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Mothering a neonate/young infant with feeding and swallowing difficulties: Barriers, facilitators, and support

by

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Glossary

Aspiration: The process of substances (i.e., food, liquid or secretions) bypassing the level of the vocal folds and entering the trachea either before, during or after swallowing (Arvedson, 2008; Arvedson et al., 2020; Gosa & Dodrill, 2017).

Dysphagia: Any interruption in the swallowing process that affects the safety, effectiveness, or sufficiency of nutritional intake (Dodrill & Gosa, 2015).

Feeding: A multifaceted process involving the integration of the central and peripheral nervous systems, the oropharyngeal mechanism, the cardiopulmonary system and the gastrointestinal (GI) tract, all supported by the craniofacial structures and the musculoskeletal system (Goday et al., 2019). This coordinated effort depends on the development and acquisition of skills that align with a child's physiological and developmental milestones (Goday et al., 2019).

Feeding difficulties: Inadequate oral intake that does not align with the age expectation of the infant and is linked to nutritional issues, feeding abilities, medical conditions and/or psychosocial challenges (Goday et al., 2019).

Infant: Children from birth up to 12 months of age (Heydarpour et al., 2017).

Low birth weight (LBW): A neonate with a birth mass of 2.5 kg or less (World Health Organization, 2019).

Neonate: Infants from birth until 28 days of age (Tayman et al., 2011).

Oropharyngeal dysphagia (OPD): An amalgamation of several difficulties occurring during the oral and pharyngeal phases of swallowing (Viviers, 2016).

Swallowing: The coordinated muscular movements of the respiratory and gastrointestinal systems that transport food from the mouth to the stomach (Arvedson et al., 2020). Swallowing is typically divided into four phases, namely: the oral preparatory, oral, pharyngeal and oesophageal phases (Arvedson et al., 2020).

1. *Oral preparatory phase*: The process of actively ingesting food substances into the mouth and forming a bolus. This process in neonates uniquely includes rooting and latching onto a breast/bottle, creating an effective oral seal with the lips, and lifting and propelling the bolus with their tongue to their velum (Arvedson et al., 2020; Geddes & Sakalidis, 2015; Willging et al., 2019).

2. *Oral phase:* The posterior propulsion of the bolus into the pharynx. In infants this solely includes sucking and suck-swallow coordination and movements (Willging, 2019), achieved when the tongue makes contact with the palate in a stripping motion, propelling the bolus toward the pharynx (Arvedson, 2020; Willging, 2019). This phase

is still under voluntary control and ends with the triggering of the pharyngeal swallow (Arvedson et al., 2020).

3. *Pharyngeal phase*: This involuntary phase includes a number of actions ensuring the bolus is transferred from the pharynx into the oesophagus, and includes elevation of the velum closing off the nasopharynx, activation of the airway protection mechanism with elevation and anterior movement of the larynx and laryngeal closure, opening of the upper oesophageal sphincter, and propulsion of the bolus into the oesophagus (Arvedson et al., 2020; Dodrill & Gosa, 2015; Willging et al., 2019).

4. *Oesophageal phase*: The movement of the bolus through the upper oesophageal sphincter, which is then transported by a series of automatic coordinated peristaltic movements to the lower oesophageal sphincter and into the stomach (Arvedson et al., 2020; Dodrill & Gosa, 2015; Viswanathan & Jadcherla, 2020; Willging et al., 2019).

Very Low Birth Weight (VLBW): A neonate with a birth mass of 1.5 kg or less (Arvedson et al., 2020).

Abbreviations

FHS	Faculty of Health Sciences
FSD	Feeding and swallowing difficulties
FCC	Family centred care
HCP	Healthcare professional
HREC	Human Research Ethics Committee
KMC	Kangaroo Mother Care
LMIC	Low-middle income country
MMH	Mowbray Maternity Hospital
NICU	Neonatal Intensive Care Unit
OPD	Oral paediatric dysphagia
RA	Research assistant
RCWMCH	Red Cross War Memorial Children's Hospital
SLT	Speech-language therapist
UCT	University of Cape Town
WHO	World Health Organization

Abstract

Background: The anticipation of a new infant is typically characterised by feelings of joy, excitement, and hopeful expectations for the future. However, these positive emotions can be altered when mothers are faced with the reality of caring for an ill, hospitalised infant, particularly one with feeding and swallowing difficulties (FSD). FSD in infants significantly impacts not only the infant's health and development but also the mother's emotional and psychological wellbeing. Caring for neonates and young infants with FSD in hospital settings presents unique challenges, especially in resource-constrained environments like South Africa. Limited research exists exploring mothering an infant with FSD, highlighting a gap in understanding the maternal experience.

Research aim and objective: This research aimed to explore 'mothering' a neonate/young infant with FSD in a South African healthcare context. To achieve the aim, mothers' experiences of barriers, facilitators and support needs within a neonatal healthcare context are described.

Methods: A qualitative, exploratory case study design was used. Semi-structured interviews were conducted with mothers whose infants presented with FSD in neonatal/infant units. A total of seven mothers were interviewed (*n*=7) whose infants (aged from birth to three months) were admitted at either Mowbray Maternity Hospital or Red Cross War Memorial Children's Hospital, for a minimum of seven days. The data were thematically analysed, allowing the emergence of key themes that represent maternal experiences.

Results: The overarching theme of 'mothering' emerged, encapsulated by the quote: "Baby comes first in everything." Six distinct themes then emerged from the overarching theme, represented by relevant quotes from the participants: "Information helps"; "They help a lot", "It's not home", "Everything on you", "It affects me emotionally", "Not on your own" and lastly, "It's my baby". These themes emerged from the accounts of the mothers, which were then described in terms of barriers such as separation and burden of care, facilitators such as information and maternal strength, and support structures. The findings outline the dedication and resilience of mothers when navigating the challenges of caring for infants with

FSD, while also highlighting the intricate and often dichotomous realities they face in the hospital setting.

Conclusion: This study highlights the complex experiences of mothers caring for infants with FSD in South African healthcare settings. While deeply committed to their infants' wellbeing and feeding, mothers face barriers such as inadequate communication, separation, and limited support, which heighten stress and guilt. Facilitators, including clear communication, practical support from healthcare professionals, and peer and family networks empower mothers and alleviate their emotional burden. A collective effort by healthcare professionals, families, and hospital systems is essential to ensure care that supports both the recovery of infants and the wellbeing of their mothers. These insights can inform healthcare practices and future research in similar resource-limited settings.

Keywords: mothering, neonate/infant, feeding and swallowing difficulties, paediatric dysphagia, NICU, speech-language therapists, South Africa

Chapter 1: Literature Review

Introduction

An infant's birth is usually anticipated with excitement and feelings of hopeful expectation for the future. However, these positive emotions can change when mothers are faced with the reality of caring for an ill, hospitalised baby, particularly one diagnosed with feeding and swallowing difficulties (FSD). FSD significantly impacts an infant's health and development, and may affect the mother's emotional and psychological wellbeing (Buys, 2020). Such challenges can transform the anticipated experience of motherhood, introducing complex layers of stress, anxiety, and emotional upheaval that accompany turbulent infant health and prolonged hospitalisation (Hewetson & Singh, 2009).

For mothers, the experience of caring for a newborn in hospital can be both daunting and transformative, shaped by several facilitators, barriers, and support structures within these hospitals. Facilitators such as access to medical information, emotional support, and mother-infant bonding opportunities can significantly enhance the mothering experience (Ericson & Palmér, 2019; Feeley et al., 2013). Conversely, barriers like limited resources and inadequate healthcare infrastructure can hinder effective mothering and contribute to stress and anxiety (Carton et al., 2020; Ncube et al., 2016).

Implementing a family-centred care approach, which emphasises the involvement of the family in the treatment process, can improve health outcomes for both the infant and the mother by fostering a supportive and informed caregiving environment (Feeley et al., 2013; Mirlashari et al., 2020). Therefore, it is essential to review existing research and investigate current practices to identify effective strategies and structures that can be implemented to better support mothers and their infants in neonatal units. While much has been written about mothering and the associated stresses in a hospital environment, there is limited research specific to this experience for mothers of infants with FSD. Understanding the intricacies of mothering an infant in a hospital setting is crucial for providing adequate support

and resources to all mothers (Wang et al., 2021) but especially for underrepresented groups of mothers such as those of infants with FSD.

This dissertation strives to fill the gap in knowledge by exploring 'mothering' a young infant with FSD in a South African healthcare context. The objective of the research was to explore the barriers, facilitators and support structures available to mothers during this experience, as explained by them.

