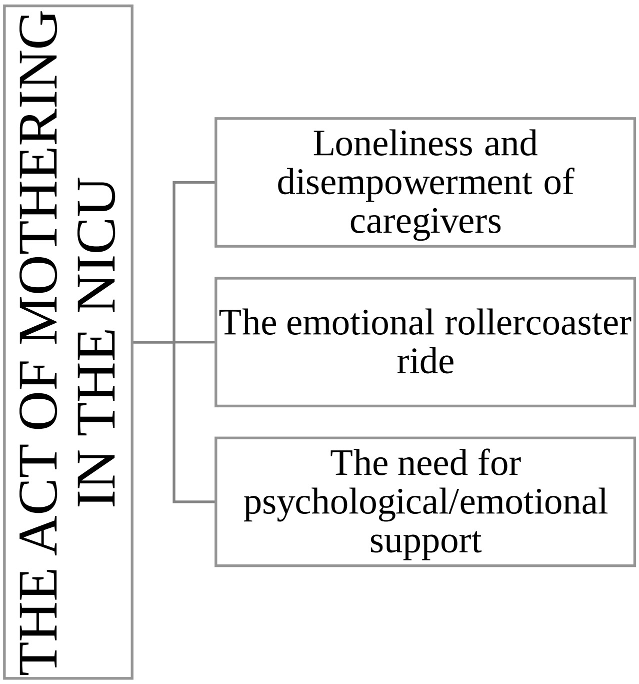
Theme	*Sub-theme*
Theme 1: The Act of Mothering in the NICU	1) Sub-theme 1: Loneliness and disempowerment of caregivers 2) Sub-theme 2: The emotional roller-coaster ride 3) Sub-theme 3: The need for psychological/emotional support
Theme 2: Culture in the NICU	1) Sub-theme 1: Care in the NICU 2) Sub-theme 2: Influence of culture and caring for a Baby in the NICU 3) Sub-theme 3: Information-giving practices in the NICU
Theme 3: A Sense of missing out	1) Sub-theme 1: Unexpected pre-term birth 2) Sub-theme 2: Feeling estranged 3) Sub-theme 3: The tension between society's image and the reality of having a baby in the NICU

4.1 THEME ONE: THE ACT OF MOTHERING IN THE NICU

Caregivers are often exhausted by the physical and emotional demands of the NICU as it is a demanding environment with various mechanical equipment and machinery that are unknown to most caregivers (Buissinne et al., 2018). This can seem very foreign and frightening (Buissinne et al., 2018). The NICU may be further associated with the prolonged hospitalization of infants which causes further stress, trauma, and feelings of hopelessness for caregivers which can lead to negative consequences for attachment and bonding (Buissinne et al., 2018). The fact that infants are often admitted in the NICU for a period means that caregivers are faced with taking part in the acts of caring for an infant in the NICU environment.

Figure 1.

Visual representation of theme 1 and subsequent sub-themes.



4.1.1 SUB-THEME ONE: Loneliness and disempowerment of caregivers

Caregivers of premature infants or infants who are medically ill often experience a range of negative emotions, one of these being isolation (Dahan et al., 2022). The social isolation that caregivers experience is often characterized by visitation restrictions in the NICU, medically protecting their infants from possible infection by meeting new people which leads to caregivers being socially isolated (Givrad et al., 2021).

Caregivers often feel disillusioned from the experience of being a parent due to (1) social isolation that is characterized by separation from their infant and separation from the world and (2) reduced support from family and friends due to strict NICU visitation rules. The narrative of being a watched parent which is caused by (1) reduced chances for caring for your infant as it is predominantly done by nursing staff (2) when you do have an opportunity to care for your infant is done under the supervision of nursing staff. This causes elevated stress as caregivers learn how to parent in this very stressful NICU environment, but also feeling judged by staff while doing so.

The above was substantiated by caregivers interviewed for this study especially when looking at familial support that was limited by visitation rules in NICUs, while most caregivers understood the need for precaution to keep their infants safe, they also had a need to bond with their infant.

Caregivers expressed that being separated from their own family, especially their parents negatively impacted their mental health and ability to cope in the NICU. As stated by Rose *"But the fact that I didn't have that close support from my parents was very isolating. The whole process I was doing all alone, I found myself getting very emotional and very nervous."*.

Caregivers further expressed that because friends and family were not able to visit in the NICU or experience the NICU they often did not truly understand what caregivers went through. Pink stated *"And…and no one else really understands. If you haven't been in a NICU then you don't really understand. No one sees what they do to her. All the pain she goes through."*. This led to caregivers often feeling misunderstood and isolated as no one else understood what they were going through.

This feeling of loneliness and isolation then exacerbated the disempowerment caregivers experienced in the NICU. Disempowerment in the NICU is a theme that has surfaced in the literature surrounding caregiver experiences in NICU's because they are often no longer the primary caregivers of their infant, but rather the medical staff (Palmquist et al., 2020). Not conducting activities of daily living with their infants often makes caregivers feel lonely as they then struggle to attach to their infants (Palmquist et al., 2020). June expressed that she worried if her infant was truly attached to her and not a medical professional as they were caring for her infant *"I am the mom, but has she really attached to me? Even though I held her so many other professionals also held her and cared for her. It's just something that till today really stresses me out"*.

Further eluding to the idea that you feel separated from your infant which increases feelings of loneliness and disempowerment as you feel as if your infant is not your own, but rather just a patient at a facility said Bonny *"Secondly, they make you feel as if that child is not your own, it is their property as a patient. You need to ask permission to interact with your child or touch your child. It's their child or their property and they dictate what you can and can't do. But* *they assume you don’t know anything and assume you can't do anything for your child.”* an employed mother.

Caregivers often also expressed feeling estranged from their infant and from being a parent as they often were not able to care for their infant, but even when they could provide an act of caring such as bathing it was done under the supervision of nurses, constantly critiquing them. Pink described *“You are just a visitor, not a mom. So, you sit there day in and day out like a third party. It's about empowerment, when you walk into the NICU, they make you feel like you aren’t the mom. It feels like you have no right to mother your own child, you are merely an observer.”*

Lily further expanded on this concept *“I couldn’t hold them for about a month, so it felt like I didn’t give birth to babies- I'm not even sure they knew who I was. It just kind of made the whole experience of being a mother very unworthy. Um, yeah it felt infiltrating having so many people care for them and see them, and not just us. NICU journey kind of robs you of being a mother and that title. Especially, when you see other moms who have a normal journey. We were deprived of the normal caring and bonding. So yeah, that takes a toll on you.”*.

Finally, the feeling of being a watched parent in a highly stressful environment, the NICU, with a sick infant and trying to learn how to be a parent, especially when you are a first-time parent, makes the journey so much more difficult a caregiver; Loretta explained *“One of the things that the OT said to me and it just never left me was; one of the most traumatic experiences as parts of the NICU is being a watched parent and you have to parent while you're being watched by a nurse a doctor a physio you name it. And especially for a first-time parent. There were moments when I got very frustrated and very angry because I was like I know what my child needs I know I am a first-time mom but I'm telling you I know what she needs.”*.

In conclusion, caregivers often feel disillusioned from the experience of being a parent in the NICU due to (1) social isolation that is characterized by separation from their infant and separation from the world and (2) reduced support from family and friends due to strict NICU visitation laws. The narrative of being a watched parent which is caused by (1) reduced chances for caring for your infant as it is predominantly done by nursing staff (2) when you do have an opportunity to care for your infant is done under the supervision of nursing staff. This causes elevated stress as caregivers learn how to parent in this very stressful NICU environment, but also while feeling judged while doing so.

4.1.2 SUB-THEME TWO: The emotional roller-coaster ride

Caregivers of infants in the NICU experience an elevated level of stress which may cause emotional and psychological trauma such as anxiety and depression which could have a negative impact on attachment and bonding (Byiringiro et al., 2021; Phuma-Ngaiyaye & Kalembo, 2016). Caregivers often experience various negative feelings apart from anxiety and depression such as frustration, hopelessness, guilt, and feelings of unpreparedness (Hall et al., 2020; Schecter et al., 2020).

Caregivers referenced the emotional trauma they experienced when their infant was admitted to the NICU and often disillusioned by this new reality they faced. *"I first had to immerse myself and sort of dwell on the pain I was experiencing of seeing my children in that state. I was in shock and pain. I couldn't believe my eyes."* said Lily. As often referenced in current literature negative emotions such as anxiety and depression such as frustration, hopelessness, guilt, and feelings of unpreparedness were experienced (Śliwerski, 2020). Mary stated "*The depression hit me hard. I'm surrounded by four walls, feeling lonely and overwhelmed."*.

The expectations around becoming a parent, especially a first-time parent, and what that typically holds is often taken away by the NICU, causing this disillusionment. *"So that was really a big event for us, as first-time parents. Within minutes you go from the best moment of your life and almost experience heaven and then suddenly go to this dark hole that you're thrown into, and you have no idea what's going on or what's going to happen. So, whiplash, emotionally. I was not necessarily very emotional while in the hospital, but during those first two weeks at home, I was very emotional. I cried a lot about what happened."* said Daisy.

The emotional roller coaster continued even after the infant was discharged from the NICU and went home. It is well known that caregivers often experience PTSD which affects the well-being of caregivers thereby compromising their ability to bond with their infant, therefore negatively impacting attachment and bonding in the NICU context (Sabnis et al., 2019). Another caregiver, Kate mentioned *"It is a traumatic thing, you don't ... you don't… I wasn't even told that I might experience post-partum depression and PTSD because of it. And it took* *me 5.5 months to realize something was wrong and it's not getting better. But if I knew I could look out for signs and know and decide faster of getting myself help. So yeah."*

A large narrative that also arose from analysing data was the physical stress that a mother's body had undergone and how that worsened their emotional well-being in the NICU. The physical recovery from childbirth oftentimes results in being in pain, not being able to immediately visit their infant or assist in the care of their infant, and the physical limitation of not being mobile immediately when you have an infant in the NICU. Lily reported *"I was overwhelmed. I was in physical pain. I was just a human being that was woken up by an alarm to go see my babies day in and day out."*

Rose stated *"The hardest things were more like recovering from a c-section and being bedridden for a week. So, I couldn't see my son for a week after he was born because there is nowhere to sit with a wheelchair and so. This meant I spent less time with him and didn't see him the whole first week which was difficult."*

In the above evidence, it becomes clear that caregivers experience a variety of emotions, usually that come at a very quick pace and that have highs and lows creating a rollercoaster effect. Caregivers experience these emotions as a consequence of their infant being admitted to the NICU which is, in most cases, worsened by the little knowledge they have of the NICU and the unexpectedness of it. Another interesting narrative was that of the physical pain and how that impacted their ability to attach and bond with their infant and how it negatively impacted their well-being.

It is apparent that the NICU causes stress and negative emotions in caregivers resulting in their mental and physical well-being being affected. It then becomes important to consider the FCC framework and how we can implement it to assist caregivers in coping with the NICU. Some factors that has been referenced in literature regarding the well-being of caregivers and how FCC may assist these include being involved in the care of the neonate such as feeding and holding which allowed for time to bond with the infant thereby also improving attachment (Buissinne et al., 2018). Furthermore, supportive training, education, and communication from healthcare workers aided in developing hope (Buissinne et al., 2018). This related to the core components of FCC being respect and dignity, information sharing, family participation, and family collaboration (Oude Maatman et al., 2020).

4.1.3 SUB-THEME THREE: The need for psychological/emotional support

The prolonged hospitalization and NICU stay complicates the bonding process between caregivers and infants as normal caring opportunities are often limited within the first 1000 days (Coertze, 2019; Gibson, 2017). The hospitalization of an infant to the NICU can cause potentially traumatic emotional and social sequelae for parents and caregivers causing feelings of stress and trauma (Schecter et al., 2020).

When addressing the need for psychological or emotional support under caregivers in the NICU three main areas were identified; (1) the need for the development of educational material for caregivers (2) the layout and design of the NICU and (3) receiving psychological support from a professional.

4.1.3.1 Need for development of educational material for caregivers.

A popular request amongst caregivers, when asked how their journey could have been improved, was the need for a physical guide on how to navigate the NICU, what to expect, who the stakeholders are, and protocols they need to be aware of. Caregivers made it clear that a verbal handover alone was not enough as they were so overwhelmed and emotional on that first day that they could barely remember anything. Many caregivers reported that they didn't even get a verbal handover and were just thrown into the deep end.

*"Uuum, and especially as new parents you don't know what's going on and nobody is saying you can do this or that. There is no intro to it. There is just too much information that is also too overwhelming. Just give us a website or pamphlet that we can read later again. There was just, I don't know, none of that communication. Uhm, yeah, it's very frustrating. Then you must figure out what's going on, while doing that navigate which nurses are on duty and which nurses are approachable. Those little things that must figure out were also very frustrating. "*Lily said.

Pink mentioned "*I think that they need a booklet that parents get that explains the NICU, who the team members are and how to get in contact with them, what you can and can't do. When the doctors have their rounds is also valuable information. When they verbally dictate all of this you often can't remember much because you are so stressed, so something to refer to."*

"Like the one thing that I think was missing from you know make your journey especially in the beginning there was no guidance on what do. Like a how to navigate." Daisy said.

The need for caregivers to be orientated to the NICU while also receiving ongoing information about their babies especially when they are sick was expressed among caregivers. *"So, I would say that the staff of the NICU at least, if you unexpectedly had a preemie baby, should be given a tour or run down of the NICU and what's common, what's going to happen. For example, I would panic any time her infection levels would rise. I panicked when they would call me for authorization for blood transfusions, but now I know those are common in most NICU babies."* Kate expressed.

4.1.3.2 The layout and design of the NICU

Comfort and privacy were often lacking in NICUs. NICUs were described as overcrowded with limited space and poor seating for caregivers. *"Uhm, and it was really crowded. So even personal time when you want to talk to baby was hard people other people are around you, it's just noisy with alarms going off. You're freaking out and overwhelmed."* said Ally, a mother and wife.

Caregivers reported that most of them tried to be present in the NICU all day, but with nowhere comfortable to sit when they have just given birth made this reality difficult. An area as basic as a lunchroom where you could hear your food or rest a bit was often missing from NICUs, especially in the public sector NICUs. *"What I said to our hospital is they need to have more comfortable chairs there for moms. We had this old hard wooden chair, now you are recovering from a c-section and waiting with your baby all day on these uncomfortable chairs. There weren't facilities to go express milk either, you had to go to the front of the hospital and express there in public and walk back to the NICU with your expressed milk. Logistically, it was difficult. Just a lounge where moms can express for example. Also, chairs where KMC could take place."* Pink mentioned.

4.1.3.3 Psychological support from a professional

As discussed earlier, many caregivers felt as if they could not confide in their friends and family as they often did not understand the NICU and how it may affect an individual. There was a global expression of the need for an in-house psychologist that is either familiar with the NICU experience or has specialized in it in some manner to provide support for caregivers. Rose expressed *“Having psychologists to come and see the moms after having such a traumatic birth and then being in the NICU. We need to see a psychologist. That would help so much!”*.

The ease of psychological access was key here, mothers especially expressed that they cannot get to another location to access psychological support when they themselves are not allowed to drive and they have just given birth and they want to be present in the NICU for their infant. *“I think a simple thing like if we had a psychology session there at the NICU, your mental health could’ve been in a better place. And you know, in the NICU so that it isn’t another extra thing a mom has to go do. “*Kate mentioned.

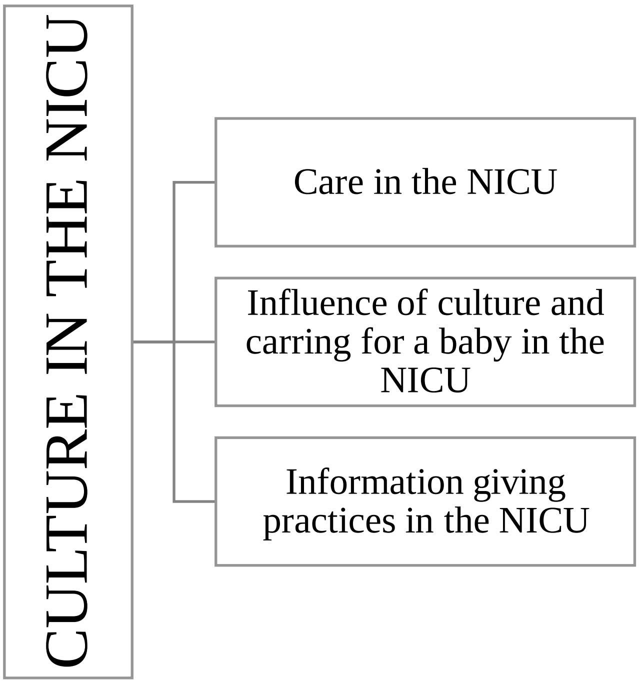
It is apparent that there is a great need for the support of caregivers within the NICU environment. This study specifically references (1) the need for the development of educational material for caregivers (2) the layout and design of the NICU and (3) receiving psychological support from a professional. It is then required to find a feasible way in which to implement the above in the NICU environment. The FCC framework is a collaborative neonatal care model that aims to improve outcomes in a NICU (Scala et al., 2020). With the use of this model recommendations such as the above may be implemented in a structured and feasible way (Waddington et al., 2021).

4.2 THEME TWO: CULTURE IN THE NICU

Cultural beliefs and practices are an integral part of who we are and influence childrearing patterns and how we use healthcare services (Nyaloko et al., 2023). Healthcare professionals need to ensure culturally sensitive care, particularly in the neonatal intensive care unit (Nyaloko et al., 2023). Considering the influence of context and culture on attachment and bonding, it is crucial for healthcare workers to understand these tenants in order to be sensitive and competent in the care of patients due to cultural differences sensitivity is required in terms of their respective norms and practices (Dawson et al., 2021). This theme will discuss how the attitudes and beliefs systems that are linked to our culture may influence caregivers’ attitude towards caring for an infant, how caregivers communicate to one another, how caregivers go about caring activities for an infant, and how caregivers navigate the being a parent but also allowing medical staff to care for your child.

Figure 2.

Visual representation of theme 2 and subsequent sub-themes.



4.2.1 SUB-THEME ONE: Care in the NICU

The care culture inside a NICU, referring to the work ethics amongst healthcare professionals in how they care for infants, plays a large role in framing all infant caring activities (Holdren et al., 2019). Ensuring that the care culture within the NICU is effective as well as culturally appropriate increases the health and well-being of infants and their families by increasing parent-infant interaction and relationship and positive mental health outcomes (Holdren et al., 2019). This is especially done with the use of FCC, however, the application thereof varies from NICU facility (Holdren et al., 2019).

The care culture experienced by caregivers in the NICU varied from hospital to hospital. The following key areas were mentioned that negatively impacted the experience of caregivers (1) lack of continuity of care from nurse to nurse, (2) the willingness of staff to make accommodations, and (3) positive interactions with nursing staff. This reduced their ability to attach and bond with their infants and had a negative impact on the well-being of caregivers.

4.1.3.1 Lack of continuity of care from nurse to nurse.

Caregivers were often frustrated and stressed out by the fact that there are frequent rotations of healthcare professionals caring for their infant. This meant that the continuity of care was affected, especially by the handover between nurses. Pink, a mother who accessed services from a private healthcare facility mentioned *"Many of the nurses on this side were also locums, so they came in and out and rotated often. On that side, I really had a lot of stress. I had to find a nurse who would go the extra mile for my baby so that she could come out."*

Nursing staff were not always aware of the healthcare plan for the infant causing a disruption in the communication chain between healthcare professionals and caregivers. The care style of nurses also varied which was frustrating. If caregivers were allowed to bathe the infant with one nurse, but the next nurse reprimands them for doing so this can negatively impact the caregivers' autonomy and self-confidence and reduce the predictability within the NICU. Zani stated, *"What did make it harder was the fact that because he… he wasn't sick like the other babies his nurses were rotated more frequently and it was often someone locum at work and that makes things a bit unfamiliar, and you always have to trust someone new every day."* Zani mentions the element of trust and that it is difficult to establish trust if there is no consistency in who cares for your infant in the NICU.

4.1.3.2 The willingness of staff to make accommodations.

When caregivers are not accommodated as far as feasible or allowed to be part of the care of their infant the effects thereof are evident. Caregivers feel sidelined and removed from their infants which in turn affects their bonding and attachment and thereby their well-being. *"So, I expressed breast milk and took it to the NICU, but asked to be present for feeds because I would like to go on with breastfeeding and assist with paced feeding. Then I got to the NICU they'd already fed her, and I'd missed out on that bonding, drove 35 mins to the hospital and I can't even feed her."* Bonny said. Bonny accessed private healthcare services while facing the challenge of staff not accommodating her wishes to be part of the care of her infant.

Caregivers who are already under so much stress then also must navigate this tricky relationship with staff to find a compromise to be part of their infant's NICU journey. Rose stated *"A nurse yelled at me and said she was going to take the bottle away from me and that I wasn't allowed to feed my baby. It made me feel like a parent that didn't know what I was* *doing. "*. Unprofessional behaviour and shouting are not an effective communication strategy, however, as Rose has stated it is being used by health professionals.

Due to a lack of information and guidance on how to navigate the NICU caregivers lose out on caring opportunities as they are not aware of them, which further debilitates the bonding experience. *"We only found out later that he could also have performed Kangaroo mother care for her. Until we asked towards the end of her stay, no one even offered to let him hold her or carry her."* Here Kate, explains that her husband was never explicitly given the chance to perform KMC in a private healthcare facility.

Pink sheds light on the fact that often caregivers are not allowed to voice their concerns or preferences, this impacts their autonomy and decision-making skills which could negatively impact their mental well-being *"And then losing further control, the head nurse had this attitude that if you complained you weren't welcome in the NICU. So, keep quiet and be around your child, or go home. "*

4.1.3.3 Positive interactions with nursing staff

Caregivers also explored factors that facilitated bonding and attachment in the NICU, this included positive interactions with staff. *"Uuum, so yeah, I think the good part was one of the head NICU nurses, she was the nurse that saw him the first time and she was fantastic! She had such good communication skills and was so good with him and caring. So that really helped. She was always the one to relay how much milk he took.* " expressed Christelle. The way in which a lack of communication can cause distress and uncertainty has been previously explored in this study, here Christelle mentions how good communication from staff facilitates her experience in the NICU in a private healthcare facility.

The positive effects of trust in the NICU can be seen in the above interactions and how they positively impacted the well-being of caregivers. Having someone within the NICU whom a caregiver can rely on appears to be a great protective factor in coping with the NICU. *"Hahaha, yeah, it's not great you know. But there was one nurse who we still talk to today that was superb. She really looked after him, and us (laughs). She would give little bits more details of his state, and like what medication he is on. We just needed someone to be real with us."* Jack stated.

In conclusion, the care culture in the NICU can either positively influence the experiences of caregivers or have a negative impact on their well-being and ability to bond with their infant. Here, given the fact that each NICU is organized in a different manner and the resource and staff constraints experienced in South Africa are challenges that will be faced. However, the need to find a solution, possibly using FCC, is required in order to improve the attachment and bonding process and improve outcomes for both caregivers and infants.

4.2.2 SUB-THEME TWO: Influence of culture on caring for a baby in the NICU

The NICU and culture influenced one another in multifaceted ways, the one influencing the other. How the NICU was experienced by caregivers is going to be discussed in two main areas namely (1) the belief system attached to parenthood and the NICU as well as (2) the physical consequences of having an infant admitted to the NICU.

Caregivers reported a variety of cultural factors that were significant in their NICU journey. Firstly, stating which practices or ceremonies were affected by the NICU admission of their infant. Lily reported *"But for my partner, his parents needed to see the babies only after 10 days. But because the babies were so sick, we didn't know if they would make it, so they saw them sooner because of that. Normally they would then bring the babies gifts and clothes, but that didn't happen".*

Having an infant in the NICU affected which ceremonies were able to take place and when they were able to take place, especially considering that many caregivers were faced with a situation where the birth happened unexpectedly and often early meaning that ceremonies taking place both before and after birth were affected. Pink stated *"Mmmmh, well I mean I only had my baby shower after she was born, so it wasn't taken away, it was just different. That collectiveness between friends and family and the celebration that goes with it wasn't there. That was difficult. We also couldn't send pictures of her because she was connected to so many pipes and tubes and you don't want people seeing her like that. But we still got to do most of the ceremonies, it was just later or a bit different. It was just that initial period. It's not the picture that society paints."*

Another interesting nuance that arose when analysing data was how culture shapes our beliefs around parenthood from a young age and that the NICU journey then contradicts those beliefs as reported by Rose *"Definitely, I grew up with the notion that holding your baby is how you* *get to love them. Having that taken away was very hard. They put everyone in a box saying everyone must breastfeed. For me, I never grew up with breastfeeding it wasn't something I wanted to do that. But the provincial hospital made that so difficult.".*

Another example was highlighted by Kate "*Uuum, I would actually say it did teach me a lot of things that are actually not true and are old wives' tales."* Here Kate mentioned that not all information that was shared with her by more senior family members ended up being medically correct, but rather "an old wives' tale" or superstition.

While for some breastfeeding was not important, for others the closeness of breastfeeding was an important practice to have as a new parent. Bonny mentioned *"I was supposed to have her with me and breastfeeding her. Being in a bubble with my baby was important to me for the first few days. It was completely taken away from me. This dreamed-up reality of being a mom was taken away. I felt like I was only there for my milk, and not be. A mom. There is no baby for you yet. It's difficult."*

The NICU can influence cultural practices related to the caregiver-infant relationship such as religious practices like prayer and privacy more physically as well in terms of physical space, visitation hours and rules, facilities that allow for privacy, and so forth. Kate explained *"Uhm, so for us being covered is quite important and I did appreciate most of the nurses that I saw were ladies as well and covered. So, I did appreciate that. Uhm, I feel like hospitals should have prayer facilities, even if it's one room for everyone to do their thing in. A room where you could go in to observe what you need to. And specifically, our hospital didn't have that. NICU spaces are very compact, what can you say, so yeah. I do feel like it was a bit difficult at that time- my husband and I weren't allowed at the same time in the NICU, so it was me or him and that was difficult.".*

Christelle reported how the NICU impacted some religious practices that were important to them *"I think the visiting for sure, even after the NICU, so much had happened we didn't have the time or energy to see family and friends. If we could have shared it, it would have been more happy and joyful. We also couldn't send a pastor in to pray for him, it's something we wanted to do but they wouldn't allow it. They did let him talk to the doctors, but he couldn't go in to pray.".*

How nursing staff cared for an infant, communicated with staff, and went about their work was also perceived to be influenced by culture for some caregivers. *"I also found the culture of the nurse played a big role. If I found a black nurse that day, they would let me be more active in the care of the baby than maybe some other cultures. So, a black nurse would let me hold the baby, but a white nurse would maybe say "No, you can't hold the baby now they have many drips. In terms of race, the motherhood context is very different, you understand. I'm not bashing everyone, but people of my own culture understood that holding a baby was important. That a mother needs to hold and touch her baby despite everything that is going on. Those were the things that made it easier. Also having parents see the babies helped."* Lily said.

Caregivers expressed that they saw a difference in how nurses would let them be involved in the care of their babies based on culture. *"Culturally, I think there is a difference between getting a white and black nurse. I don't mean it offensively, and I think most people don't want to say anything, but in a way, there is a difference in how you deal with the baby and with you. It's totally different. The black staff are more supportive of breastfeeding, but the white staff were hesitant to allow that or allow for holding. If you asked the black staff, they would be like "Sure have your kid". And that makes a massive difference. Especially, kangaroo*-mother-care. *So yeah, not all staff made the effort to let you hold your child. It's a different balance to it."* Christelle said.

Pink mentioned how activities related to caregiving might differ from culture to culture *"Yes, something simple like the mom might have certain needs from a cultural thing like she needs to be the primary caregiver and bathe her baby, and not having everyone look after the child. But, looking back, I know my child needed to be there, but you only see that once you are out of that fight-or-flight environment.".*

Each individual has a unique perspective on the world which is influenced by their culture and will influence their ideals around parenthood and therefore will influence how they perceive the NICU and deal with the NICU environment. There is a fluid relationship between culture and experiences we have, namely, having an infant admitted to the NICU.

It was further noted that there were physical consequences in terms of cultural practices and ceremonies for caregivers. For example, social practices such as having a baby shower, religious practices such as prayers, and the physical space of the NICU not allow for privacy.

While caregivers noted these challenges, the major consensus was that they either modified the practice or ceremony or did it at a later stage. Caregivers noted that these did not have a major impact on their well-being or attachment to their infant, mostly as they are in a "life-and-death" situation with their infant who might be fighting for their life on a daily. These cultural expectations almost fell away until the infant was home and stable.

In conclusion, considering that culture influences our belief systems and how important belief systems are when interpreting how individuals cope with stress it becomes evident that culture not only plays a role in how caregivers attach to their infants, but more importantly how they cope with stress. The belief system and ideas of parenthood attached to them had a greater impact on the well-being of caregivers and how they coped with stress than the physical limitation of having an infant admitted to a NICU.

4.2.3 SUB-THEME THREE: Information giving practices in the NICU

It can be overwhelming for caregivers to receive an overload of information on the status of their infant that is often filled with jargon or over or understatements (Coertze, 2019; Labrie et al., 2021). If information is provided in a sensitive and effective manner this can aid in parents feeling in control, reduce stress, and therefore acts as a facilitator in the well-being of caregivers (Labrie et al., 2021; Waddington et al., 2021). The relationship between caregiver and healthcare workers may cause stress, emotional distress, poor communication, and a lack of support if the relationship is not positive (Coertze, 2019).

The working relationship between caregivers and healthcare professionals was largely influenced by communication and access to information under caregivers. A concern noted by caregivers included the need for health information on the medical state of the infant. Some mothers also expressed the need for good health education during the pre-natal stage. *"I didn't even know high blood pressure was a silent killer, so I was basically educated about it on the spot. But being educated by professionals- that was really lacking. If they had given me more information about the NICU journey or the issues during my pregnancy it would've given so many options to think about. Like, should I keep the babies, is it right to keep them if they will suffer so much? Or to prepare me on how the journey will be in the NICU and the rollercoaster it is."* said Lily.