Through an exploratory case study design, this research seeks to add to the understanding of what mothers feel 'mothering' is in this context, by analysing rich accounts of their experience and providing a voice for them in research-based literature. The purpose of this work is to generate contextually relevant information that can be used to support the improvement of care and environments for mother-infant dyads, ultimately aiming to improve the outcomes for both the infants and their mothers within resource-limited countries such as South Africa.

This chapter will detail the rationale for this research and its relevance after examining the available literature. Importantly, it should be noted that the literature discussed does not pertain only to mothering an infant with FSD, but additionally highlights information on neonatal/infant and maternal healthcare, facility frameworks, and healthcare worker approaches within hospitals in South Africa.

Mothering

Historically, the role of a mother has been central to child-rearing (Lumby & Azaola, 2014). Several theoretical frameworks define 'motherhood' and 'mothering'. In line with essentialism, mothering is viewed as an innate and biologically-driven act that emphasises that it is natural and instinctive (Gaunt & Deutsch, 2024). Such frameworks have shaped many ideologies, such as the 'good mother' ideology, which depicts mothering as an instinctive role for women, emphasising an inherent capacity and desire to nurture and child-rear (Williamson et al., 2023). Other studies have adopted a social constructionist approach, defining mothering as a social construct that is not 'natural and biological' but rather a role

that is outlined by maternal practices that are expressions of nurturing, training, and preservative love (Lumby & Azaola, 2014; O'Reilly, 2010; Spjeldnæs, 2021). Practice theory has also been used to outline mothering as a set of practices where mothers perform the social norms of their title (Schmidt et al., 2023). However, doing something well is measured against a socially accepted view of what 'good' is, and the desired outcome thus follows social rules underpinning the theoretical framework of normology (Schmidt et al., 2023). The ideology of 'intensive mothering' characterises parenting as a highly demanding, child-focused, individualised task where the child's needs always come before the mother's, even to the mother's own detriment (Williamson et al., 2023). A popular discourse in research explains how 'attachment theory' is fundamental to mothering as it emphasises the importance of a mother's responsiveness and sensitivity to her infant's needs in fostering a secure attachment that is crucial for the child's emotional and social development (Benoit, 2004; Hong & Park, 2012). Ethnographic studies observe diverse child-rearing practices influenced by race, class, sexuality, and social status (Barlow & Chapin, 2010), which contribute to the various shapes mothering takes. These theories mould how society and women define mothering in addition to their lived experience of mothering or being mothered.

Mothering is universally recognised for its nurturing and caring aspects, yet it encompasses a vast array of functions and emotional depths. These key components include nurturing and emotional support (Barlow & Chapin, 2010; Hewetson & Singh, 2009), ensuring health and welfare (Buys, 2020), feeding and nutrition (Buys, 2020; Ericson & Palmér, 2019), providing protection and security (Cassidy et al., 2013), education and development (Lumby & Azaola, 2014), and advocacy (Ncube et al., 2016) while also experiencing their own range of emotions (Arnold et al., 2013).

The complexity of mothering is highlighted by the multifaceted aspects it encompasses and the multiple roles it includes. Mothers assume these various roles and serve as educators, playmates, disciplinarians, caregivers and attachment figures (Benoit, 2004). Mothers also provide physical safety and emotional security, which helps the child develop trust and a sense of safety (Cassidy et al., 2013). Mothers want to create safe environments where children can explore and grow while feeling protected (Ericson & Palmér, 2019). The intricacy

of mothering is nuanced by the emotions of these aspects because human experiences are deeply rooted in emotions that underpin human relationships and interactions, such as those between a mother and infant (Bornstein et al., 2022). The emotions experienced by mothers are not only relevant to their wellbeing but have an impact on the infant too. Mothers provide consistent emotional support and create a nurturing environment for their children that is fundamental for healthy emotional and social development (Cassidy et al., 2013). The emotional connection between mother and child is a critical component of the mothering experience, as it forms the foundation for a secure attachment and healthy child development in accordance with attachment theory (Cassidy et al., 2013; Hong & Park, 2012). This connection involves being attuned to the infant's needs, offering them comfort, and fostering a secure attachment (Cassidy et al., 2013).

Mothering in a South African context

The complexity of mothering is also influenced by socio-cultural factors. In South Africa, mothering reflects a unique blend of traditional and modern practices, influenced by the country's socio-economic and cultural landscape, as well as its history (Rabe, 2017; Robinson, 2014). In some communities and cultures, mothering extends beyond the nuclear family model to embrace a collective approach, where the responsibilities of raising children are shared among extended family members, such as grandmothers, aunts, and older siblings (Rabe, 2017). Approximately one third (33.6%) of households in South Africa were described as 'extended' in the country's recent census, including parents, children, in-laws, grandparents and other family members within one household (Statistics South Africa, 2022). This collective mothering provides resilience against the challenges posed by poverty, high unemployment rates, and the lingering effects of apartheid, which disrupted family structures and economic stability (Spjeldnæs, 2021). Socio-economic disparities along racial lines still exist in the country and influence mothering experiences. For instance, black African women, and mothers particularly, frequently juggle multiple roles, often balancing informal, low-paid work while managing households and caregiving (Robinson, 2014). The 2021 South African census indicated that over 42% of households were led by women, with female-headed households being particularly prevalent in rural areas at nearly 48% (Statistics South Africa,

2022). The socio-political history of South Africa, characterised by colonialism and apartheid, continues to impact mothering practices, necessitating reliance on extended family and community networks while mothers are out working, in attempts to compensate for the absence of adequate state support (Mtombeni, 2020). Moreover, South Africa has a diverse linguistic and cultural population, yet English remains the language of choice in many healthcare settings, where there may not be adequate provision of information in the native languages of mothers, potentially creating a linguistic barrier that limits access to care and increases stress (Van Schalkwyk, 2021). Mothering in the South African context is also strained by issues such as domestic violence, HIV/AIDS, and the prevalence of single motherhood, which require mothers to navigate complex social and economic pressures while maintaining their caregiving roles (Spjeldnæs, 2021). Thus, mothering in South Africa is a dynamic and adaptive process, rooted in collective cultural practices and shaped by the socio-economic realities of the broader society (Rabe, 2017; Spjeldnæs, 2021).

Feeding as an act of mothering

Feeding is important for an infant's physical health and is a central activity in mothering as the infant depends on the mother for nutrition. Mothers are responsible for ensuring their children receive sufficient nutrition, establishing feeding routines, and sometimes managing feeding challenges if they arise. Through feeding, mothers communicate love, care, and security, which are essential for the child's emotional wellbeing and development. This nurturing activity helps establish security and contributes to the child's sense of safety and trust in the world (Cassidy et al., 2013).

For the mother, feeding times are opportunities to observe and respond to the infant's cues, fostering a deeper understanding of the child's needs and behaviours (Ericson & Palmér, 2019). Feeding also supports cognitive and social development. The interaction during feeding times can stimulate cognitive growth and communication, and foster language development and social skills, as the child learns to recognise and respond to social cues (Rabe, 2017; Steyn et al., 2017). The emotional connection established during feeding is also pivotal in reinforcing the mother's sense of competence and fulfilment in her role (Ericson &

Palmér, 2019; Wang et al., 2021). Successful feeding experiences can boost maternal confidence and reinforce the emotional bond between mother and child, creating a positive feedback loop that enhances the caregiving experience (Van Schalkwyk et al., 2021). The above underscores the importance of feeding in mothering, where it serves as a cornerstone for both physical nourishment and emotional bonding. Each act of mothering is complex in its meaning and function, reflecting the intricate nature of mothering as a whole.

Mothering an infant with FSD

The picture of mothering and raising a child is different when an infant is born prematurely, becomes ill or has a health condition requiring them to be hospitalised after birth. These circumstances significantly impact the mothering experience, as mothers are faced with medical challenges and uncertainties associated with their infant's health (Carter et al., 2007; Steyn et al., 2017). These challenging circumstances may be compounded by FSD, which is particularly common in infants who are born prematurely or have complex medical conditions (Goday et al., 2019). FSD in neonates and young infants, more specifically oropharyngeal dysphagia (OPD), is prevalent, as swallowing and feeding are core functions during infancy and can be influenced by many factors, including physiological stability, suck-swallow-breathe coordination and orofacial muscle tone (Arvedson et al., 2020; Da Costa et al., 2019; da Costa et al., 2008). Furthermore, swallowing requires the integration of the central and peripheral nervous systems, oropharyngeal mechanism, cardiopulmonary system and gastrointestinal (GI) tract, all supported by the craniofacial structures and musculoskeletal system (Goday et al., 2019). Swallowing is typically divided into the oral preparatory phase, oral phase, pharyngeal phase and oesophageal phase (Arvedson et al., 2020), where a breakdown at the oral or pharyngeal levels results in OPD (Viviers, 2016). The stages of swallowing additionally rely on neuromotor and neurosensory feedback systems to manage the coordination of sucking, swallowing, and breathing. Any disruption in this intricate process can result in FSD (Goldfield et al., 2017; Zimmerman & Rosner, 2018).