It was commonly mentioned by caregivers that there was both a lack of information regarding their infant's medical state and prognosis, but also in how it was communicated and the effectiveness thereof. The emotional stress and frustration this lack of communication caused under caregivers was made clear during the interviews. "*So yeah, they never communicated well what her state was or why she was admitted to the NICU. Really a lack of communication,"* said Bonny.

Further not receiving effective and clear communication often caused self-doubt amongst caregivers as the burden was often placed on them to find out information or step-up and confront a staff member to receive an update. When caregivers are communicated with effectively, they gain self-confidence in their role as caregivers and are often able to better make decisions and take part in the decision-making process. This integrates them into the team caring for their infant and gives them a purpose. Christelle mentioned *"So yeah, a lot of lacking information, no one giving clear answers made the whole thing worse."*.

Here Loretta discusses the issue of power dynamics in the NICU between health professionals who are medically caring for an infant and caregivers who also need to be in a position of making decisions with the medical team. *"I think that's quite a sad loss in the NICU you know and that's why I was there so much because I wanted to see what was going on and there were times when I disappointed myself because I didn't speak up when I didn't agree with something, and I knew something was wrong. But you second guess yourself because you are a watched parent. You feel like you don't know any better umm so yeah ... part of being you know in the team that makes the decision I think it empowers the role of mom or dad. Right because in my mind you are taking away the instinct that the baby relies on their survival is dependent on your instinct so if you remove that you've ... it's going to have a knock-on effect. And then turn that whole attachment process also is affected if you know the moms' confidence in making decisions and trusting her intuition is affected."* Loretta said.

The experience of receiving culturally appropriate communication from healthcare professionals was also mentioned. Further, it was evident that culture often influenced how communication was given by the staff and how it was received by caregivers. Pink expressed *"I also think it's a cultural thing. In some cultures, they don't necessarily have empathy for certain aspects that other cultures have. So, some things are seen as being cold, but to them, they might be doing their job. So, I think culture in the NICU is important because we value* *different things in different cultures, so having understood for that as well. Little can change that, but that mindset can make a difference.”.* Jack said *“Uhm, no not really. I do think that there was a difference in communication. I'm sorry to say, but the white staff communicated in a softer way, while the black staff would say it as it is. Which sometimes is better than sugarcoating things.”*

Caregivers did express their “saving grace” in communication, and that was building a good relationship with one staff member they could trust, and this singular staff member became their source of information. Ally explains *“Everybody else ... just needs to work on it, man. Eventually, you must as a parent make friends with the nurses so that you can try and extract information out of them just by talking to them as people. I get that they are also people that are stressed out. Eventually, they would tell me about things about baby so that I wouldn’t have to extract it from them so hard. That was tough.”.*

From the above three larger areas were identified during analysis in order to breakdown how communication is central in the NICU in improving attachment and bonding as well as caregiver well-being while using the FCC framework and the core pillars it stands on information sharing, family participation, and family collaboration (Oude Maatman et al., 2020).

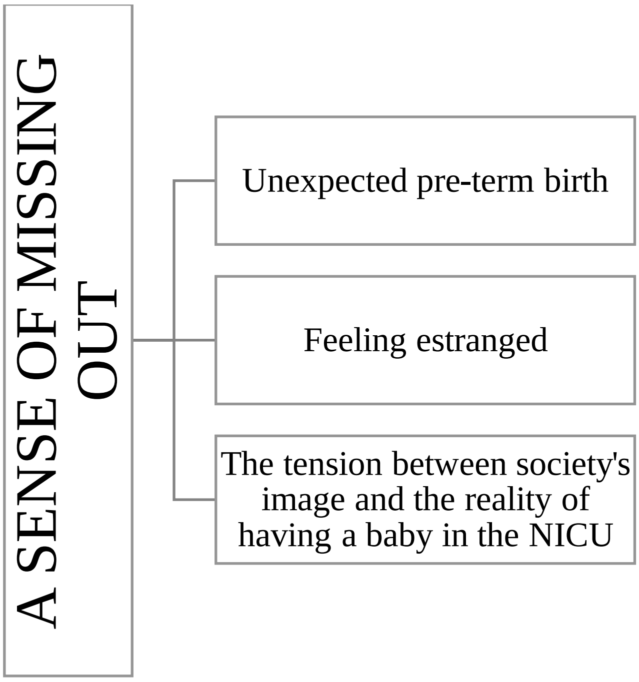
The parent-infant relationship, the process of attachment and bonding, was expressed to be influenced by the well-being of the caregiver, access to the infant, caring opportunities for the infant and KMC, and the medical condition of the infant. Caregivers expressed that their confidence in taking part in caring activities was influenced by the information they received. When parents were involved in the decision-making process and care of their infant they were able to attach more successfully. Their ability to be part of the decision-making process was influenced by the education they received. The above three areas were identified to directly influence the well-being of the caregiver are fluid and interacting with one another. All three pillars need to be considered when communicating with caregivers.

4.3 THEME THREE: A SENSE OF MISSING OUT

In most cases where an infant is born pre-term or with medical complications caregivers miss out from the get-go on important bonding-related activities (Citter & Ghanouni, 2021). This involves sometimes not even being able to hold their infant after birth. The NICU parenthood journey is characterized by missing out on important events or milestones from the beginning (Citter & Ghanouni, 2021). The role of mothering is often missed out the lack of psychological readiness struggling to claim the role as a caregiver as someone else may be caring for your infant, and the challenges in attaching and bonding with a medically complex infant in a stressful NICU environment (Citter & Ghanouni, 2021; Gorsky et al., 2023).

Figure 3.

Visual representation of theme 3 and subsequent sub-themes.



4.3.1 SUB-THEME ONE: Unexpected Preterm Birth

The unexpected or preterm birth of an infant can cause stress and feelings of disappointment (parental expectations), worry, frustration, anger, guilt, and despair (Byiringiro et al., 2021; Abeasi & Emelife, 2020). Especially considering the anticipation that caregivers have of a normal, healthy, full-term infant and anticipation and expectations around that journey, which are now taken away due to hospitalization of the neonate, caregivers enter a psychologically unprepared state which elevates negative feelings (Leahy-Warren et al., 2020).

A negative birth experience, in this case an unexpected or pre-term birth, may lead to Post-Partum Depression (PPD) which holds negative sequelae for attachment and bonding (Lasheras et al., 2022). Mothers expressed the trauma associated with an unexpected birth, especially the whirlwind experience of admission to the hospital and the birth happening quickly. *"So, I was initially admitted for a day or two, and they stopped the labor with medication. And then two days I had to deliver on that day. It really was traumatizing. I think it took a long time for me to realize the impact it would have on me. I think you are on adrenaline at that point."* Nicky said.

The physical trauma of having, for example, an emergency c-section was also reported by some mothers and the toll it took on their bodies. *"It happened basically overnight; I was rushed to the hospital and a Doctor checked me out and from then they airlifted me to a provincial hospital to get a c-section as my body went numb and I was in a lot of pain. Yeah, quite traumatic."* Rose expressed.

A few participating mothers who had low-risk pregnancies reported that if they then had a pre-term birth, which was unexpected as they had a normal pregnancy, they felt very unprepared for it. Pink mentioned *"And I think when the pregnancy is normal, you don't expect it. It was totally jumped onto us."*.

In this study, caregivers expressed that the emotional trauma of suddenly or unexpectedly giving birth and then having a subsequent NICU admission had stress-related impacts on them both in the short- and long-term. It is apparent that caregiver undergo large amount of stress related to health, which then prompts the question; How do we better facilitate their well-being?

4.3.2 SUB-THEME 2: Feeling estranged

As the normal pattern for acquiring that emotional closeness to an infant is disrupted by the NICU caregivers can be left feeling uncertain about their position in caring for the neonate which consequently affects attachment and bonding (Thompson et al., 2020). This causes an estrangement from their role as a parent, but also an estrangement to their infant (Provenzi et al., 2015).

Caregivers expressed three main areas that contributed to feeling estranged and that in turn need to be addressed going forward (1) physical separation from their infant, (2) contributing to infant health and the care of the infant, and (3) being acknowledged as a parent. These feelings of estrangement also often continued into the home environment once the infant had been discharged from the NICU, which emphasized the importance of addressing these feelings and attitudes in the NICU.

Caregivers expressed that they often questioned their role as a caregiver due to frequently missing out on milestones and caring activities creating an uncertainty in their attachment and bond with their infant. June said *"Even when we brought her home and even now it's still something I'm working through. I am the mom, but has she really attached to me? Even though I held her so many other professionals also held her and cared for her. It's just something that till today really stresses me out. So yeah, I think, I keep telling myself I shouldn't be so harsh, and I keep telling myself I am her mom and we have bonded. But yeah, (caregivers voice breaks) it's just hard.".*

Bonny describes the power dynamics that are present in the NICU between healthcare workers and caregivers, she specifically states that she felt healthcare professionals dismissed the knowledge that caregivers may have towards the care of their infant. *"Secondly, they make you feel as if that child is not your own, it is their property as a patient. You need to ask permission to interact with your child or touch your child. It's their child or their property and they dictate what you can and can't do. But they assume you don't know anything and assume you can't do anything for your child."* expressed Bonny.

Having information and actively being involved in the care and decision-making for your infant in the NICU were protective factors to feeling empowered as a parent. Pink mentioned *"It's about empowerment, when you walk into the NICU, they make you feel like you aren't the mom. And I started telling new moms "Remember you are the mom". It feels like you have no right to mother your own child, you are merely an observer. And that is not how it is, so you need to be empowered to enforce that. So having information helps that. You can't let nurses take that role from you.".*

4.3.3 SUB-THEME THREE: *The tension between society's perception of having a baby and the reality of having a baby in the NICU*

When parents are expecting a baby there is a lot of anticipation that goes into the pregnancy journey, the birth, and that special time after birth when caregivers are intimately close to their newborn (Leahy-Warren et al., 2020). This is often greatly influenced by society and the pictures that society paints of what this journey looks like (Leahy-Warren et al., 2020). When there is now a deviation, preterm birth, or NICU admission, it is almost a secondary loss caregivers experience as they won't have this idealized picture (Leahy-Warren et al., 2020).

Caregivers expressed that they were stripped of this romanticized idea of being pregnant and giving birth, especially when the birth was unexpectedly premature or traumatic "*It's always looked like other twin mamas carry their babies so well, so I was not prepared for the dangers around carrying twins. Why couldn't I have the normal journey and enjoy motherhood? But I enjoyed my blessing in hurt."* Lily expressed.

Nicky said, "*So look, you get a baby, and the ideal picture is you have this "golden hour" and photos with cute clothes, and you know how you are going to introduce your baby to the world. I couldn't do any of those things. Her first three days she lay in diapers connected to pipes and drips. Those aren't pictures that you share with the world. So that was definitely taken away from me."*

Pink did express that while she felt she missed out on the picture-perfect version of having a baby, the perspective change of having an infant that is healthy and alive is what got her through the experience. Her priorities changed, instead of having the perfect picture to post on Instagram she was celebrating small wins on the road to recovery with her infant. *"That Instagram-romanticized idea of having a baby was taken away. For you to realize that it's not about that, your child is alive and healthy, that's what really matters. That was a mind shift. I put in a lot of effort to be by my baby's side. I took an extended maternity leave to make up for lost time."*

While society paints an idealized picture of having an infant that is often difficult to give up once a NICU admission has taken place, it is also difficult to then see other parents have that ”normal” journey. *"It was just ... not what we expected. Especially, when you hear the stories* *of other moms who just pop a baby out and are on their way home. Very weird."* Christelle said.

Furthermore, there was a hesitancy expressed by caregivers once infants were discharged from the NICU. The expectation or idealized image of having friends and family visit to meet your infant was disrupted by the fear of possibly exposing your medically ill infant to the world. *"Because she was so prem, I didn't see people for months, it was just me and her for long. We couldn't even do a gender reveal for her. Also, no baby shower because she came early. So missed out on a lot. And quite isolating."* June said.

Another area that was apparent from data analysis was that of the role of the father. Especially how gender roles are split in the more modern era where fathers generally seem to be more present and active in the care of their babies. However, Jack (a father who participated in the study) explained that because the mother is typically seen as the primary caregiver his involvement was often limited in the NICU. This ranged from visitation rules, physical closeness to the infant, and willingness to share information with him.

Jack said *"The other is also for the fathers, I think across the board, modern-day fathers want to be more involved, but it gets overlooked. Fathers are seen as like the second-grade kind of parents. That's the attitude you get from a lot of the nurses, the doctors as well. Waiting for my wife before giving information. I want to be very involved with my son, and my son as well."*

Jack further mentioned that he felt especially unprepared for the NICU experience compared to his wife as fathers don't typically talk about these problems when socializing. He expressed the need for more open talk amongst fathers regarding possible trials and tribulations; *"Dads talk and socialize about very different aspects of parenthood. So having some kind of normalization or something for the NICU. Making it more known to everyone. The last thing anyone would ever throw at you is this. And most guys are oblivious to the reality of like birthing and prem babies and stuff. Dads don't talk about those things, so that needs to change as well."*

Lastly, how gender roles influence who the main caregiver is and on whom the burden falls was explored by Daisy; *"I ... so I think I don't know if it would be like a cultural thing you know as such but a lot of it was on my shoulders. My boyfriend found it very stressful, he found* *the machines and the beeping traumatizing. So, it was I felt a lot of pressure for me to be the one who was there every day.".*

In conclusion, the tension between society's image and the reality of having a baby in the NICU was evident when exploring the anticipated expectation of being pregnant, giving birth, and the early period post natally. The romanticized idea of having a baby was often stripped away by the NICU, however, some caregivers attached hope to celebrating the small wins in the recovery of their infant. This can be linked to the COPE framework in analysing how individuals cope with stress.

Caregivers also expressed a hesitancy post-NICU discharge to "socialize" their medically fragile infant in terms of friends and family coming to visit, which again, changes this idealized picture that society often creates. Finally, the role of the modern-day father was explored, how the NICU impacts this role, and how society impacts this role.

Chapter Five: Discussion

This study explored the experiences of caregivers concerning attachment and bonding practices in the NICU, specifically relating to how culture may or may not influence bonding practices. Current literature, while sparse on the topic, seems to demonstrate that culture and context influence attachment and bonding practices, and that these practices are often not prioritized during a NICU admission (Cabrera, 2022; Arafat et al., 2020). This study demonstrates that culture may influence the experience of caregivers in the NICU, due to its influence on how caregivers experience and cope with the NICU.

Bonding practices between a caregiver and an infant such as ceremonies related to attachment, visitation practices, and gift-giving practices, are influenced by culture and context. However, the finding from this study suggests that in the context of a NICU admission caregivers' focus shifts from bonding with their infant to focusing on the medical health of their infant. If certain bonding practices are missed out on due to the medical health of the infant caregivers reported that these practices were made up post NICU discharge, and while caregivers would like these practices to take place the health and medical stability of the infant takes the forefront.

5.1 The influence of context and culture in coping in the NICU:

This study found that some cultural practices, such as gift giving and visitation practices, could not take place immediately due to a NICU admission. The importance of the cultural practices falls away and the health of the infant takes precedence which in most cases is necessitated as NICU goals are to preserve life and ensure optimal outcomes for the infant. In other words, while certain visitation from family and friends could not take place due to strict NICU visitation rules, this was not an immediate or impactful stressor on the well-being of caregivers. The well-being of caregivers in the NICU was largely influenced by (1) the health of the infant, (2) and interactions with staff in the NICU.

Data did however suggest that culture and context influence the caregiver experience in the NICU in terms of (1) what and how staff communicate with caregivers, information-giving practices that are influenced by culture, (2) how culture influences how the staff cares for an infant and how willing they are to accommodate the wishes of the caregivers, and (3) society's image and how that contradicts the reality of having an infant in the NICU. However, it was pertinent that caregivers did not express that those practices related to bonding greatly influenced their experience in the NICU as their priorities shifted toward the health of their NICU. Caregivers often mentioned going into a "fight or flight mode" leaving little room to worry about cultural bonding practices that are not necessitated in that moment.

Individuals respond to and interpret stress differently (Treyvaud et al., 2019). Stressful events in the NICU, such as the medical state of the infant, lack of communication from healthcare professionals, and the physical NICU environment are responded to and interpreted differently amongst caregivers. Understanding what underpins caregivers' ability to cope with stress can aid NICUs in supporting the mental well-being of caregivers more efficiently. The COPE framework can aid NICUs and NICU staff in understanding what underpins this emotional response and how to support caregivers through NICU admission (Treyvaud et al., 2019).

When parents are expecting there is a lot of anticipation that goes into the pregnancy journey, the birth, and that special time after birth when caregivers are intimately close to their newborn (Leahy-Warren et al., 2020). This is influenced by society and the pictures that society paints of what this journey looks like (Leahy-Warren et al., 2020). When there is now a deviation, preterm birth, or NICU admission, it is almost a secondary loss caregivers experience as they will not have this idealized picture (Leahy-Warren et al., 2020).

The tension between society's image and the reality of having an infant in the NICU was evident when exploring the anticipated expectation of being pregnant, giving birth, and the early postpartum period. The romanticized idea of having an infant was often stripped away by the NICU, however, some caregivers attached hope to celebrate the small wins in the recovery of their infant. This can be linked to the COPE program in analysing how individuals cope with stress by understanding the mental representations that the individual has on the stressful event taking place (Parkes & Trace, 2023).

Caregivers often have an idealized idea of how it will be and what to expect when having an infant which the NICU admission robs them of (Parkes & Trace, 2023). Caregivers are often not fully prepared for what that realistically looks like leaving them shocked and unable to process and cope with the stress (Parkes & Trace, 2023). The COPE program provides ways in which we better equip caregivers for the NICU experience so that their mental representation thereof increases their ability to cope with the stress of the NICU?

Utilizing the COPE program in NICUs means that the mental representations that caregivers have of the NICU and their infant are addressed to ensure that caregivers know what to expect and therefore can cope with the stress thereof. If the mental representations that caregivers have of what the NICU journey will entail are realistic and accurate caregivers will be able to better cope with the stress of the NICU.

The orientation that caregivers receive from NICU staff on what the NICU is, how it works, and who the stakeholders are may be one of the most overlooked, but most important steps in the caregiver‘s NICU journey. Educating caregivers on the above and incorporating a COPE program into NICU leaves caregivers empowered thereby creating an environment where caregivers can take part in decision-making and care for their infant. Using a COPE program to allow for the involvement of the caregiver in the NICU their experience and ability to cope is increased thereby improving the mental well-being and outcomes for caregivers.

The experiences of caregivers who participated in this study often mentioned not having an in-depth orientation to what the NICU is, how it works, and who the stakeholders are leaving them overwhelmed and confused. The majority of the caregivers who participated mentioned that having a better and more detailed orientation to the NICU with an information booklet they could refer back to would have greatly improved their NICU journey.

The COPE program is one of the most beneficial, but most overlooked programs in the NICU (Shafaroodi et al., 2022). The fact that participants from this study shared that they required a proper orientation to the NICU further elucidates why incorporating a COPE program into NICUs is beneficial and aids in addressing the mental representations that underpin how we respond to and cope with stressful events. The findings from this study support the need for a COPE program in NICUs as it addresses the very needs highlighted by caregivers who participated in this study.

Cultural beliefs and practices are an integral part of who we are and influence childrearing patterns and how we use healthcare services (Nyaloko et al., 2023). Considering the influence of context and culture on attachment and bonding, healthcare workers must understand these tenets to be sensitive and competent in the care of patients due to cultural differences sensitivity is required in terms of their respective norms and practices (Dawson et al., 2021).

While it is unrealistic to expect healthcare workers to accommodate every need and want of every caregiver in the NICU, creating a platform where caregivers can voice their needs, wants and concerns could be beneficial. Caregivers who participated in the study mentioned that having a group meeting between caregivers in the NICU, the matron, and possibly a counsellor to raise any matters would have been hugely beneficial for their mental well-being.

As mentioned by a participant, Kate, *"I think a simple thing like if we had a psychology session there at the NICU, your mental health could've been in a better place. And you know, in the NICU so that it isn't another extra thing a mom has to go do. "*. Some participants mentioned that such groups existed, but they only found out about the existence of the group late into their NICU journey.

If the mental representations of caregivers can be addressed and realistically changed, as per the COPE program, such group meetings caregivers and their individual needs may feel heard and understood. While not all accommodations can be made, this can serve as a platform to voice concerns, make improvements, or discuss why an accommodation cannot be made. Linking individualized cultural beliefs and practices to the COPE program can aid in understanding how culture and context influence how we respond to and cope with stress.

The care culture inside a NICU, and work ethics amongst healthcare professionals in how they care for infants, play a large role in framing all infant caring activities (Holdren et al., 2019). The care culture experienced by caregivers in the NICU varied from unit to unit. The following key areas were mentioned that negatively impacted the experience of caregivers (1) lack of continuity of care from nurse to nurse, (2) the willingness of staff to make accommodations, and (3) positive interactions with nursing staff. This reduced their ability to attach and bond with their infants and had a negative impact on the well-being of caregivers.

Culture shapes attitudes, belief systems, experiences, and thereby caregiving practices (Voges et al., 2019). From the current literature, we know that NICU staff often serve as role models to caregivers through supportive interactions such as aiding in the understanding of the NICU environment and taking charge in the daily care of the infant (Citter & Ghanouni, 2021; Coertze, 2019) which is integral to supporting the psycho-social well-being of caregivers. If how staff care for an infant mismatch the contextual and cultural framework of the caregiver miscommunication or negative interactions may take place in the NICU.

Caregivers who participated in this study mentioned that they experienced culture to influence how staff communicates, how willing staff are to include caregiver in care-taking activities, how much skin-to-skin staff allows them to have with their infant, and how willing staff were to share true information that gave them realistic expectations on the health of their infant. Communication or the lack thereof is the most salient feature mentioned by caregivers in this study that was influenced by culture, but that also influenced the experience in the NICU most.

Considering information sharing as a core component of the FCC framework Family-centered care models can encourage effective communication between healthcare workers and caregivers (Jordan, 2018). Giving caregivers access to information and education about the state of their neonates empowers them to actively participate in the decision-making process, thereby following Family-centred guidelines (Labrie et al., 2021).

If information is provided sensitively and effectively this can aid in caregivers feeling in control and therefore acts as a facilitator in the well-being of caregivers (Coertze, 2019; Labrie et al., 2021; Waddington et al., 2021). Caregivers who understood their infants' condition, prognosis, and current care often experienced more positive feelings in the NICU (Byiringiro et al., 2021). The findings from this study found that the health of the infant and interactions with staff were the biggest influencers on the mental well-being of caregivers as opposed to access to caring opportunities. Many caregivers shared that when they understood what was medically happening with their infant, it gave them hope, but also allowed them to cope from a psychological point of view.

The findings from this study motivates for the inclusion of FCC in NICUs as communication, the sharing of information, is a core pillar of the FCC framework (Fonesca et al., 2020). By sensitively and effectively communicating with caregivers they can play an active role within the NICU, such as taking part in activities of daily living and being involved in the decision-making process thereby improving attachment and bonding and empowering caregivers (Fonesca et al., 2020).

When considering family participation and collaboration as core components of the FCC framework caregivers from this study corroborated that when they were included in the care and decision-making process it gave them confidence as caregivers. This empowered them in the role of a caregiver and gave them a sense of purpose which all contributed to the psychological well-being of the caregiver. If the core components of the FCC framework are implemented and caregivers are involved in the care and decision-making around their infant and mental well-being is improved, the need for psychological support services may be reduced.

By empowering caregivers in the above-mentioned ways family-centered care can alleviate feelings of anxiety and helplessness and allows for a feeling of safely controlling a very stressful situation thereby improving emotional well-being (Carter et al., 2021). Caregivers in this study mentioned that receiving information about the health and care of their infant did indeed allow them to actively partake as a team member in the NICU, thereby reducing negative emotions such as anxiety and depression.

The influence that culture and context had on caregivers in the NICU was multifaceted. Each individual has a unique perspective on the world which is influenced by their culture, their lived experiences, knowledge around parenting, and socio-demographics such as age and gender. These factors will influence the ideals that caregivers hold around parenthood and therefore will influence how they perceive the NICU and deal with the NICU environment. The perception of the NICU is further influenced by our context and culture as context and culture influence our beliefs about health and illness.

Belief systems are important when interpreting how individuals cope with stress (Treyvaud et al., 2019). It becomes evident that culture not only plays a role in how caregivers attach to their infants but more importantly how they cope with stress. The belief system and ideas of parenthood attached to them had a greater impact on the well-being of caregivers and how they coped with stress than the physical limitation of having an infant admitted to a NICU.

5.2 Identified needs of caregivers identified in this study:

The need for psychological support for caregivers is globally recognized as being a supportive factor in improving outcomes for caregivers in the NICU (Scala et al., 2020). This study further confirms the need for psychological support for caregivers in the NICU and references (1) the need for the development of educational material for caregivers (2) the layout and design of the NICU and (3) receiving psychological support from a professional. It is then required to find a feasible way in which to implement the above in the NICU environment.

Psychological and emotional support for caregivers in the NICU includes measures put in place to improve the mental well-being of caregivers by improving their ability to cope (Citter & Ghanouni, 2021) When addressing the need for psychological or emotional support for caregivers in the NICU the need for the development of educational material for caregivers was commented on by a large portion of the caregivers. If caregivers received an orientation to the NICU it was often done quickly and with little supporting material. Data showed that caregivers are so overwhelmed that they remember little of this orientation and would have benefited from some form of a written orientation as well.

The FCC framework may be applied to this study to aid in (1) exploring the importance of psychological support services in the NICU, (2) and it may give insight into how this can be applied in future research. The FCC framework talks about involving the family in the care and decision-making process of the infant thereby improving the relationship between the caregiver and the infant and improving the caregiver and infant’s well-being (Fonesca et al., 2020; Oude Maatman et al., 2020).

The core components of the FCC framework are respect and dignity, information sharing, family participation, and family collaboration (Oude Maatman et al., 2020) which guides how the FCC framework can be implemented. The literature cites that the FCC framework allows for the incorporation in the care of the neonate such as feeding and holding which allows for time to bond with the infant thereby also improving attachment (Buissinne et al., 2018). Findings from this study support the importance of being involved in the care of the infant but go further to add the need for supportive training, education, and communication from healthcare workers.

Some caregivers mentioned not receiving an orientation at all leaving them unsure of how the NICU operates and what they may or may not do. The NICU is an unknown and complex environment with high physical and emotional demands on caregivers (Liu et al., 2022). This can seem very foreign and frightening to caregivers, as explained by caregivers who participated in this study. Findings from this study encourage NICUs to place more emphasis on the orientation of caregivers to the NICU to provide psychological and emotional support.

This study highlighted the need amongst caregivers for easily accessible psychological support services. Further examining psychological support amongst caregivers in the NICU, there was an overwhelming number of caregivers that expressed there were no psychological support services offered which is concerning. Secondly, those who mentioned that there were psychological support services said these were not easily accessible to them. Two reasons were given for the inaccessibility (1) counselors were not readily available for consults and (2) caregivers were required to travel to a counselor.

The majority of the participants from this study accessed the private healthcare sector, the private sector is known for how expensive it is to cover medical aid bills and pay for all auxiliary treatments such as medication, or rehabilitation services such as counseling services (Young, 2016). The private sector has further been critiqued in literature for the dispersity of healthcare professionals, which stands in line with the reports from this study as many caregivers reported not having access to a psychologist or the limited time that the psychologist was available for consultations. More insight is required in terms of experiences of caregivers in the NICUs relating to access to service delivery in both the public and private sector.

The FCC framework then may aid the NICU in developing protocols and procedures related to the orientation of caregivers to the NICU, providing sensitive and effective communication and improving access to psychological support services. Currently, the FCC framework is critiqued in the literature on the application thereof in NICUs due to the diversity of the acute care setting (Abukari & Schmollgruber, 2023). There is especially limited research in African contexts on the application of the FCC framework and given the diversity in these populations the application of a standardized framework may pose difficulties.

5.3 Loneliness among caregivers:

Current literature supports the role of involving caregivers in the decision-making process, however, caregivers often experience conflicts between what medical staff recommend and what they want or feel is necessary (Citter & Ghanouni, 2021). The data from this study supports this. Caregivers expressed that they oftentimes felt torn between listening to what healthcare professionals advised, but also being realized as a parent and stepping into that role with some autonomy, whether that involved caring for their infant or making decisions regarding their care.

Caregivers reported this mismatch between the medical care and their gut instinct on what their infant needs due to (1) power dynamic between the healthcare professional and the caregiver and (2) the fact that their wishes or needs are overlooked by healthcare professionals. This contributed the feelings of loneliness and disempowerment among caregivers and their voices are not heard, their needs and wishes are not respected and their role as primary caregivers is not realized. The findings from this study stand in line with reports in current literature regarding conflicts between what medical staff recommend and what they want or feel is necessary (Citter & Ghanouni, 2021).

While caregivers who participated in this study acknowledged that they have very limited medical expertise, they felt as though their parental instinct was overlooked or dismissed due to that fact. This made being realized as a caregiver and the autonomy that comes with it a difficult process as typically a caregiver would be making decisions regarding the care of their infant, however, in a NICU context this is not true. Involving caregivers in decision-making, even if just by educating them, aids in forming autonomy and being realized as the caregiver.

The social isolation that caregivers experience is often characterized by visitation restrictions in the NICU, medically protecting their infants from possible infection by meeting new people which leads to caregivers being socially isolated (Givrad et al., 2021). Caregivers often feel disillusioned from the experience of being a caregiver due to (1) social isolation that is characterized by separation from their infant and separation from the world and (2) reduced support from family and friends due to strict NICU visitation laws.

The above was substantiated by caregivers interviewed for this study especially when looking at familial support that was limited by visitation rules in NICUs, while most caregivers understood the need for precaution to keep their infants safe, they also had a need to bond with their infant. It was often expressed that being separated from their own family, especially their parents negatively impacted their mental health and ability to cope in the NICU. The above findings stand in line with current literature.