Infants with FSD may have underlying medical conditions that affect their ability to feed. These conditions include neurological, structural and genetic disorders, and others may be

secondary to systemic illnesses (Arvedson et al., 2020). The occurrence of FSD in children is reportedly rising, largely due to the improved survival rates of infants born prematurely and/or with complex medical complications (Lefton-Greif et al., 2024; Panizzolo et al., 2023). As 1 in 10 babies globally are born prematurely (before 37 weeks) there is a significant population at risk for FSD (World Health Organization, 2023). In South Africa, this may be a greater problem, with one in seven babies born prematurely according to a 2022 report (Statistics South Africa, 2022). South Africa has one of the highest rates of prematurity, being significantly higher than the global rates (Beck et al., 2010; Ramokolo et al., 2019). In the South African context, these statistics are influenced by inadequate antenatal care and maternal health services, coupled with high risk of infection, malnutrition, poverty and other socio-economic factors that contribute to poor maternal and neonatal outcomes, including low birth weight (LBW) infants and premature delivery (Blencowe et al., 2013; Hoque et al., 2011; Jeena et al., 2020; Porter, 2024).

The population of neonates with medical conditions is at high risk for developing FSD, including infants with a broad spectrum of health conditions. Conditions such as premature birth place infants at risk for developing FSD, with approximately 40% to 66% of all infants born preterm experiencing FSD/dysphagia (Arvedson et al., 2020; Lefton-Greif et al., 2024). A recent South African study researching the prevalence and risk factors for OPD found that more than 76% of the sample (*n*=160) were born prematurely and more than 83% of their population either had low birth weight (LBW) or very low birth weight (VLBW), of which 20% presented with OPD (Porter, 2024). Dewi et al. (2024) found that 62.5% of premature infants had suck-swallow-breathe incoordination, a critical issue due to an immature cardiorespiratory system, leading to apnoea and bradycardia during feeding and an inability to show hunger readiness and maintain alertness during feeding, making it difficult to manage and regulate cardiorespiratory coordination effectively.

Preterm infants are also at risk for other neurological and respiratory conditions, which may predispose an infant to or exacerbate FSD (Arvedson et al., 2020). Approximately 43% of children with congenital heart disease (Adams-Chapman et al., 2015) exhibit FSD, often due to the increased metabolic demands and respiratory challenges associated with congenital heart disease (Norman et al., 2022). Locally, neurological conditions that are particularly

prevalent in South Africa, such as hypoxic-ischaemic encephalopathy, are becoming more commonly linked to FSD. Da Costa et al. (2019) explored the prevalence of OPD in high-risk infants in South Africa, and found that infants with neurological conditions were three and a half times more likely to present with OPD (Dewi et al., 2024). Additionally, neonates in South Africa may be exposed to alcohol and other substance abuse, HIV and antiretroviral therapy prenatally, presenting further risks to neurodevelopment that impacts feeding (Da Costa, 2019; De Beer et al., 2010; Salihu et al., 2012). These varied factors underscore the complexity of the at-risk factors for FSD among neonates.

The impact of FSD/dysphagia in the neonatal population carries significant implications for the infant's physical health and development, and for the emotional and psychological wellbeing of their mothers. These challenges extend from immediate medical concerns to influencing broader components such as speech, language, emotion, social behaviour, and cognition (Zimmerman & Rosner, 2018), as well as the dynamic of the mother-infant dyad and their mother's identity (O'Farrell-Walsh, 2019). Feeding difficulties can prevent the infant from receiving adequate nutrition for growth and development (Kalhoff et al., 2024; Viviers, 2016; Hewetson & Singh, 2009). Beyond compromised nutrition, these difficulties can also negatively impact other areas of health, such as respiratory function (Zimmerman & Rosner, 2018). Feeding difficulties put infants' respiration at risk due to reduced airway protection, which can damage their vulnerable lungs (through aspiration and respiratory infection), ultimately worsening or causing pulmonary disorders, and increasing the duration of oxygen dependency and hospitalisation (Kamity et al., 2021).

The rise in the prevalence of infants with FSD has led to a growing need for specialised feeding interventions in neonatal care (Panizzolo et al., 2023). The treatment of infants with dysphagia in hospital is typically holistic and undertaken by a multidisciplinary team. The role of the speech and language therapist (SLT) includes assessment and diagnosis of the presence of FSD (Bath et al., 2018; Pagnamenta et al., 2022). Subsequently, SLTs deliver therapeutic interventions specifically targeted at FSD to facilitate initial feeding abilities and early communication skills (Bath et al., 2018; Murphy et al., 2021; Pagnamenta et al., 2022). The SLT role is broad in scope and further includes optimising outcomes for preterm infants and their families by prioritising early interactions, strengthening the feeding relationship to

enhance overall wellbeing of the dyad, and providing support and education to mothers and caregivers (Bath et al., 2018; Murphy et al., 2021; Pagnamenta et al., 2022). In conjunction with other healthcare professionals (HCPs) treating infants with FSD in-hospital, SLTs are crucial to mitigate the impact of their difficulties and providing intervention and support where needed.

FSD can further include psychosocial elements, where the difficulties in feeding affect the infant's interactions with the caregiver and the caregiver themselves. Feeding offers infants and caregivers valuable opportunities for communication and interaction-attachment, which lays the foundation for future interactions (Lefton-Greif, 2008). When there are difficulties in this aspect of health, the mother-infant bond is disrupted. Mothers may encounter challenges in fully embracing their maternal role when faced with difficulty or inability to feed their infants, often leading to them doubting their competency as mothers (Hewetson & Singh, 2009; Ilich, 2012). Breastfeeding has numerous benefits for mothers and infants, and is held as the gold standard for infant feeding (UNICEF, 2023). To many women who prenatally strive to breastfeed their infant, being unable to meet that goal due to prematurity, LBW, or other FSD is seen as a failure to fulfil their role as a mother (Jackson et al., 2022). The necessity of tube-feeding their infant due to feeding issues may evoke feelings of sorrow, self-blame and even trauma when infants require gastrostomies (Judson, 2004; Wilken, 2012). A South African study by Hewetson and Singh (2009) found that mothers who were unable to actively participate in their infant's feeding time as a primary feeder experienced feelings of inadequacy, helplessness, failure to be the 'ideal' mother, and a perceived loss of serving as an important role player in their child's development within the early period postpartum. For mothers, the ability to provide breastmilk or feed their infant contributes to a sense of competence in caring for their infant (Carton et al., 2020). This emphasises how the feeding interaction between infant and mother can shape the mother's experience and wellbeing.

During their infant's hospitalisation, emotional responses fluctuate, with many mothers describing the experience as particularly sensitive and emotionally challenging (Ilich, 2012). Caregivers have highlighted that feeding their hospitalised infant was a significant contributor to stress as feedings resulted in stressful exchanges (Lefton-Greif et al., 2014; Palmquist et al., 2020; Van Schalkwyk et al., 2021). These exchanges can create an increasingly difficult cycle

as stress and anxiety in both the infant and the caregivers can exacerbate feeding issues (Buys, 2020). Furthermore, mothers and caregivers might find themselves feeling overwhelmed and ill-equipped to manage the demands of caring for their infant who needs specialised feeding interventions (Hewetson & Singh, 2009), contributing to their apprehension and anxiety as caregivers.

While FSD impacts mothering, hospitalisation further affects the mother's experience of caring for their infant both physically and emotionally.

Mothering and hospitalisation

Caring for an infant becomes significantly challenging for mothers when prolonged hospitalisation is required (Carter et al., 2007). The hospital's physical environment is often perceived as clinical and intimidating, with the mother's overall experience being shaped by factors such as limited physical contact and bonding opportunities, parental anxieties and emotional responses (Ncube et al., 2016). Mothers' perceptions of their own capabilities and their experience are affected by these and other factors, examined in greater detail in the sections that follow.