Receiving support from family, friends, healthcare workers, and other caregivers can facilitate well-being and interactions with the neonate (Coertze, 2019). This study corroborated the importance of support from friends and family for the well-being of the caregiver. Caregivers largely reported that when feeling isolated from their friends and family their well-being was negatively impacted. However, the difficulty came in that the NICU, given the strict visitation rules, does not create much opportunity for direct support from friends and family.

Caregivers mainly reported that the loneliness between themselves and family and friends was centered around understanding the NICU environment and the toll it takes. Caregivers did not feel supported by family and friends as they did not understand the NICU, so while strict visitation rules are necessary for the prevention of infection for infants if family and friends can gain a better understanding of the emotional toll of the NICU, caregivers will be better supported. This can involve having an orientation session for family and friends where they are not directly inside the NICU but can observe and learn about the NICU.

There is a paucity of research detailing how to practically implement an FCC framework into NICUs due to the diversity of NICU setups. In a resource-constraint country such as South Africa, there are further difficulties that are faced such as understaffing, decreased budget, and high patient loads. For example, the possible use of technology, i.e. video calls could aid in providing a support system for caregivers, but that is not a possibility for all caregivers or in all NICUs. Accommodations also need to be feasible for NICUs, so while caregivers are mentioning a need for the family to visit their infant in the NICU with them, from an infection-control point of view this might not be feasible. This study did not explore how to feasibly introduce and FCC framework to assist with these accommodations and therefore calls upon future research to do so.

The COPE program improves caregiver beliefs about what to expect in their infant and the NICU journey thereby empowering them to care for their infant (Chertok et al., 2014; Treyvaud et al., 2019). Utilizing a COPE program to assist caregivers in coming to terms with their new reality of having an infant admitted to the NICU can facilitate hope and resilience in caregivers thereby improving their well-being.

5.4 Disempowerment:

Mothers often perceive the lack of involvement in the NICU as dehumanizing considering that a healthcare worker is caring for their child while they are side-lined (Palmquist et al., 2020). This study validated that caregivers feel devalued and dehumanized by the NICU experience and the healthcare workers who work in it. Caregivers described that this lack of involvement made them feel like a third-party observer of the life and health of their infant, making them question in the validity of their role as a caregiver.

Feelings of uncertainty can be created as nurses are the primary caregivers of infants in the NICU, leaving caregivers unsure about their position in caring for the neonate which consequently affects attachment and bonding (Citter & Ghanouni, 2021; Gorsky et al., 2023). This can cause a power struggle between staff and caregivers which in turn negatively affects the well-being of caregivers (Givrad et al., 2021).

Developing a parental identity amongst caregivers in the NICU is important as it facilitates psychological resilience and reduces stress and is usually done by establishing some form of control over the care of your infant (Parkes & Trace, 2023). Disempowerment as a main finding alludes to the power dynamic that exists between healthcare professionals in the NICU and caregivers. Mothers especially noted that they would have to fight to hold their infant, after having physical closeness both the mother and infant od seemingly better.

As the normal pattern for acquiring that emotional closeness to an infant is disrupted by the NICU caregivers can be left feeling uncertain about their position in caring for the neonate which consequently affects attachment and bonding causing an estrangement (Provenzi et al., 2015; Thompson et al., 2020). Caregivers who participated in this study expressed three main areas that contributed to feeling estranged and that in turn need to be addressed going forward (1) physical separation from their infant, (2) contributing to infant health and the care of the infant, and (3) being acknowledged as a caregiver.

Knowing what to expect when dealing with a stressful event enables an individual to cope with the stressor through increased understanding, predictability, and confidence by creating cognitive schemas for the event (Melnyk et al., 2008). When this is then extrapolated to caregivers of hospitalized children and premature infants who undergo extreme stress, anxiety, and possibly depression the need for a framework to support their ability to cope with stress becomes necessary (Treyvaud et al., 2019) such as the COPE program. The COPE program consists of two types of educational information; firstly information around the child's behaviour that teaches caregivers about typical emotions and behavioural responses that the child may display and secondly education around the parental role on how to interact with their child and support their development thereby addressing how to parent their child in the NICU (Melnyk et al., 2008).

When incorporating feedback from caregivers who participated in the study and the COPE program this study recommends that caregivers be supported through a thorough orientation session for caregivers by a healthcare professional in the NICU such as a nurse, psychologist, or social worker. Here a physical informative handout needs to be given. The ins and outs of the NICU, how it functions, and who works in it are explained as well as realistic expectational counselling on what to expect as a caregiver in the NICU.

The role of the father in the NICU is oftentimes an overlooked subject as mothers are seen as the primary caregivers (Beck & Vo, 2020). A participant mentioned that his role as a father was limited due to (1) the fact that healthcare workers would not disclaim updates on his infants without his wife being present (2) that he was not included in many caregiving activities such as KMC, and (3) that he was given less access to the NICU in terms of how long he was allowed to visit in the NICU than his wife. He also mentioned that fathers do not get much paternity leave and can therefore be less involved. This caused a further disillusionment from his role as a parent as he was not seen as the primary caregiver.

It becomes important for future research to explore how the continuity of care within the NICU and the willingness of staff to accommodate caregivers can be applied. Here, given the fact that each NICU is organized differently and the resource and staff constraints experienced in South Africa are challenges that will be faced. However, the need to find a solution, possibly using FCC, is required to improve the attachment and bonding process and improve outcomes for both caregivers and infants.

Chapter Six: Conclusion

Attachment and bonding are the foundations for early infant development to form a secure bond from which to explore the world safely allowing for psychological skills, social skills, cognitive skills, physical skills, and language-based skills to develop (Ettenberger et al., 2021; Keller, 2013). It is widely accepted that context and culture influence attachment and bonding between caregivers and infants in terms of bonding and attachment practices, maternal responsiveness, maternal sensitivity, and child-rearing practices to ensure a secure attachment is formed (Carter et al., 2015; Gaskins, 2013).

While international literature on how the NICU affects caregiver well-being and bonding with an infant, there is a paucity of research on the South African experience of caregivers (Buissinne, 2018; Buys, 2020; Dawson et al., 2021; Minde et al., 2006). Little is known about how South African caregivers might experience the NICU environment in relation to how it influences attachment and bonding practices. There is a further dearth of literature informing current practices and policies in NICUs relating to how healthcare workers can facilitate the unique bonding process in the complex NICU context while being culturally sensitive. Considering the rich cultural diversity that South Africa holds it becomes highlighted that rich and diverse data did emerge from this country, given cultural, linguistic, and financial diversity and access to services.

This study found that culture and context correlate with caregiver experience in the NICU in terms of (1) information-giving practices and how culture influences them (2) how culture influences how the staff cares for an infant and how willing they are to accommodate the wishes of the caregivers, and (3) society's image vs the caregiver experience of being in the NICU with a sick baby. However, it was pertinent that caregivers did not express that those practices related to bonding greatly influenced their experience in the NICU as their priorities shifted toward the health of their NICU.

This study demonstrated that culture influenced the care style of staff in the NICU in terms of how much information staff were willing to share, how sensitively staff conveyed the message or how direct staff were, and how much skin-to-skin staff would allow between the caregiver and the infant. Caregivers who participated in the study explained that certain staff with a specific cultural background would be more likely to care for their infant in a certain way. For example, white staff would allow less skin-to-skin time and prioritize the infant being connected to all machines and drips while black staff would prioritize skin-to-skin.

While this study had a homogenous sample of participants in terms of socio-demographics, their experiences within the NICU were rich and diverse. Participants' experiences showcased that the most influencing factors within the NICU were the medical health status of the infant and interactions with staff in the NICU. Both of these guiding factors were influenced by culture and context. Participants' cultural and contextual belief systems influenced how they coped and reacted to the NICU and the health status of their infant. Culture and context further influenced how participants perceived and interpreted their interactions with staff in the NICU, and which communicative intents were most important to them. Some caregivers preferred a very direct and honest communication method, while others wanted a softer communication method.

In the NICU environment with vulnerable caregivers and infants, the act of attachment and bonding is essential. This heightened need for caregivers to be able to connect with their infant in a culturally, socially, and contextually appropriate manner becomes essential to the well-being of both the caregiver and the infant (Buissinne et al., 2018; Gibson, 2017). It is therefore imperative to ensure that the NICU environment and NICU staff allow for attachment and bonding practices related to context and culture to occur within the NICU.

The NICU and culture influenced one another in multifaceted ways, the one influencing the other. Each individual has a unique perspective on the world which is influenced by their culture and will influence their ideals around parenthood and therefore will influence how they perceive the NICU and deal with the NICU environment. There is a fluid relationship between culture and experiences we have, namely, having an infant admitted to the NICU.

To support the bonding experience between caregivers and infants a better understanding of how bonding takes place in different contexts and thereby drawing a link between the influence of context and culture on attachment and bonding (Dawson et al., 2021). This study highlighted how each individual has a unique way of coping with stress and interpreting situations that are guided by culture and context. If healthcare workers are aware of the individual needs and preferences of caregivers in the NICU, they may be able to better accommodate caregivers.

In order to summarize key findings from this study in a way that makes applying the findings more concrete the following is important; we need a more individualistic approach to the NICU that takes the context and culture of the caregiver into account. Therefore, care that is contextually and culturally relevant. And include more caregiver-centered care in the NICU compared to just the infant being the main focus as the caregiver is an integral part of the infant and their care.

Challenges presented by the NICU environment to the well-being of caregivers and therefore the process of attachment and bonding include negative attitudes, feelings of stress, emotional distress, poor communication, and a lack of support (Coertze, 2019). Information or the lack thereof is often a barrier experienced in the NICU and ties in with communication, Waddington et al., (2021) and is rarely provided in the home language of caregivers therefore a lot of the information may go lost in translation or be misunderstood (Buissinne et al., 2018).

The need for the following services was identified (1) the need for the development of educational material for caregivers and (2) receiving psychological support from a professional. It is then required to find a feasible way in which to implement the above in the NICU environment. Caregivers experience a variety of emotions that are fast-paced and quick changing creating a rollercoaster effect which, in most cases, is worsened by the little knowledge they have of the NICU and the unexpectedness of it.

Using an FCC framework to assist in addressing the needs highlighted by caregivers who participated in this study the following core components need to be addressed; respect and dignity, information sharing, family participation, and family collaboration (Oude Maatman et al., 2020). This can practically be done by developing support services for caregivers supportive training, education and access to information, and communication from healthcare workers.

The hospitalization of an infant in the NICU can cause potentially traumatic emotional and social sequelae for parents and caregivers causing feelings of stress and trauma (Schecter et al., 2020). The need for psychological support was globally reported by caregivers. Firstly, there was an overwhelming number of caregivers that expressed there were no psychological support services offered which is concerning. Secondly, those who mentioned that there were psychological support services said these were not easily accessible to them. Two reasons were given for the inaccessibility, (1) counselors were not readily available for consults and (2) caregivers were required to travel to a counselor.

There is a need for psychological support services to be included, as a package, in the NICU care for caregivers given the high demand for psychological support as demonstrated by the findings of this study. Given the South African context that is generally resource and staff-constrained the psychological support services would need to be delivered and a cost- and time-efficient manner. Here, group sessions could be beneficial, but further research is necessary to determine the efficacy of such groups being run for NICU caregivers as well as facing the issue of which NICU staff would be able to run the groups.

It should also be noted that majority of the sample included participants who accessed private healthcare services and still experienced significant difficulty in developing a bond with their infant and forming an attachment, despite being in a well-resourced setting and having relatively easy access to services such as transport etc. this is concerning considering that such a large portion of South Africans access public healthcare which are under-resourced, under-staff and face access challenges to service delivery.

Ways in which caregivers can be properly orientated is first to have dedicated staff members, such as a social worker or psychologist, who has some counselling capabilities to run the orientation. The orientation needs to include general functioning of the NICU such as visiting times and when staff will be available for communication with parents, what is allowed and what is not allowed, an orientation to machinery in the NICU, and an orientation to all the staff members. This initial orientation needs to be accompanied by written material to consolidate the information as it is often overwhelming for caregivers.

As the normal pattern for acquiring emotional closeness to an infant is disrupted by the NICU caregivers can left feeling uncertain about their position in caring for the neonate which consequently affects attachment and bonding causing an estrangement (Provenzi et al., 2015; Thompson et al., 2020). Caregivers expressed three main areas that contributed to feeling estranged and that in turn need to be addressed going forward (1) physical separation from their infant, (2) contributing to infant health and the care of the infant, and (3) being acknowledged as a caregiver.

Knowing what to expect when dealing with a stressful event enables an individual to cope with the stressor through increased understanding, predictability, and confidence by creating cognitive schemas for the event (Melnyk et al., 2008). When this is then extrapolated to caregivers of hospitalized infants and premature infants who undergo extreme stress, anxiety, and possibly depression the need for a framework to support their ability to cope with stress becomes necessary (Treyvaud et al., 2019) such as the COPE framework.

Estrangement from the role of parent was noted due to (1) physical separation from their infant, (2) contributing to infant health and the care of the infant, and (3) being acknowledged as a caregiver need to be addressed in terms of how to better facilitate them in NICUs. If we consider this feeling of estrangement with the parental role which is directly related to the parental identity of caregivers a COPE framework could yield an in-depth understanding on how these mental representations are underpinned in the NICU and how to change them.

The disempowerment is caused by (1) reduced caregiving opportunities for caring for their infant as it is predominantly done by nursing staff (2) when caregivers do have an opportunity to care for their infant is done under the supervision of nursing staff. This causes elevated stress as caregivers learn how to parent in this very stressful NICU environment, but also feel judged while doing so.

This study utilized the FCC framework and the COPE program to assist in the interpretation of results. The FCC framework aided in extrapolating accommodations that should be made to the NICU environment to better support caregivers through it. The core pillars of the FCC framework aided this study to identify that a proper orientation program and psychological support program is necessary in the NICU to allow for contextually and culturally relevant care for caregivers and their infants. It further aided in elucidating the role of involving the caregiver in decision-making and the care of the infant to improve the caregiver-infant relationship and therefore improve the mental well-being of caregivers.

The COPE program illuminated that healthcare professionals need to address the mental representations of caregivers around health and illness, the NICU and their infant to ensure that caregivers are then able to cope with the NICU. This involves realistic expectational counselling and orientation on the NICU and what to expect from the journey. This major recommendation from this study makes sense in the context of the COPE program and this program aided in developing this recommendation.

6.1 Limitations

The findings of this study must be interpreted considering some limitations which may be seen as weaknesses; however, the discussion of these limitations will hopefully guide future research on this topic.

This study faced methodological limitations with the sampling procedures that were selected. The use of non-probability purposive sampling on Facebook forums for caregivers resulted in a very small sample size being collected. Likely, the fact that recruitment took place on online forums, rather than a data collection site may have resulted in this shortfall. It is recommended that future research in this area targets a health facility in order to recruit participants. The majority of the participants from this study accessed the private healthcare sector, while the majority of South Africans accessed the public healthcare sector. Future research should focus on participants accessing the public sector.