Environment

Hospitals are clinical environments that are filled with unfamiliar machines, alarms and routines, all of which have been described as overwhelming and frightening by mothers in previous studies (Leonard, 2008; Pascoe et al., 2016; Trombini et al., 2008). Mothers describe Neonatal Intensive Care Unit (NICU) environments as intimidating, with physical equipment often restricting the contact between the mother and the infant, which is a common barrier for infants nursed in incubators (Ncube et al., 2016). Young infants with FSD are hospitalised either in a NICU or other paediatric units and typically require the use of medical equipment that reduces mothers' bonding opportunities, affecting infant and maternal wellbeing and interaction (Buys, 2020; Craig et al., 2015). However, as overwhelming as the environment and its procedures are perceived, mothers of newborns in the NICU reported that receiving

detailed explanations about medical equipment, its functions and the significance of alarms and alerts, greatly alleviated maternal stress (Williams et al., 2018).

Certain procedures in hospitals that involve separating mothers from their infants can exacerbate existing stress and negatively impact the mother-infant bond (Steyn et al., 2017). Baird et al. (2015) carried out a study examining how the rules of the Paediatric Intensive Care Unit (PICU) affect patient and family-centred care (PFCC). The study found that the unit's rules were a major point of conflict between parents and nurses. The parents expressed significant frustration over the restrictions that limited their ability to spend time freely with their children and made their interactions less natural and more rigid (Baird et al., 2015). Additional PICU rules, such as not having a bathroom available for caregivers in the unit and banning eating within the unit caused parents to break the rules to be with their children, overextend themselves so that they did not leave, or feeling stressed while they were away (Baird et al., 2015). A study conducted in South Korea explained that within most NICUs, even those in prestigious medical centres, mothers had to abide by restricted visitation protocol allowing them to see their infants only three times a day for a maximum of one hour (Kim, 2020). PICUs and NICUs are different environments with their own specific rules. Nonetheless, research findings in this section highlight the challenges that the physical environment presents to mothers.

Separation

Physical separation occurs in some contexts where infants are admitted but mothers do not stay with them in the same unit. Early physical separation from an infant shortly after birth can increase stress among caregivers, and prolonged separation may lead to heightened maternal stress, anxiety and depression (Flacking et al., 2012). Mothers highlighted that in the NICUs, physical separation is a critical barrier to the mother-infant dyad's relationship as it prevents interaction and bonding and amplifies maternal anxiety (Ncube et al., 2016). Separation may be due to the technological support required for the infant's survival but can also make mothers feel less confident and disconnected from their infants (Flacking et al., 2012). Separation reportedly cultivated fear in mothers in previous studies because they

worried about how it would impact the neonate (Carton et al., 2020; Martel et al., 2016; Nyström & Axelsson, 2002).

Physical contact between mother and infant has been noted as a key aspect to mitigate maternal fear and facilitate connection with the infant (Carton et al., 2020; Feeley et al., 2013; Fegran et al., 2008; Flacking et al., 2006; Hall et al., 2015; Heydarpour et al., 2017; Jabraeili et al., 2018; Ncube et al., 2016; Nyström & Axelsson, 2002; Schenk & Kelley, 2010). Mothers explain that physical contact is essential to "feel like a mother" (Carton et al., 2020; Fegran et al., 2008; Heydarpour et al., 2017; Jackson et al., 2022; Schenk & Kelley, 2010; Spinelli et al., 2016). Separation may also result when mothers are hesitant to touch and engage with their infants due to their illness or perceived fragility (Craig et al., 2015; Koliouli et al., 2022). In a study by Fernández Medina et al. (2018), some mothers explained that the appearance of their preterm or LBW infant incited feelings of rejection, apprehension and perceived distance as they felt the infants were foreign to them. The fear of physically touching and engaging with their infant in conjunction with physical separation consequent to the environment can significantly impact the dynamic between the dyad.

The World Health Organization (WHO) recognises that separating mothers and infants postnatally places infants at risk of mortality or long-term medical complications (Rao et al., 2021). This is particularly notable for infants born with LBW or prematurely and who require hospitalisation. Additionally, separating the dyad is a known inhibitor of breastmilk production and consumption (Madiba & Sengane, 2021). The WHO thus recommends the implementation and utilisation of Kangaroo Mother Care (KMC) as the best practice for premature and LBW infants (Madiba & Sengane, 2021; World Health Organization, 2020). South Africa was among a few countries that promptly accepted this recommendation and widely implemented KMC as the clinical standard in most of its healthcare facilities, recognising its cost-effective nature and evidence-based benefits (Bergh et al., 2014; Madiba & Sengane, 2021). KMC is an approach with empirical evidence known to decrease infant illness and death (Chan et al., 2017). KMC is widely regarded as the standard practice in many facilities, serving as a valuable tool to promote bonding, breastfeeding, maternal wellbeing, and close physical contact, while minimising infection intensity and improving sleep (Aziz, 2024). KMC is used in the research sites in this study, and is the established standard of care

as per the Western Cape Department of Health KMC policy and guidelines (Kangaroo Mother Care Provincial Task Team, 2003). The environments aim to align with WHO guidelines, ensuring a baby-friendly approach that supports both infant and maternal health and minimises the separation between infant and mother.

Effects on bonding and confidence

The natural bonding opportunities that a mother-infant dyad would have at home may be limited or delayed in the hospital setting. These activities include skin-to-skin contact, breastfeeding and other nurturing acts (Wang et al., 2021) that foster infant development and promote maternal welfare (Williamson et al., 2023). The lack of natural bonding opportunities places stress on the mother (Pascoe et al., 2016; Van Schalkwyk et al., 2021) and the infant, as early mutual bonding activities that would occur during the normal day-to-day routine are different/delayed in hospital. Bonding opportunities may be altered due to the constant presence of HCPs or other mothers, potentially impacting the way the dyad bonds as mothers feel 'watched' (Maleki et al., 2024; Prinsloo, 2024). Thus, being hospitalised interferes with the natural relationship formation between the dyad (Carter et al., 2007). Mothers feel more confident and attuned to their infant's behavioural cues with increased contact (Carton et al., 2020). Restricted interactions that prevent contact and bonding may cause skewed negative maternal perceptions of their parenting abilities and of their neonate (Van Schalkwyk et al., 2021). Bonding through physical touch during feeding times, soothing infants when they cry and responding to their cues are vital for maternal confidence and wellbeing.

Effects on emotions

The hospitalisation of a neonate can stir up an assortment of intense emotions ranging from distress and depression to moments of guilt and anger (Koliouli et al., 2022). Global studies illuminate the emotional toll having an ill or hospitalised infant has on the mother. Studies identify negative emotions like fear (Steyn et al., 2017; Wang et al., 2021), helplessness and incapability (Ncube et al., 2016; Steyn et al., 2017; Wright, 2011). The fear of causing harm to their neonates can compound apprehension to touch their fragile infant (Arnold et al., 2013;

Ncube et al., 2016; Wang et al., 2021). Spinelli et al. (2016) examined motherhood with a preterm infant, finding that mothers viewed themselves as potentially harmful to their infants. In another study by Steyn et al. (2017), mothers explained that they felt sad that they were unable to do more for their infants or spend more time with them.

Having infants admitted to units such as the NICU has been shown to magnify parental anxiety beyond the already existing stress about the infant's health (Carton et al., 2020), which may cause lasting trauma to mothers (Wang et al., 2021). Yaman and Altay (2015) studied the posttraumatic stress of parents with infants in the NICU and confirmed the increased likelihood of mothers presenting with and/or developing post-traumatic stress disorder (PTSD) due to the intensity and uncertainty of the stressful NICU environment, regardless of the severity of infant illness and length of hospitalisation. A Turkish study by Mizrak et al. (2015), which explored the anxiety levels of mothers of newborns in a NICU, found that mothers often experienced elevated levels of anxiety. Contributing factors were extended stays in the NICU, insufficient information regarding the infant's health status and the inability to provide direct care for their infants. Garg et al. (2023) found that mothers of premature infants in the NICU suffered notably increased stress, anxiety and depression in comparison to the control group in their study.

The experience of mothers caring for infants in NICUs may incite other feelings, such as uncertainty, helplessness and guilt (Obeidat et al., 2009). Mothers of premature infants can experience guilt brought about by feeling responsible for their child's prematurity (Thivierge et al., 2023). Guilt was also mentioned by mothers of children with dysphagia in a study highlighting the emotional load associated with paediatric feeding difficulties (Silva et al., 2023). Furthermore, feelings of guilt and shame emerged in mothers when there was a mismatch between the feeding expectation that was set during pregnancy and the reality of unforeseen challenges after the infant was born (Jackson et al., 2022).

Despite the negative feelings experienced, some mothers maintained hope for their infant's improvement (Ilich, 2012). The positive emotion of hopefulness can emerge when caring for a fragile or hospitalised infant, contributing to maternal coping (Alinejad-Naeini et al., 2021; Folkman & Moskowitz, 2004).

Role shift

Mothers find themselves navigating a complex medical environment in hospital, where their primary role shifts from traditional caregiver to becoming advocates and caretakers in a clinical setting (Carter et al., 2007). Mothers of infants in the NICU find themselves in the unique situation of having to give up a certain degree of responsibility for their infant (Carton et al., 2020). A significant component that affects mothers is how the care-taking roles alter during hospitalisation. In this environment, the usual familial structure is absent. Caretaking is not in the home but rather in a clinical environment where the HCPs are the major caretakers. One key issue is the feeling of alienation, where mothers are often left out of critical care processes such as feeding and medical decision-making. This shift can be disconcerting for parents, who have reported that the different parental role is the most worrying aspect of having their neonate in the NICU (Carter et al., 2007). Some mothers report feeling an emotional disconnect when nurses take their babies and assume most of the caregiving responsibilities (Wang et al., 2021). Mothers also express frustration when nurses take over tasks such as bathing or feeding without including the mothers in the process, leaving them feeling like bystanders in their own child's care (Grundvig Nylund et al., 2020). When mothers experience a sense of being an outsider in their infant's care (Carton et al., 2020), they feel a profound loss of their expected caregiving role, leading to feelings of inadequacy and helplessness (Koliouli et al., 2022). This suggests that in settings such as the NICU, mothers are reliant on the HCP to care for their infant, include themselves as mothers in their infant's care and, importantly, aid in facilitating the bonding between mother and infant (Alinejad-Naeini et al., 2021; Carton et al., 2020).

Healthcare providers' influence on the maternal experience

In hospital settings, HCPs play a central role in caring for the infant and involving parents, including providing information and counselling. In this setting, some mothers are faced with barriers such as lack of support, disjointed information and contradictory advice (Ericson & Palmer, 2019). Other challenges faced by parents include negative attitudes of healthcare

staff, complex administrative procedures (such as signing documents, and waiting for test results), lack of sufficient information about their newborn, and restrictions on visitation in some contexts (Yaman & Altay, 2015). Providing support to mothers and caregivers is multifaceted and breakdowns in any aspect can act as a barrier to mothering.

Inconsistent communication

Mothers have frequently identified inconsistent communication and lack of involvement in decision-making during critical periods of care as significant barriers to fulfilling their mothering role (Ncube et al., 2016; Steyn et al., 2017; Williams et al., 2018). Many mothers report that HCPs failed to clearly explain changes in their infant's care plan to them, leading to confusion and fear regarding the wellbeing of their child (Crowe et al., 2011; Williams et al., 2018). This issue is particularly evident in feeding decisions, where inconsistent or conflicting information from hospital staff has been shown to increase maternal stress, anxiety and feelings of being disregarded (Grundvig Nylund et al., 2020). A study detailing the parental experience of feeding their extremely premature infants revealed that such inconsistencies undermined maternal confidence and trust in the medical team (Ericson & Palmér, 2019). The lack of clear, timely and consistent communication hinders a mother's ability to make informed decisions about their infant's treatment (Steyn et al., 2017). Conflicting guidance from HCPs often results in feelings of uncertainty, causing mothers to question their ability to care for their infants and delaying their involvement in critical caregiving activities. In some cases, caregivers waited for explicit permission from HCPs before feeling comfortable engaging in caregiver tasks, further delaying their active participation in their child's care (Feeley et al., 2013). The delay in parental engagement can exacerbate feelings of detachment and helplessness during an already overwhelming period (Grundvig Nylund et al., 2020).

Caring for an infant in the hospital is undoubtedly a challenging experience. However, positive components also arise that facilitate caregiving and mothering in this setting. HCPs play a pivotal role in the hospital environment, offering essential support to caregivers by providing adequate information, encouragement, and hands-on training. These components empower

parents to navigate the complexities of their infant's care (Ncube et al., 2016; Steyn et al., 2017).

Positive interactions with HCPs

Positive interactions with HCPs can significantly improve mothers' experiences when caring for hospitalised infants. Mothers who reported encouraging interactions felt reassured by staff who actively listened and provided both emotional and practical support to help them cope with the challenges of caring for their infants (Ncube et al., 2016). These interactions often included HCPs facilitating greater involvement for mothers, which helped them participate more fully in their infants' care and decision-making processes and enhanced their sense of control and competence (Kestler-Peleg et al., 2022). In particular, nurses were frequently noted for their emotional and verbal support, offering a comforting presence and practical advice, which mothers found invaluable during their often stressful and uncertain time in the NICU (Steyn et al., 2017; Wang et al., 2021). This type of emotional encouragement strengthened mothers' sense of connection to their infants, increased their confidence in their caregiving abilities, and contributed to better psychological outcomes for both the mother and the infant, as a well-supported mother is more likely to bond effectively with her infant and experience less anxiety during hospitalisation.

The attitude and skills of HCPs significantly affect the overall experience of caregivers. Some mothers report feelings of anger towards doctors, who they perceive as unresponsive to their infant's pain or to their concerns (Steyn et al., 2017). Several studies have even described certain HCPs as "gatekeepers" who inadvertently obstruct parent-infant bonding opportunities (Carton et al., 2020; Feeley et al., 2013). Many mothers report feeling unwelcomed or excluded by the healthcare staff, leading to emotional distress and a lack of control over their child's care. Williams et al. (2018) explored environmental stressors and supports in the NICU, explaining that mothers in their study frequently noted how nurses' negative attitudes and rough handling of their infant incited significant stress. The HCPs'

attitude towards caregivers can also positively influence the maternal experience and caregiver wellbeing. HCPs who demonstrated empathy, addressed emotions, and actively involved caregivers by asking them questions and encouraging participation contributed to improved health outcomes and reduced psychological stress in caregivers (Williams et al., 2018). This underscores the significant impact of HCPs attitudes and interactions, which can serve as facilitators to mothering when positive or, conversely, as barriers when negative.

Support

Hospitals offer various support systems, both formal and informal, to mothers. Both systems are vital for mothers caring for their hospitalised infants. Formal support systems in the context of this study include professional services provided by HCPs such as doctors, nurses, SLTs, and social workers (Kestler-Peleg et al., 2022). These services may involve medical interventions, caregiver education, counselling, and family-centred care programmes. Informal support networks arise naturally through emotional and practical assistance from family, friends and peers (other mothers in the hospital) (Eduku et al., 2024; Kestler-Peleg et al., 2022). These resources create a space for mothers and caregivers to manage their emotional and taxing experiences (Wang et al., 2021).

In-hospital support

HCPs and counselling services offer structured assistance to mothers. Access to professional counselling is particularly beneficial in helping mothers cope with the overwhelming stress and anxiety associated with having a sick infant, as it offers a safe space for them to process their emotions and develop effective coping strategies (Carter et al., 2007). Kestler-Peleg et al. (2022) explored both informal and formal support for mothers' psychological distress during their infant's NICU hospitalisation. This study showed how formal, in-hospital support from medical staff significantly reduced the psychological distress experienced by mothers during their infant's hospitalisation in the NICU, more so than informal support systems (Kestler-Peleg et al., 2022). Formal support structures are essential for creating supportive and reassuring environments, ultimately contributing to better mental health outcomes for mothers and allowing them to better mother their infants.

Information provided by HCPs led to increased maternal confidence and reduced anxiety (Abdeyazdan et al., 2014; Eduku et al., 2024; World Health Organization, 2023). When parents were provided with accurate and regular information and were encouraged by the staff, their hopefulness significantly increased (Steyn et al., 2017; Williams et al., 2018). Mothers' confidence in their own abilities increased when they received comprehensive education about their infant's condition and caregiving techniques, leading to improved neonatal outcomes, such as shorter hospital stay and improved breastfeeding incidence (Ncube et al., 2016; Wang et al., 2021; World Health Organization, 2023; Zhang et al., 2021). Furthermore, the literature suggests that caregivers feel more at ease when medical staff normalise the infant's appearance and symptoms through open discussions, one-on-one training and education (Goral & Geçkil, 2022; Miles et al., 1992; Trombini et al., 2008). Yilmaz and Küçük Alemdar's (2022) randomised control study examined supportive nursing strategies and their effect on maternal anxiety in NICUs. The authors found that clarification and information on the infant's status decreased anxiety in mothers. By providing clear and empathetic explanations, HCPs can help alleviate parental concerns and clarify medical conditions, reducing stress and fostering a sense of understanding and control for parents. Caregiver education and training by HCPs includes teaching mothers about their infant's condition, the impact of FSD and certain medical procedures, in addition to providing hands-on guidance (World Health Organization, 2023; Johnson, 2008; Yilmaz & Küçük Alemdar, 2022). These educational aspects are key to supporting mothers and are linked to improving perceived competence and reducing anxiety about their roles (Steyn et al., 2017). Kim's (2020) study aimed to address the needs of mothers caring for infants in NICUs. The author explained that mothers in their study mainly sought more support from NICU staff in educating them on their infant and advising on infant care. Mothers of neonates explained that the hands-on demonstrations of feeding practices by the nurses (e.g., how to breastfeed) were vital to making them feel supported and confident (Ericson & Palmér, 2019). This finding underscores the importance of effective communication and support from HCPs, as addressing parental perceptions, concerns and confidence can significantly alleviate stress and improve the overall caregiving experience (Trombini et al., 2008).