The sample size was small with only fourteen participants recruited which has limitations for how representative the sample is of the population being targeted. This was seen by the homogeneity of the sample collected by this study in terms of ethnicity and socio-demographic status. This study may have been able to collect a larger sample size, but due to time constraints, the data collection period could not be further extended. The findings of this study were further limited by the limited access to participants from diverse cultural and contextual backgrounds. It is also notable to mention the possible effects of bias in collecting and interpreting the data of this study given the abstract nature thereof. However, the researcher kept a reflexive journal recording where she thought she might have been biased in both the data collection phase and data analysis phase and was very critical of her own standpoint, motivations, and biases.

6.2 Implications and Recommendations

6.2.1 Policy:

Policy recommendations include accommodations that can be made in NICUs to provide psycho-social support to caregivers. Caregivers highlighted social isolation from family and friends, not due to not seeing those family and friends, but as family and friends rarely understood what caregivers went through with a NICU admission. While strict NICU visitation rules are necessary to ensure proper infection prevention control, policy accommodations could include close family members such as the parents of the caregiver being allowed in the NICU.

Or to allow friends and family to observe the NICU environment and orientate them on it so that they can be a more relevant support system to caregivers.

6.2.2 Practice:

Caregivers identified a need for psychological and emotional support services in the NICU. Many of the caregivers who participated in the study mentioned that either there were no psychological support services available or that the psychological support services were not easily accessible. This included having to travel to a psychologist or difficulty with consulting times being inaccessible.

It is therefore a recommendation of this study that psychological support services be more readily available for caregivers with an infant admitted to the NICU, specifically with the presence of a psychologist in the NICU as part of the MDT NICU team. Here either the utilization of group therapy sessions or teletherapy should be utilized where appropriate as not all caregivers in South Africa may have access to the teletherapy.

Caregivers further identified the need for educational material regarding an orientation to the NICU environment, the policies, procedures, and protocols. Caregivers stated that they mostly received a brief introduction to the NICU by a nursing staff member once their infant had been admitted. Caregivers reported this orientation to be brief and overwhelming in terms of the amount of information that needed to be retained during a period of such acute emotional distress. Caregivers expressed the need for some form of physical information pamphlet they could refer to on what the NICU is, how it works, who the team members are, how to get in touch with the team members what they as caregivers are allowed to and not allowed to do.

6.2.3 Research:

Recommendations for future research will relate to methodological and analytical shortcomings in terms of the study design and analysis of data. The sampling methods used in this study namely, non-probability and purposive sampling were not effective in producing a robust sample size that is heterogeneous. Alternative data collection sites should be considered as online recruitment via Facebook forums was not a viable method of data collection.

Research in the future also needs to consider the father's role and perspective on being a parent in the NICU. A participant from this study highlighted the fact that the role of the father is often times overlooked as the mother is seen as the primary caregiver. This leaves fathers feeling even more disillusioned from their role as caregiver as they are often not communicated with and left out of caring activities such as KMC.

Future research implications include that future studies should focus on ensuring a large enough sample size to draw generalized conclusions from and therefore changing sampling and data collection methods. Future research regarding how to implement a framework in the NICU such as FCC and or the COPE framework and how to best implement it given South Africa's resource-constrained environment would be salient in understanding how to better support the well-being of caregivers to promote attachment and bonding and therefore further improve outcomes for infants admitted to the NICU. While this study set out to explore how culture and context influences the experience of caregivers, a major finding was rather on how the culture of the health care professionals influenced the bonding and attachment of caregivers with their infant in the NICU. Future research in this area could yield novel and interesting findings.

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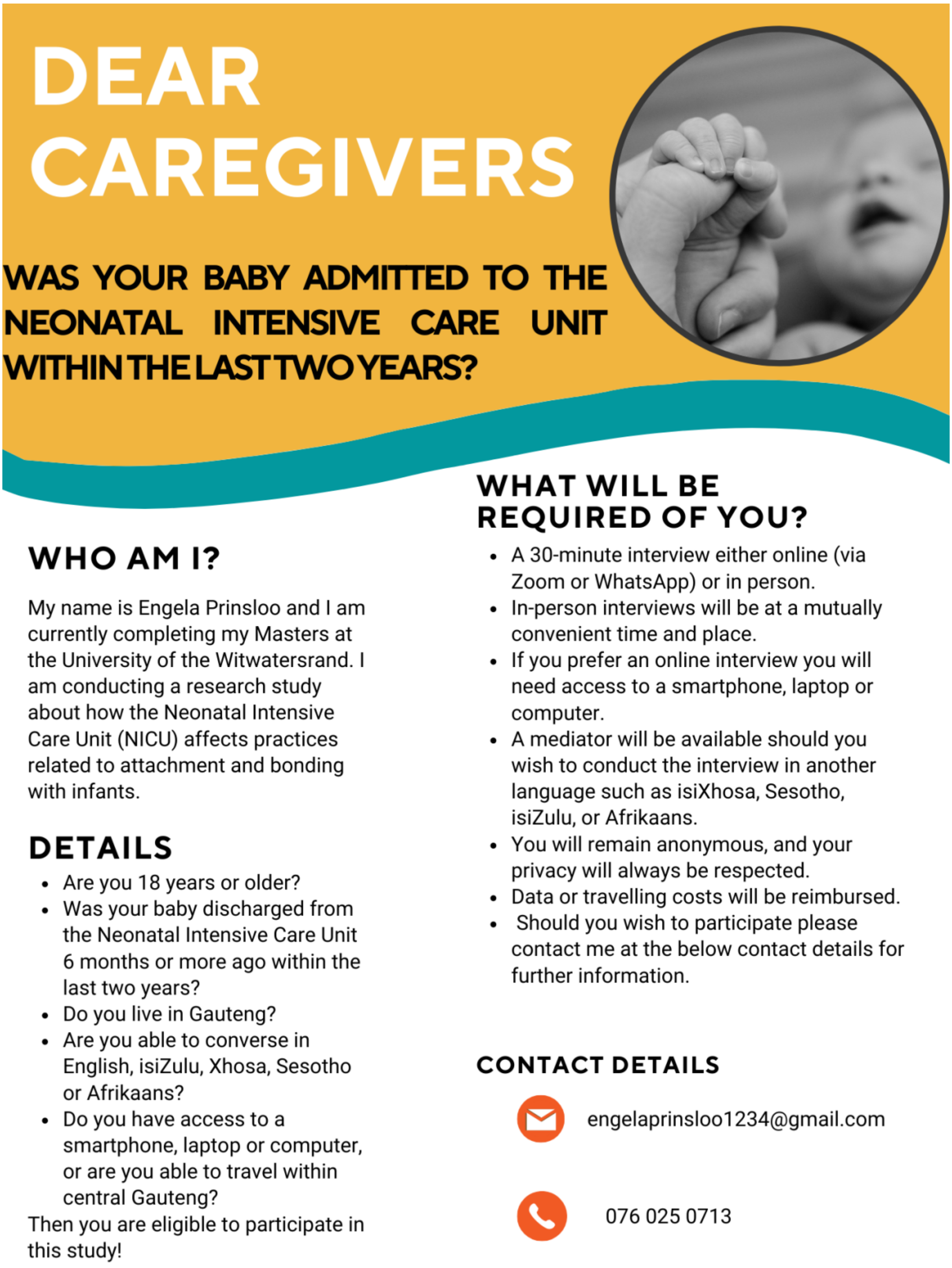
Appendix A: Advertisement that will be used for inclusion of the study



DEAR CAREGIVERS

WAS YOUR BABY ADMITTED TO THE NEONATAL INTENSIVE CARE UNIT WITHIN THE LAST TWO YEARS?

WHO AM I?

My name is Engela Prinsloo and I am currently completing my Masters at the University of the Witwatersrand. I am conducting a research study about how the Neonatal Intensive Care Unit (NICU) affects practices related to attachment and bonding with infants.

DETAILS

- Are you 18 years or older?
- Was your baby discharged from the Neonatal Intensive Care Unit 6 months or more ago within the last two years?
- Do you live in Gauteng?
- Are you able to converse in English, isiZulu, Xhosa, Sesotho or Afrikaans?
- Do you have access to a smartphone, laptop or computer, or are you able to travel within central Gauteng?

Then you are eligible to participate in this study!

WHAT WILL BE REQUIRED OF YOU?

- A 30-minute interview either online (via Zoom or WhatsApp) or in person.
- In-person interviews will be at a mutually convenient time and place.
- If you prefer an online interview you will need access to a smartphone, laptop or computer.
- A mediator will be available should you wish to conduct the interview in another language such as isiXhosa, Sesotho, isiZulu, or Afrikaans.
- You will remain anonymous, and your privacy will always be respected.
- Data or travelling costs will be reimbursed.
- Should you wish to participate please contact me at the below contact details for further information.

CONTACT DETAILS

✉ engelaprinsloo1234@gmail.com

☎ 076 025 0713

Appendix B: Permission Letter for "NICU mom's and Family support group"

University of the Witwatersrand,
School of Human and Community Development
Speech Pathology and Audiology

20/03/2023

Dear Administrator,

Re: Permission to access participants through "NICU mom's and family Support group" Facebook group

My name is Engela Prinsloo.

I am studying for a Masters in Speech Pathology in the School of Human and Community Development at the University of the Witwatersrand. The study title is Caregiver experiences of attachment and bonding practices in the Neonatal Intensive Care Unit (NICU) in Gauteng, South Africa. My supervisors are Prof. Joanne Neille and Mrs. Cynthia Sawasawa. I am seeking permission to do research through Facebook forums.

I am conducting a research study about how the Neonatal Intensive Care Unit (NICU) affects practices related to attachment and bonding with infants. The study title is Caregiver experiences of attachment and bonding practices in the Neonatal Intensive Care Unit (NICU) in Gauteng, South Africa.

The research will entail inviting individuals who form part of "NICU mom's and family Support group" Facebook group for caregivers to participate in this study. This specifically includes caregivers who have had a neonate admitted to a NICU. If they agree, they will be asked to participate in a 30-minute-long interview that may be remote (online) or at a mutually convenient location should they be more comfortable with that in Gauteng. With the participants' permission, the interview will be audio recorded.

Participants will be asked to give their written or verbal consent before the research begins. Their responses will be treated confidentially, and identities (their names and the name of the forum) will be anonymous unless otherwise expressly indicated. Individual privacy will be maintained in all published and written data resulting from the study.

The results will be communicated through a research report, potentially a publication or a potential conference presentation. The report will be available on the university library website and a summary thereof will be available to participants should they so wish.

The research participants will not be advantaged or disadvantaged in any way. They will be reassured that they can withdraw their permission at any time during this project without any penalty. During the interview some personal questions may be asked that could be sensitive, therefore, free counselling services will be available disposal at Emthonjeni Center on the East campus of the University of the Witwatersrand in Johannesburg. The participants will not be paid for this study.

I, therefore, request permission in writing to conduct my research through "NICU mom's and family Support group" Facebook group.

Please let me know if you require any further information. I look forward to your response as soon as is convenient.

Yours sincerely,

Engela Prinsloo

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Appendix C: Permission Letter for “Dear NICU mama”

UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

University of the Witwatersrand,
School of Human and Community Development
Speech Pathology and Audiology

20/03/2023

Dear Administrator,

Re: Permission to access participants through “Dear NICU mama” Facebook group

My name is Engela Prinsloo.

I am studying for a Masters in Speech Pathology in the School of Human and Community Development at the University of the Witwatersrand. The study title is Caregiver experiences of attachment and bonding practices in the Neonatal Intensive Care Unit (NICU) in Gauteng, South Africa. My supervisors are Prof. Joanne Neille and Mrs. Cynthia Sawasawa. I am seeking permission to do research through Facebook forums.

I am conducting a research study about how the Neonatal Intensive Care Unit (NICU) affects practices related to attachment and bonding with infants. The study title is Caregiver experiences of attachment and bonding practices in the Neonatal Intensive Care Unit (NICU) in Gauteng, South Africa.

The research will entail inviting individuals who form part of “NICU mom’s and family Support group” Facebook group for caregivers to participate in this study. This specifically includes caregivers who have had a neonate admitted to a NICU. If they agree, they will be asked to participate in a 30-minute-long interview that may be remote (online) or at a mutually convenient location should they be more comfortable with that in Gauteng. With the participants’ permission, the interview will be audio recorded.

Participants will be asked to give their written or verbal consent before the research begins. Their responses will be treated confidentially, and identities (their names and the name of the forum) will be anonymous unless otherwise expressly indicated. Individual privacy will be maintained in all published and written data resulting from the study.

The results will be communicated through a research report, potentially a publication or a potential conference presentation. The report will be available on the university library website and a summary thereof will be available to participants should they so wish.

The research participants will not be advantaged or disadvantaged in any way. They will be reassured that they can withdraw their permission at any time during this project without any penalty. During the interview some personal questions may be asked that could be sensitive, therefore, free counselling services will be available disposal at Emthonjeni Center on the East campus of the University of the Witwatersrand in Johannesburg. The participants will not be paid for this study.

I, therefore, request permission in writing to conduct my research through “Dear NICU mama” Facebook group.

Please let me know if you require any further information. I look forward to your response as soon as is convenient.

Yours sincerely,

Engela Prinsloo

Researcher:
Engela Prinsloo,
1612871@students.wits.ac.za
0760250713

Supervisor:
Prof. Joanne Neille,
Joanne.neille@wits.ac.za
+ 27 (11) 717 4574

Mrs. Cynthia Sawasawa,
Cynthia.Sawasawa@wits.ac.za

Appendix D: Permission Letter for “South African mothers and fathers with disabled children”

UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

University of the Witwatersrand,
School of Human and Community Development
Speech Pathology and Audiology

20/03/2023

Dear Administrator,

Re: Permission to access participants through “South African mother and fathers with disabled children” Facebook group

My name is Engela Prinsloo.

I am studying for a Masters in Speech Pathology in the School of Human and Community Development at the University of the Witwatersrand. The study title is Caregiver experiences of attachment and bonding practices in the Neonatal Intensive Care Unit (NICU) in Gauteng, South Africa. My supervisors are Prof. Joanne Neille and Mrs. Cynthia Sawasawa. I am seeking permission to do research through Facebook forums.

I am conducting a research study about how the Neonatal Intensive Care Unit (NICU) affects practices related to attachment and bonding with infants. The study title is Caregiver experiences of attachment and bonding practices in the Neonatal Intensive Care Unit (NICU) in Gauteng, South Africa.

The research will entail inviting individuals who form part of “NICU mom’s and family Support group” Facebook group for caregivers to participate in this study. This specifically includes caregivers who have had a neonate admitted to a NICU. If they agree, they will be asked to participate in a 30-minute-long interview that may be remote (online) or at a mutually convenient location should they be more comfortable with that in Gauteng. With the participants’ permission, the interview will be audio recorded.

Participants will be asked to give their written or verbal consent before the research begins. Their responses will be treated confidentially, and identities (their names and the name of the forum) will be anonymous unless otherwise expressly indicated. Individual privacy will be maintained in all published and written data resulting from the study.

The results will be communicated through a research report, potentially a publication or a potential conference presentation. The report will be available on the university library website and a summary thereof will be available to participants should they so wish.

The research participants will not be advantaged or disadvantaged in any way. They will be reassured that they can withdraw their permission at any time during this project without any penalty. During the interview some personal questions may be asked that could be sensitive, therefore, free counselling services will be available disposal at Emthonjeni Center on the East campus of the University of the Witwatersrand in Johannesburg. The participants will not be paid for this study.