Mothers who spend most of their time caring for their infant in the NICU either stay in hospital or spend most of their day going to hospital to care for their infants. Thus, they typically have few opportunities to be with their personal support systems out of hospital, and often perceive a shift in their support system (Steyn et al., 2017). As the mother is away from her network, she is reliant on the available support within the hospital environment, which includes both HCPs and other mothers in their units (Ncube et al., 2016). Mothers of other hospitalised infants may be able to understand and share the experience and help each other through it (Rossman et al., 2017). This peer support, in hospital, allows mothers to share their experiences, advice and emotional support, creating a sense of community to mitigate feelings of isolation and provide practical tips for caring for their infant (Steyn et al., 2017). Some parents explored online support and joined digital groups of parents that are currently in, or have experienced, the same situation (Neu et al., 2020). Informal online networks can offer an accessible means of sharing stories and support, done at the pace and choice of the caregiver (Ericson & Palmér, 2019; Feeley et al., 2013).

Out-of-hospital support

Family and community support outside of the hospital also play a crucial role in helping mothers to cope with the challenges of having a hospitalised infant with FSD (Eduku et al., 2024). Several studies highlight the significance of support structures that mothers rely on during this difficult time, ranging from close family members to community networks.

A major source of support comes from family members, particularly partners, who are often cited as pivotal in providing emotional and practical assistance during the hospitalisation (Kestler-Peleg et al., 2020; Wang et al., 2021). As a primary source of emotional support, partners can help share the caregiving burden and offer comfort and reassurance during stressful moments. Their presence helps alleviate feelings of isolation and anxiety, making it easier for mothers to cope with the demands of caring for an ill infant (Ncube et al., 2016; Wang et al., 2021). In addition to partners, parental figures, such as the mothers' own parents, also play a significant role in offering support (Rossman et al., 2017). They may assist with caregiving responsibilities, provide reassurance, and often help by managing household tasks or caring for other children at home, allowing mothers to focus on their hospitalised infants

(Steyn et al., 2017). Extended family members, particularly grandparents, further contribute by stepping in to share the load, assisting with daily chores, and offering emotional backing (Feeley et al., 2013). This support network may significantly reduce the mothers' responsibilities, creating a less stressful environment that enables them to focus on their child's wellbeing.

In addition to family, community support systems, including friends, neighbours, and community organisations, also play a vital role in the informal support network for mothers (Köse & Ayran, 2024). Practical assistance from friends and neighbours, such as transportation to the hospital, meal preparation, and childcare, can significantly alleviate some of the everyday burdens faced by mothers (Buys, 2020). Community organisations and peer support groups also provide emotional and social support, offering mothers an outlet to share their experiences and feel understood in a non-judgemental space (Hall et al., 2015; Steyn et al., 2017). These external support systems can help reduce the overwhelming responsibilities that mothers might face, contributing to better emotional outcomes during their infant's hospital stay.

Despite the availability of external support, not all mothers are able to seek help or have open conversations with friends and family about their experiences. Some mothers report that family dynamics, fear of being perceived as unable to manage the situation, and fear of causing additional worry for their loved ones, deter them from reaching out for assistance, which can lead to feelings of isolation despite the availability of support (Steyn et al., 2017). Other mothers reported that they distanced themselves from individuals typically in their support circles because they were unable to understand their experience, leaving them unable to support them (Gibson et al., 2021; Rossman et al., 2017). These barriers underscore the importance of creating more accessible support systems and encouraging open communication between caregivers and their networks (Steyn et al., 2017).

Maternal coping

Maternal coping in the context of caring for medically vulnerable infants, such as those with FSD in neonatal units, is a dynamic and multifaceted process. Mothers in this context often face overwhelming emotional, physical and psychological challenges as they adapt to their unfamiliar environment and caring for a fragile hospitalised infant (Kestler-Peleg et al., 2020). Mothers frequently develop remarkable resilience, drawing on a combination of internal strength and external support systems to navigate their caregiving responsibilities and make use of coping strategies throughout their journey (Kestler-Peleg et al., 2022; Sih et al., 2019; Stacey et al., 2015). Coping strategies have been well-defined into two categories: problem-focused and emotion-focused coping, as explained by Folkman and Moskowitz (2004) and Stanisławski (2019). Problem-focused coping includes tackling the issue that is causing distress directly through planning, active problem-solving and addressing the problem directly (Folkman & Moskowitz, 2004). This aligns with mothers seeking more information from HCPs to better understand the condition and be trained on how to administer and carry out certain tasks to play an active role in caring for their child and their health needs. Emotion-focused coping pertains to regulating emotions during periods of stress by finding acceptance or reframing the situation in a positive light (Folkman & Moskowitz, 2004). This includes turning to religion and/or spirituality to give them strength or staying positive and 'strong' for the infant and maintaining a hopeful disposition throughout the experience (Rossman et al., 2017; Sih et al., 2019).

A study detailing resilience in mothers of VLBW infants in the NICU found that mothers managed their experience by remaining composed and focusing on their infant's needs (Rossman et al., 2017). The authors grouped coping strategies into three categories, namely, meaning-making, managing distress, and fostering positive emotions. Meaning-making mothers navigated the challenges of their situation by leading meaningful and fulfilling lives despite their struggles. They viewed challenges as opportunities to learn or increase their appreciation of moments with their infants and, ultimately, life (Rossman et al., 2017). Mothers managing distress developed the ability to endure and process negative emotions, while those fostering positive emotions did so through reflection, self-awareness and prioritising their psychological health to promote improved infant outcomes (Rossman et al., 2017). The coping strategies described by Rossman et al. (2017) provide clear examples of emotion-focused coping. In another study investigating coping strategies and the maternal

role of Iranian mothers with preterm neonates in the NICU, Alinejad-Naeini et al. (2021) divided coping into support-seeking, spirituality, hope creation, and energy generation from the infant. Support-seeking involved mothers drawing on assistance from peers, spouses, and other caregivers to manage challenges. Spiritual support was used by mothers who engaged with faith-based practices, seeking help through prayer, believing in destiny and fostering a spiritual mindset (Alinejad-Naeini et al., 2021). Similarly, a South African study by Sih et al. (2019) found that praying, along with infant attachment and acceptance, was a main strategy used by mothers with infants in the NICU. Mothers prayed for strength and/or gave thanks (Sih et al., 2019). Hope creation (Alinejad-Naeini et al., 2021) was a strategy mothers implemented as they built their inner self-hope by either thinking of positive moments and being hopeful for the future or generating hope when seeing progress and improvement in the infant. Lastly, mothers gained energy and joy from their babies when they experienced positive interactions with them, explaining that proximity and engaging in caregiving tasks were motivating and comforting (Alinejad-Naeini et al., 2021). Similarly, Sih et al. (2019) described how mothers wanted to spend their time bonding with their infant, being near and sharing positive moments with their child (Sih et al., 2019). Problem-focused strategies in their study included seeking support and gaining joy from caregiving tasks and proximity. Emotion-focused strategies involved managing distress, fostering positive emotions, turning to spirituality, creating hope through positive reflections, and finding meaning in the challenges faced.

The coping strategies outlined highlight the importance of both practical actions and emotional regulation in helping mothers navigate the challenges of caring for vulnerable and hospitalised infants. These finding underscore the value of creating environments that promote maternal resilience and engagement in their infants' care. This aligns closely with the principles of family-centred care (FCC), which emphasise the inclusion of families as active partners. By addressing both emotional and practical needs, FCC is a framework that empowers mothers, fosters collaboration with HCPs and supports improved outcomes for infants and families (Umberger et al., 2018).

Family-centred care (FCC)

When mothers feel supported, informed and included, their confidence and wellbeing is positively affected, which ultimately supports their care of their infant. Including caregivers in the healthcare management of the infant is central to the FCC model, an approach often used in NICU and other hospital environments. The FCC approach emphasises inclusion and active participation in healthcare, recognising the critical role that caregivers play in their infant's care. Mothers have explained that supporting them entails integrating mothers into medical decision-making and caregiving tasks, which coincides with the aims of the FCC approach (Banerjee et al., 2017). FCC is widely regarded as the ideal hospital approach globally, and there has been large scale acknowledgment of the need to understand maternal psychological wellbeing and the importance of offering support to enhance the mother and infant's health outcomes (Kestler-Peleg et al., 2022; Offer & Taubman-Ben-Ari, 2024). FCC is a preferred approach because its principles are core in guiding the formal support that medical staff provide to caregivers (Kestler-Peleg et al., 2022). However, the reality of the implementation of the FCC approach in resource-limited countries (LMICs), such as South Africa, is unclear.

Benefits of FCC

The implementation of FCC has significant benefits for infants and their caregivers, particularly within vulnerable populations, such as preterm, critically ill infants and infants with FSD. One significant advantage of FCC is that it promotes bonding between the mother and the infant, which can be particularly challenging in environments such as the NICU where parents often feel alienated due to the medicalised nature of care (Ericson & Palmér, 2019). FCC encourages parental involvement in care activities such as feeding, diaper changes and skin-to-skin contact, strengthening the mother-infant bond (Banerjee et al., 2017; Ericson & Palmér, 2019; Steyn et al., 2017; Umberger et al., 2018). These bonding opportunities are vital for the infant's emotional and psychological development and to foster a secure attachment between the infant and parents (Carter et al., 2007). When implemented correctly, FCC provides essential emotional support to caregivers during a highly stressful time. The collaborative approach helps create a supportive environment where parents can share their

concerns and receive encouragement from HCPs (Ding et al., 2019; Steyn et al., 2017). This support network, outlined above, is critical in helping caregivers cope with the emotional and physical challenges of having a hospitalised infant with FSD (Kestler-Peleg et al., 2022).

As already noted, the experience of having an ill and hospitalised infant is highly stressful and traumatic. However, these challenges can be reduced when appropriate and timely support is provided. For mothers of preterm infants, particularly in resource-limited countries, FCC offers the potential to mitigate some of the emotional and psychological burdens associated with neonatal hospitalisation. FCC fosters a sense of competence and empowerment by involving mothers directly in care, which is necessary for maternal mental health and the infant's developmental progress (Banerjee et al., 2017; Umberger et al., 2018). The FCC model significantly decreases caregiver psychological distress (Ding et al., 2019; Kestler-Peleg et al., 2022; Umberger et al., 2018). Active maternal participation in care processes, central to FCC, helps enhance mothers' sense of control, as they are contributing to their child's health outcomes (Gómez-Cantarino et al., 2020). This empowerment also leads to better preparation for the transition from hospital to home because caregivers feel more equipped to manage their infant's needs after discharge (Mirlashari et al., 2020).

Research indicates that FCC can lead to better health outcomes for infants. When caregivers are actively involved in their infants' care and caregiving tasks, infants often experience shorter hospital stays, improved weight gain and better overall health (Larocque et al., 2021; Ncube et al., 2016;). Involving mothers in promoting safe and efficient feeding with the goal of going home is emphasised because difficulty feeding is a major contributing factor preventing discharge. Additionally, the presence of family members, promoted in FCC, provides emotional comfort and stability for the infant, which is crucial for their development and recovery (Larocque et al., 2021; Wang et al., 2021; Yu et al., 2019).

Limitations of FCC in resource-limited contexts

Despite its benefits, implementing FCC involves significant challenges, particularly in LMICs. Major limitations include the lack of resources and training for HCPs in FCC practices, institutional barriers, and infrastructure to support the consistent application of FCC

principles. In such settings, overcrowded hospitals and limited staffing make it difficult for HCPs to dedicate the time and resources needed to involve parents in care (Mirlashari et al., 2020). Implementing this approach cannot be successful without ensuring all staff are trained and the necessary resources are available (Carton et al., 2020). Most research explaining the benefits of FCC was conducted in well-resourced countries. Thus, the effectiveness and reality of its implementation in resource-limited settings should be considered (Phiri et al., 2020). Some research in low-income settings reported caregiver dissatisfaction with FCC because it was ineffectively implemented with a lack of knowledge from HCPs, was not feasible in the context, created additional workload for nurses, or potentially increased infection risk if caregivers were not properly informed or compliant with health protocols and procedures (Hoffman et al., 2012; Phiri et al., 2020; Sarin & Maria, 2019). Malepe et al. (2022) investigated FCC implementation in the Gauteng province of South Africa, and found local obstacles to implementing FCC, including challenges in the nurse–primary caregiver relationship (due to negative attitudes, perceived interference, and mistrust), the level of caregiver involvement (limited communication and information sharing; limited involvement in decision-making), the layout of the ward (lack of space and privacy), and existing ward policies (on visiting times and staying in).

Inadequate training of HCPs in FCC principles further limits its implementation in LMICs. In such settings, healthcare workers may focus primarily on the infants' medical needs, neglecting the emotional and psychological support required by parents (Mirlashari et al., 2020). The scarcity of psychosocial support services also means that many families do not receive the emotional and mental health support that is integral to FCC (Mirlashari et al., 2020). These barriers underscore the need for systemic change, such as better staff training and more family-orientated policies, to fully realise the potential benefits of FCC in LMICs (Banerjee et al., 2017). Given the limited research on FCC with validated tools in resource-limited countries like South Africa, it is difficult to tailor the framework to the needs of the population (Phiri et al., 2020). A study by Toivonen et al. (2020) that investigated an intervention using close collaboration with parents to improve FCC found that educational intervention on FCC improved all components of FCC in NICU settings. In this study, the staff and parents established a mutually beneficial and collaborative partnership by training staff on how to engage with parents and value their insights about their child, allowing them

emotional space, collaboratively developing a care plan, understanding their journey and including them in decision-making. This study dispelled the notion that parental involvement should only occur once the infant is medically stable, demonstrating that parents can actively participate in their infant's care even during the intensive care phase (Toivonen et al., 2020), which ultimately alleviates some workload for HCPs such as nurses. Hoffman et al. (2012) researched the role of family/caregivers in the hospital and detailed how nurses noted that, given the shortage of healthcare workers, caregivers were essential in supporting patients' wellbeing by helping with daily care activities, monitoring their health and acting as advocates for the patients (Hoffman et al., 2012).

The challenges in implementing FCC and the essential role of caregivers highlight the need for improvement in creating comprehensive support systems within hospital settings. For mothers of infants with FSD, these challenges are particularly pronounced as they navigate emotional strain and practical caregiving demands alongside systemic barriers. Recognising these mothers' experiences and the role they play in their infants' care underscores the importance of interventions tailored to their experience and the need for supportive environments. Existing barriers must be addressed and opportunities created to improve maternal involvement, ultimately enhancing outcomes for the mother-infant dyad.

Conclusion

Mothers of infants with FSD require a comprehensive combination of informational, emotional, and practical support to navigate the challenges of caregiving in hospital settings. HCPs must be attuned to these needs to improve the facilitation of mothering, fostering greater confidence and skill in mothers and enhancing the wellbeing of both the infant and the family (Adama et al., 2022; Ronan et al., 2020). In the South African context, the development of contextually relevant resources and guidelines is essential to ensure that care practices are tailored to meet the unique challenges faced by mothers and infants, optimising their outcomes both in-hospital and after discharge. Although there has been valuable research involving caregivers of premature infants, who frequently present with FSD, it is vital to broaden the scope to specifically target the experiences of mothers of infants with FSD

across diverse medical conditions, offering a more nuanced perspective on the specific challenges and needs of this population (Hewetson & Singh, 2009).

This study will explore the multifaceted dimensions of mothering within the hospital environment, where the delicate balance between practical caregiving and emotional engagement is shaped by barriers, facilitators, and support structures. By focusing on the experiences of mothers of infants with FSD, the research seeks to uncover the unique challenges and complexities of mothering these infants in a resource-constrained hospital setting. A deeper understanding of these experiences will give mothers a voice to guide the development of more effective support systems and practices, to work towards improving the care provided in South African public hospitals. This study's insights will help inform the design of interventions for SLTs and other HCPs, so that they can better meet the emotional and practical needs of mothers caring for vulnerable infants hospitalised with FSD, contributing to better health outcomes for both mother and child.

Chapter 2: Methodology

Research question

What are the barriers, facilitators, and support to mothering, identified by mothers of young infants with feeding and swallowing difficulties in a South African healthcare setting?

Aim

To explore the experiences of 'mothering' a young infant with feeding and swallowing difficulties in a South African healthcare context.

Objective

To achieve the aim, mothers' self-reported experiences of barriers, facilitators and support needs within a neonatal healthcare context were described.