I, therefore, request permission in writing to conduct my research through "South African mother and fathers with disabled children" Facebook group.

Please let me know if you require any further information. I look forward to your response as soon as is convenient.

Yours sincerely,

Engela Prinsloo

Researcher:
Engela Prinsloo,
1612871@students.wits.ac.za
0760250713

Supervisor:
Prof. Joanne Neille,
Joanne.neille@wits.ac.za
+ 27 (11) 717 4574

Mrs. Cynthia Sawasawa,
Cynthia.Sawasawa@wits.ac.za

Appendix E: Permission Letter for “Preemie/NICU moms”

University of the Witwatersrand,
School of Human and Community Development
Speech Pathology and Audiology

20/03/2023

Dear Administrator,

Re: Permission to access participants through “Preemie/NICU moms” Facebook group

My name is Engela Prinsloo.

I am studying for a Masters in Speech Pathology in the School of Human and Community Development at the University of the Witwatersrand. The study title is Caregiver experiences of attachment and bonding practices in the Neonatal Intensive Care Unit (NICU) in Gauteng, South Africa. My supervisors are Prof. Joanne Neille and Mrs. Cynthia Sawasawa. I am seeking permission to do research through Facebook forums.

I am conducting a research study about how the Neonatal Intensive Care Unit (NICU) affects practices related to attachment and bonding with infants. The study title is Caregiver experiences of attachment and bonding practices in the Neonatal Intensive Care Unit (NICU) in Gauteng, South Africa.

The research will entail inviting individuals who form part of “NICU mom’s and family Support group” Facebook group for caregivers to participate in this study. This specifically includes caregivers who have had a neonate admitted to a NICU. If they agree, they will be asked to participate in a 30-minute-long interview that may be remote (online) or at a mutually convenient location should they be more comfortable with that in Gauteng. With the participants’ permission, the interview will be audio recorded.

Participants will be asked to give their written or verbal consent before the research begins. Their responses will be treated confidentially, and identities (their names and the name of the forum) will be anonymous unless otherwise expressly indicated. Individual privacy will be maintained in all published and written data resulting from the study.

The results will be communicated through a research report, potentially a publication or a potential conference presentation. The report will be available on the university library website and a summary thereof will be available to participants should they so wish.

The research participants will not be advantaged or disadvantaged in any way. They will be reassured that they can withdraw their permission at any time during this project without any penalty. During the interview some personal questions may be asked that could be sensitive, therefore, free counselling services will be available disposal at Emthonjeni Center on the East campus of the University of the Witwatersrand in Johannesburg. The participants will not be paid for this study.

I, therefore, request permission in writing to conduct my research through “Preemie/NICU moms” Facebook group.

Please let me know if you require any further information. I look forward to your response as soon as is convenient.

Yours sincerely,

Engela Prinsloo

Researcher:
Engela Prinsloo,
1612871@students.wits.ac.za
0760250713

Supervisor:
Prof. Joanne Neille,
Joanne.neille@wits.ac.za
+ 27 (11) 717 4574

Mrs. Cynthia Sawasawa,
Cynthia.Sawasawa@wits.ac.za

Appendix F: Permission Letter for “NICU moms support group”

University of the Witwatersrand,
School of Human and Community Development
Speech Pathology and Audiology

20/03/2023

Dear Administrator,

<u>Re: Permission to access participants through “NICU moms support group” Facebook group</u>

My name is Engela Prinsloo.

I am studying for a Masters in Speech Pathology in the School of Human and Community Development at the University of the Witwatersrand. The study title is Caregiver experiences of attachment and bonding practices in the Neonatal Intensive Care Unit (NICU) in Gauteng, South Africa. My supervisors are Prof. Joanne Neille and Mrs. Cynthia Sawasawa. I am seeking permission to do research through Facebook forums.

I am conducting a research study about how the Neonatal Intensive Care Unit (NICU) affects practices related to attachment and bonding with infants. The study title is Caregiver experiences of attachment and bonding practices in the Neonatal Intensive Care Unit (NICU) in Gauteng, South Africa.

The research will entail inviting individuals who form part of “NICU mom’s and family Support group” Facebook group for caregivers to participate in this study. This specifically includes caregivers who have had a neonate admitted to a NICU. If they agree, they will be asked to participate in a 30-minute-long interview that may be remote (online) or at a mutually convenient location should they be more comfortable with that in Gauteng. With the participants’ permission, the interview will be audio recorded.

Participants will be asked to give their written or verbal consent before the research begins. Their responses will be treated confidentially, and identities (their names and the name of the forum) will be anonymous unless otherwise expressly indicated. Individual privacy will be maintained in all published and written data resulting from the study.

The results will be communicated through a research report, potentially a publication or a potential conference presentation. The report will be available on the university library website and a summary thereof will be available to participants should they so wish.

The research participants will not be advantaged or disadvantaged in any way. They will be reassured that they can withdraw their permission at any time during this project without any penalty. During the interview some personal questions may be asked that could be sensitive, therefore, free counselling services will be available disposal at Emthonjeni Center on the East campus of the University of the Witwatersrand in Johannesburg. The participants will not be paid for this study.

I, therefore, request permission in writing to conduct my research through "NICU moms support group" Facebook group.

Please let me know if you require any further information. I look forward to your response as soon as is convenient.

Yours sincerely,

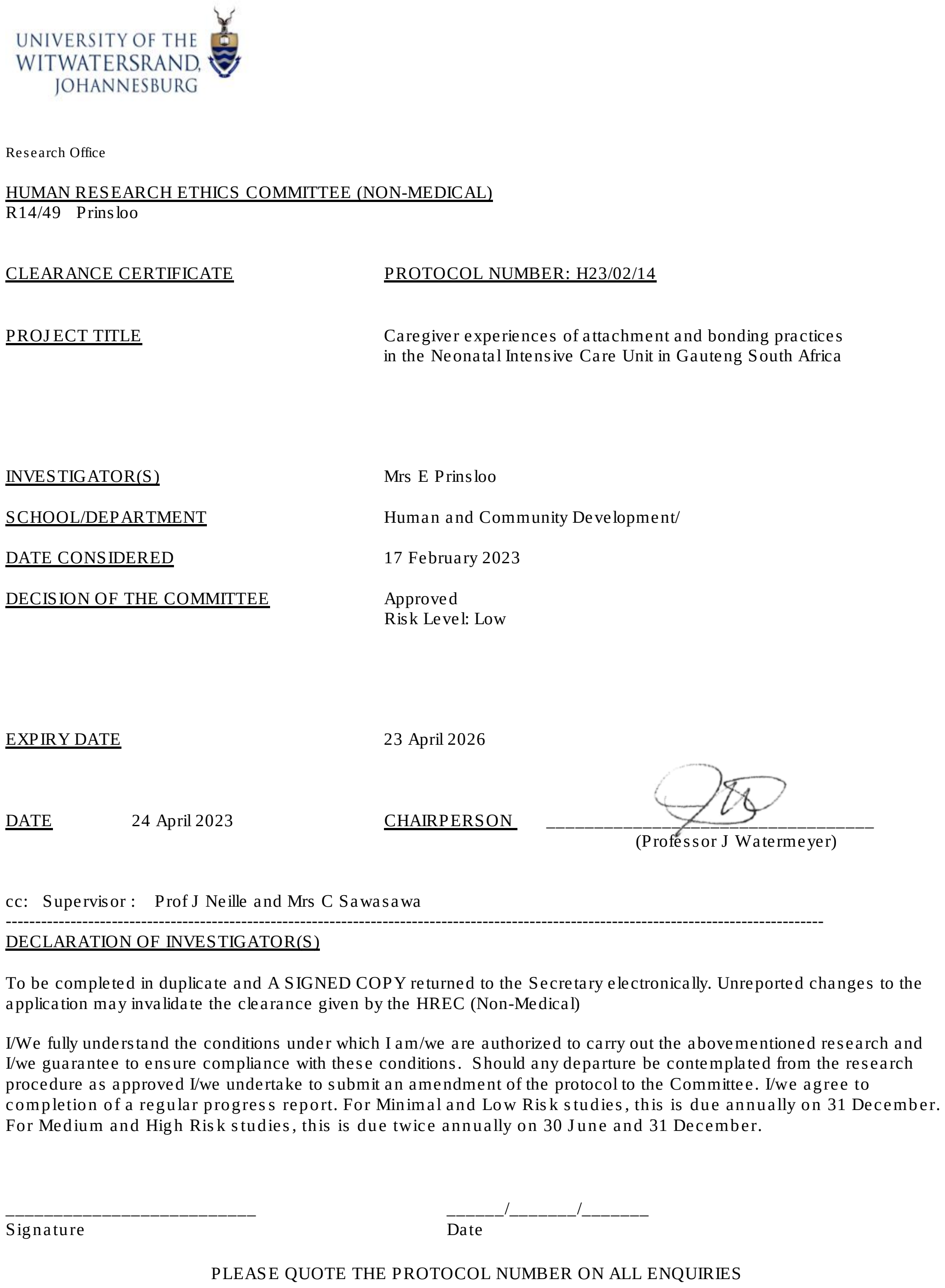
Engela Prinsloo

Researcher:
Engela Prinsloo,
1612871@students.wits.ac.za
0760250713

Supervisor:
Prof. Joanne Neille,
Joanne.neille@wits.ac.za
+ 27 (11) 717 4574

Mrs. Cynthia Sawasawa,
Cynthia.Sawasawa@wits.ac.za

Appendix G: Ethical Clearance Certificate



UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

Research Office

HUMAN RESEARCH ETHICS COMMITTEE (NON-MEDICAL)
R14/49 Prinsloo

CLEARANCE CERTIFICATE	PROTOCOL NUMBER: H23/02/14
PROJECT TITLE	Caregiver experiences of attachment and bonding practices in the Neonatal Intensive Care Unit in Gauteng South Africa
INVESTIGATOR(S)	Mrs E Prinsloo
SCHOOL/DEPARTMENT	Human and Community Development/
DATE CONSIDERED	17 February 2023
DECISION OF THE COMMITTEE	Approved Risk Level: Low
EXPIRY DATE	23 April 2026
DATE 24 April 2023	CHAIRPERSON ______________________________ (Professor J Watermeyer)

cc: Supervisor : Prof J Neille and Mrs C Sawasawa

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and A SIGNED COPY returned to the Secretary electronically. Unreported changes to the application may invalidate the clearance given by the HREC (Non-Medical)

I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure be contemplated from the research procedure as approved I/we undertake to submit an amendment of the protocol to the Committee. I/we agree to completion of a regular progress report. For Minimal and Low Risk studies, this is due annually on 31 December. For Medium and High Risk studies, this is due twice annually on 30 June and 31 December.

___________________________ Signature

______/_______/_______ Date

PLEASE QUOTE THE PROTOCOL NUMBER ON ALL ENQUIRIES

UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT
SPEECH PATHOLOGY AND AUDIOLOGY

Appendix H: Participant Information Sheet

Good day,

My name is Engela Prinsloo. I am a master's student in Speech-Language Pathology at the University of the Witwatersrand, Johannesburg. I am conducting a research study about how the Neonatal Intensive Care Unit (NICU) affects practices related to attachment and bonding with infants. The study title is Caregiver experiences of attachment and bonding practices in the Neonatal Intensive Care Unit (NICU) in Gauteng, South Africa.

I am inviting you to take part in a semi-structured one-on-one interview. If you decide to take part, your participation in this research study will last about 30 minutes. The interview will be in-person or remote (Via Zoom or WhatsApp) at a time and place or mutual convenience on a date and time of your choosing and will.

With your permission, I would like to audio record the interview. A mediator will be available should you choose to have the meeting in another language than English, such as isiXhosa, Sesotho, isiZulu, or Afrikaans. You will remain anonymous, and your privacy will be respected as data will be stored in a password-protected computer file with no identifying information. Your identity will be protected by a false name in the final report (and any subsequent publications). Only the researcher and research supervisors will have access to the data, this totals three individuals. You will be reimbursed for the data usage of the remote interview prior to the interview taking place, if you are traveling to do an in-person interview traveling costs will be reimbursed accordingly.

During the interview, I will need to ask for some personal information about you, including questions about your family's practices related to attachment and bonding. I will further need to ask you about your experience of having a baby admitted to the Neonatal Intensive Care Unit.

If you decide to take part in the research study, it should be because you want to volunteer. Your participation in this research is completely voluntary and you are free to withdraw at any stage prior to submission/publication for any reason. You do not have to answer any questions if you do not want to. You will not get any direct benefits if you choose to join the research study. You will not lose any services, benefits, or rights you would normally have if you decided not to join. Taking part in the research study will require data as the interview will be online, however, data will be provided by the researcher for the period of the interview.

Some of the questions asked may make you feel sad or upset. If this happens, I will stop the interview and continue another time. Free counseling services will be at your disposal at Emthonjeni Center on the East campus of the University of the Witwatersrand in Johannesburg.

The contact details are as follows; the contact number to make an appointment or inquire is 011 717 4513, or you can email Mrs Paballo Lepota at Paballo.Lepota@wits.ac.za.

This research study will be written up as a research report, potentially a publication, or a potential conference presentation. The report will be available on the university library website. If you would like to receive a summary of this report, I will be happy to send it to you.

If you have any questions during or afterward about this research study, feel free to contact me on the details listed below. If you have any concerns or complaints about the ethical procedures of this research study, you are welcome to contact the University Human Research Ethics Committee (Non-Medical), telephone +27(0) 11 717 1408, email hrecnon-medical@wits.ac.za.

Yours sincerely,
Engela Prinsloo

Researcher:
Engela Prinsloo,
1612871@students.wits.ac.za
0760250713

Supervisor:
Prof. Joanne Neille,
Joanne.neille@wits.ac.za
+ 27 (11) 717 4574

Mrs. Cynthia Sawasawa,
Cynthia.Sawasawa@wits.ac.za

Appendix I: Consent form to participate in the proposed research study.

Consent form to participate in study: Caregiver experiences of attachment and bonding practices in the NICU in Gauteng South Africa

Engela Prinsloo

I, ……………………………………….., agree to participate in this research project.

I agree to the following:

(Please circle the relevant options below)

The research study was explained to me. I understand what this study is about.	YES	NO
I understand that I can volunteer to take part in the study	YES	NO
I agree that the interview may be audio and video recorded.	YES	NO
I agree that direct quotations from my interview may be used by the researcher in their research report.	YES	NO
I agree that my participation will remain anonymous (my name will not be used by the researcher in their research report)	YES	NO

…………………………………… (signature)
…………………………………… (name of participant)
…………………………………… (date)

UNIVERSITY OF THE
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SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT
SPEECH PATHOLOGY AND AUDIOLOGY

Appendix J: Semi-structured interview questions

Demographic questionnaire:

1. What is your age?
2. What is your gender?
3. How old is your child?
4. What is your home language?
5. What other languages do you speak?
6. What is your race (e.g. white, black, Indian, colored etc.)?
7. What is your religion?

Semi-structured interview questions:

The proposed question will act as a guide during the interviews, but interviews will remain flexible.

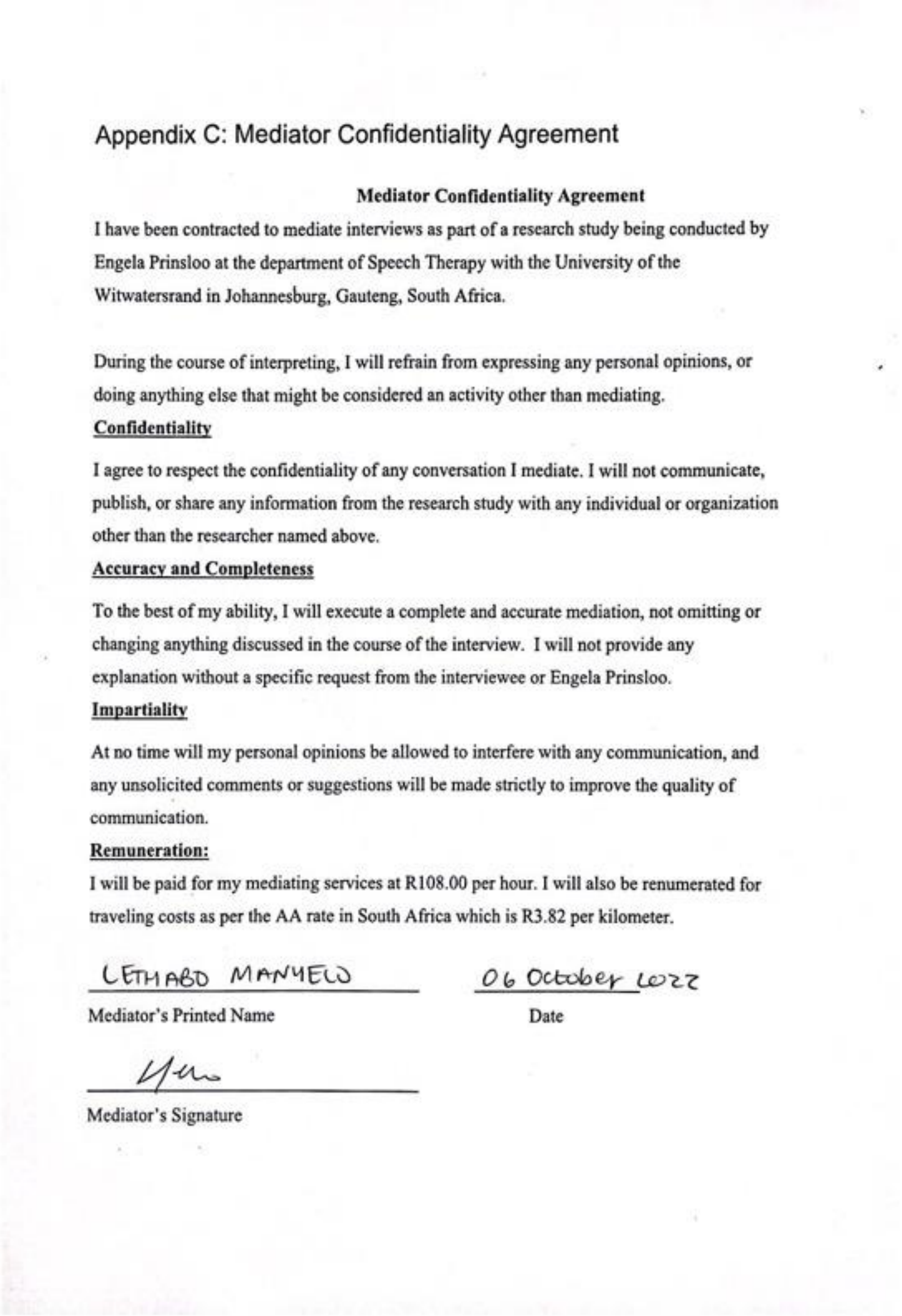
1. *Tell me about your pregnancy journey.*
2. *Why did your child was admitted to the NICU?*
3. *Can you tell me about your experience of having a baby in the NICU?*

2.1 What factors within the NICU made this process easier?

2.2 What factors within the NICU made this process more difficult?

4. *Do you feel that the NICU influenced bonding practices with your child, if so, how?*
    - 2.1 How do you describe the effect that your culture has on your bonding with your baby?
    - 2.2 Are there any special ceremonies or practices that you and your family participate in when a baby is born?
5. *Do you feel as though your well-being as a caregiver was affected during this NICU period, if so, how? For example, did you feel anxious, overwhelmed, helpless or did it affect you in any other way?*
6. *How could your experiences in the NICU have been improved?*

Appendix K: Mediator Confidentiality Agreement



Appendix C: Mediator Confidentiality Agreement

Mediator Confidentiality Agreement

I have been contracted to mediate interviews as part of a research study being conducted by Engela Prinsloo at the department of Speech Therapy with the University of the Witwatersrand in Johannesburg, Gauteng, South Africa.

During the course of interpreting, I will refrain from expressing any personal opinions, or doing anything else that might be considered an activity other than mediating.

Confidentiality

I agree to respect the confidentiality of any conversation I mediate. I will not communicate, publish, or share any information from the research study with any individual or organization other than the researcher named above.

Accuracy and Completeness

To the best of my ability, I will execute a complete and accurate mediation, not omitting or changing anything discussed in the course of the interview. I will not provide any explanation without a specific request from the interviewee or Engela Prinsloo.

Impartiality

At no time will my personal opinions be allowed to interfere with any communication, and any unsolicited comments or suggestions will be made strictly to improve the quality of communication.

Remuneration:

I will be paid for my mediating services at R108.00 per hour. I will also be renumerated for traveling costs as per the AA rate in South Africa which is R3.82 per kilometer.

LETHABO MANYELO
Mediator's Printed Name

06 October 2022
Date

Mediator's Signature

Appendix L: Distress Protocol

Pre-data collection Phase

- The researcher should consider the potential physical and psychological of the research on the particpants in describing life events and experiences.
- The researcher should consider how particpants will be provided with a safe environment while descrbing life experiences.

Data Collection Phase

- If a particpants exihibits elevated stress levels or emotional distress such as crying or shaking the interview will be stopped.
- Immediate support will be offered by the researcher who is a healthcare professional and following questions will be asked; Are you okay? Tell me what thoughts you are having? Are you able to go on?
- If the particpants is able to continue the interview will resume, if not, the particpants will be given contact details of free counselling services as stipulated in the partipant information sheet.
- Free counseling services will be available at Emthonjeni Center on the East campus of the University of the Witwatersrand in Johannesburg. The contact details are as follows; the contact number to make an appointment or inquire is 011 717 4513, or you can email Mrs Paballo Lepota at Paballo.Lepota@wits.ac.za.

Follow-up Phase

- The researcher will follow-up with particpnats with a courtesy call.
- The particpants will be encouraged to call if he/she may experience elevated distress or stress.

Draucker, C. B., Martsolf, D. S., & Poole, C. (2009). Developing distress protocols for research on sensitive topics. *Archives of psychiatric nursing*, *23*(5), 343-350.

Haigh, C., & Witham, G. (2013). Distress protocol for qualitative data collection. *Archives of Psychiatric Nursing*, *23*(5), 343-350

Appendix M: Signed letter confirming counselling services for participants.

EMTHONJENI CENTRE
THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT (SHCD)

Private Bag 3, Wits, 2050 • Tel: 011 717 4513 • Fax: 011 717 4559 • E-mail: emthonjenicentre.SHCD@wits.ac.za E-mail: Umthombo.SHCD@wits.ac.za

Attention: Human Research Ethics Committee

Confirmation of psychotherapy services

20 March 2023

This serves to confirm that, should the need arise, participants in Engela Prinsloo's research study entitled: 'Caregiver experiences with attachment and bonding practices in the Neonatal Intensive Care Unit in Gauteng, South Africa', can access psychology counselling services free of charge at the Emthonjeni Community Psychology Clinic. The name of a specific counsellor cannot be specified at this time, as the counsellor allocated to the case, if the need arises, will depend on which counsellor has availability at that time. The clinic runs every Wednesday afternoon from March to November. Mrs Paballo Lepota, who manages bookings at the clinic, is aware of Ms Prinsloo's study and will prioritise any participants from the study making contact with the clinic. Mrs Lepota can be contacted on 011 717 4513 or paballo.lepota@wits.ac.za.

Kind regards

Prof Katherine Bain

Psychology Clinic Supervisor

Emthonjeni Centre Director

University of the Witwatersrand

011 717 4558

Katherine.Bain@wits.ac.za

Appendix N: Standard operating procedure (SOP) for data collection, data storage and data management

1. Purpose

The purpose of this SOP is to provide guidance to researchers about ethical issues during data collection, storage, and management as well as possible sharing or the transfer of data for later research. This is important as data collection, storage, and management gives rise to ethical concerns regarding autonomy and confidentiality.

2. Introduction

An essential element of a research study includes the efficiency and efficacy of data collection and management. This SOP describes the full data management process.

3. Objective

This SOP describes the data management processes for the proposed research study specifically relating to the processes involved with collecting, validating and analysing such data.

4. Scope

The ethical considerations concerning the use of data involve: how to access these appropriately, how to use these appropriately, and how to manage potential privacy concerns that may arise from information management.

5. Procedure

Data Management Process: The process of data management involves converting the data collected. Data will be recorded on an audio recording device and will be transcribed to word on Microsoft Word from there. As the data being collected will be qualitative this data will not be coded. Data regarding the demographics of participants will be coded prior to data entry on Microsoft Excel.

Data Entry

Before data entry demographic data will coded using codes such as 1 for yes, 2 for no etc. codes will be in place for entries such as ‘not known’ or ‘not applicable’ e.g. 999 to show missing data. Qualitative data will be transcribed onto a Microsoft word document. All documents pertaining to data will be stored electronically.

Data Cleaning and Validation

An integral part of the data management process is validation; to ensure that an accurate ‘clean’ set of data is provided for analysis. Data validation will take place and will entail continuously monitoring data being entered with the original data to ensure that data is being captured accurately (e.g. comparing the typed transcription to the audio recording and ensuring the two are consistent).

Data Backup System

A data backup system is required and will entail a second Microsoft Word and Microsoft Excel document that will be password-protected kept on a USB memory stick in a locked cabinet. The backup is to guard against loss of data due to software or environmental disaster.

Data Protection

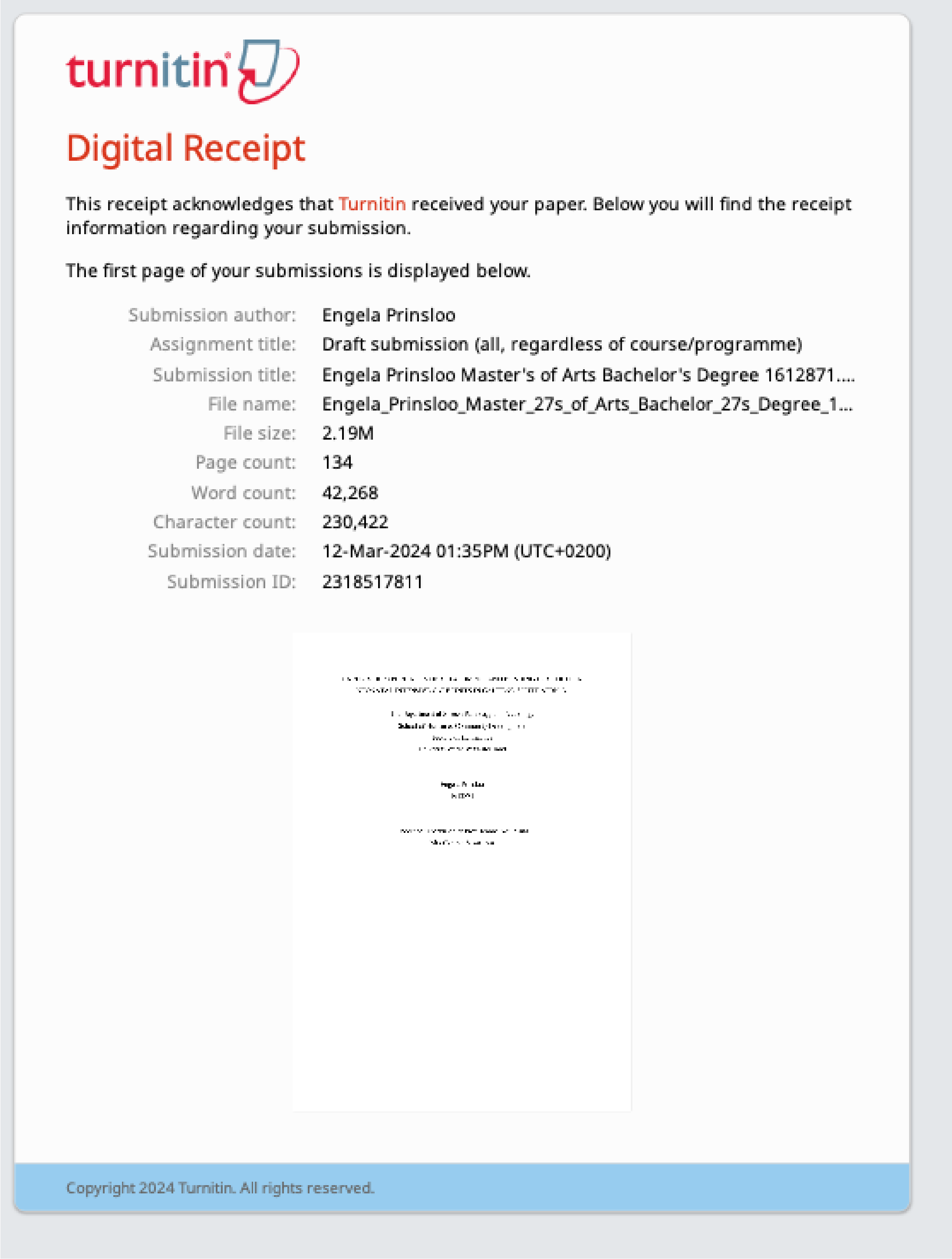
During the entire data management and validation process, it is essential that all study data are kept in a secure location. Data will be kept electronically on a password-protected computer file. This password will only be available to the researcher and the research supervisors. The following ethical principles will be upheld; participant confidentiality (pseudonyms will be used throughout data collection, management, and use). Due to the prospective size of the study, Microsoft Word and Microsoft Excel will be sufficient use of storage for data. Identified individual who will have access to the data includes;

Researcher:
Engela Prinsloo,
1612871@students.wits.ac.za
0760250713

Supervisor:
Prof. Joanne Neille,
Joanne.neille@wits.ac.za
+ 27 (11) 717 4574

Mrs. Cynthia Sawasawa,
Cynthia.Sawasawa@wits.ac.za

Appendix O: Turnitin plagiarism report



Digital Receipt

This receipt acknowledges that Turnitin received your paper. Below you will find the receipt information regarding your submission.

The first page of your submissions is displayed below.

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Assignment title:	Draft submission (all, regardless of course/programme)
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File name:	Engela_Prinsloo_Master_27s_of_Arts_Bachelor_27s_Degree_1...
File size:	2.19M
Page count:	134
Word count:	42,268
Character count:	230,422
Submission date:	12-Mar-2024 01:35PM (UTC+0200)
Submission ID:	2318517811