Research design

A qualitative, exploratory, case study research design was used for this study. A case study methodology was considered to be best suited for this research as it enabled the researcher to obtain an in-depth understanding of a particular phenomenon (Sibbald et al., 2021). Case studies use the detailed accounts of participants to offer insights into a 'case' to define a larger phenomenon (Crowe et al., 2011). In this study the 'case' was a group of mothers of neonates/young infants with FSD. The phenomenon being described was the experiences of these mothers in caring for their infants with FSD, as well as the barriers, facilitators, and support mechanisms within South African healthcare contexts. Qualitative case study research affords the researcher the flexibility to explore contextual factors (Sibbald et al., 2021), allowing the study to be moulded by the nuances of each case and provide an authentic portrayal of participants' experiences (Ebneyamini & Sadeghi Moghadam, 2018).

Qualitative research has inherent limitations, including the inability to establish causality and the lack of statistical representation (Queirós et al., 2017). However, it is important to note that the objective of this study was not to establish causal relationships or produce statistical data. Rather, the aim was to shed light on the experiences of mothers within this context. Another potential concern was the influence of the researcher's interpretation on the observations and conclusions of the study (Queirós et al., 2017). To mitigate this limitation, the researcher implemented several measures to ensure the trustworthiness of the results, outlined in the Trustworthiness section of the chapter.

Participants

The study included seven mothers of infants with FSD (*n*=7). Five participants were from Mowbray Maternity Hospital (MMH) and 2 participants from Red Cross War Memorial Children's Hospital (RCWMCH), in Cape Town, Western Cape. The mothers who participated had been admitted in the units for more than seven days.

Selection criteria

Participants in this study were mothers of young infants hospitalised in high dependency or intensive care units at either MMH or RCWMCH. The infants had been diagnosed with FSD by the facility's SLT. Participants' infants were required to be medically stable and have been hospitalised at the healthcare facility for a minimum of seven days. The age range of the infants included in the study was from birth to three months. The criterion of medical stability was established to mitigate parental distress, as stable infants are likely to elicit less emotional turmoil from their parents, thereby optimising their capacity to consent to and participate in the research. This was done to uphold the ethical obligation to safeguard this vulnerable population (Morrow et al., 2015). Additionally, the seven-day minimum hospitalisation period aimed to ensure that participants had been adequately exposed to the environment and encountered potential barriers and facilitators relevant to the research question. There were no additional exclusion criteria for participants and their neonates/young infants, fostering a diverse sample to capture a range of experiences. This inclusivity enhanced the richness of

the data and facilitated the transferability of the study findings, as suggested by Malterud et al. (2016).

Sampling method

Purposive sampling was used to select participants who met the inclusion criteria. To best explore the research question, the participants needed to be meaningfully selected so that they could provide rich accounts of their experiences. The use of purposive sampling was therefore appropriate to identify participants (Etikan, 2016).

Sample size

The sample for this study included seven participants. This size was guided by the principle of data saturation, which is frequently employed in qualitative research. This approach states that data collection and analysis are continued until there is data/theoretical saturation: the point at which no new information or themes emerge (van Rijnsoever, 2017). This method was used as it encourages collecting data until comprehensive insight about a topic is gained. The sample of seven participants was the number at which data saturation was observed, signalling the conclusion of data collection.

The small sample size in this research aligns with the methodology of case study research, which emphasises depth over breadth (Boddy, 2016). Although Hennink et al. (2017) found thematic saturation typically occurred after nine interviews, Boddy (2016) challenged that even a case study with a single participant can produce in-depth knowledge and is of equal importance. Research suggests that knowing when data saturation is reached should be left to the discretion of the researcher because it is guided by previous research experience and intuition, and thus, was used to guide this study's data collection process (van Rijnsoever, 2017). With fewer participants, the researcher could delve deeply into each individual's experience, providing rich and detailed accounts (Vasileiou et al., 2018). Additionally, multiple participant accounts allowed for the identification of common themes, enhancing the representativeness of the findings within the context of maternal experiences in this study setting. As this study aimed to generate comprehensive insights into the experiences of

participants and identify central themes within those experiences, a sample size of seven made that achievable.

Research context

The research context included paediatric or neonatal units at MMH and RCWMCH. Mothers of young infants with FSD admitted to these units and who met the inclusion criteria were invited to participate.

MMH is a level 2 public sector hospital specialising in maternal and newborn care. It is situated in Metro West, Mowbray, Cape Town and treats patients with complicated obstetric and neonatal referrals from the surrounding primary care units (Mowbray Maternity Hospital, Obstetrics and Gynaecology, 2022). MMH has 73 neonatal beds and delivers 10 000 babies annually (Mowbray Maternity Hospital, Obstetrics and Gynaecology, 2022).

RCWMCH is in Rondebosch, Cape Town. It is a tertiary level facility that provides extensive paediatric services with a full range of sub-specialties at quaternary, tertiary, and secondary levels of care (Red Cross War Memorial Children's Hospital: Overview, Western Cape Government, 2022). The 10-bed neonatal high care unit and medical wards were the context for this study.

Researcher

I am an SLT who obtained her qualification from the University of Cape Town in 2020. Following this, I completed my community service year in rural Mpumalanga where I discovered a passion for neonatal dysphagia. Concurrently, I embarked on studies to become a South African Certified Lactation Consultant, achieving certification in August 2022. My experiences as the sole SLT and a lactation consultant at a hospital provided first-hand insights into the challenges faced by mothers and their infants, particularly when admitted for extended periods because of feeding difficulties. Witnessing the profound impact of these challenges on maternal wellbeing ignited a need to delve deeper into this area of study. I am committed to giving a voice to mothers of neonates/young infants with FSD.

Research personnel

The data collection process made use of a research assistant (RA). The RA who was selected to assist with the study took on the role of recruitment and conducting interviews under the guidance of the research supervisor and in collaboration with the researcher. The researcher initially aimed to conduct the interviews herself. However, there was difficulty recruiting participants, and after being in Cape Town for 6 weeks the researcher had to return to Gauteng. The RA used in this study was an SLT who works in the clinical area of neonatal and paediatric dysphagia and had experience conducting interviews for research with participants of the same population. An interpreter, a qualified HCP, assisted with four interviews where the participants' home language was isiXhosa. Both the interpreter and RA signed confidentiality agreements to protect the participants and the integrity of the research (Appendix A).

Recruitment

After ethics approval was obtained from the University of Cape Town's Human Research Ethics Committee (HREC) (Appendix B) the study was registered with the National Health Research Database (NHRD) (Appendix C). Permission was then requested and obtained from the research committees of RCWMCH (Appendix D) and MMH (Appendix E). Once all permissions had been obtained, recruitment began. The researcher met with the SLT at RCWMCH and gave a brief overview of the study, explained the selection criteria for participants and asked the SLT to contact either the researcher or research supervisor if potential candidates were identified so that they could be recruited. After this discussion, the SLT working in the selected healthcare facility identified potential participants based on the study's selection criteria. The SLT at MMH was the research supervisor and thus was aware of the selection criteria for the participants. Thereafter, the identified mothers were invited to participate in the study by the RA, who provided the potential participants with information about the study in their preferred language of English, Afrikaans or isiXhosa, as the predominant languages spoken in the Western Cape (Appendix F). Once the RA was confident that the mother fully understood the nature of the study and all its implications, the mother could decide whether to participate in the study or not. The mothers were given an opportunity to ask the RA about the study and were given time to consider the participation

request, usually between 1–2 days. Those who agreed to participate completed an informed consent form (Appendix G) before becoming a participant. Thereafter, a date and time for the interview were scheduled at the participant's convenience at the hospital.

Materials

1. Interview guide

Semi-structured, in-depth interviews were employed as the primary method of data collection for this research study. This approach was chosen to delve into the nuanced thoughts, feelings, and experiences of the participants, given that semi-structured interviews generate in-depth descriptions of the experiences of the participants (Baumbusch, 2010), which was the cornerstone of this study. Semi-structured interviews also offer flexibility and foster reciprocity between the researcher and participants (Kallio et al., 2016).

Each interview session followed a discourse format guided by an interview guide (Appendix H), which comprised general biographical information, open-ended questions, follow-up inquiries, and probes (DeJonckheere & Vaughn, 2019). This guide served as an aid to direct the conversation to be relevant to the research question. The development of the interview guide involved crafting a series of questions aimed at eliciting data relevant to the study aims and objectives. The interview guide was thoughtfully devised, with the questions based on previous similar studies conducted by the research supervisor and studies published locally and internationally. The compilation of the guide was important as the quality of the guide influences the interviews and the data collected (Kallio et al., 2016).

The sequence of questions followed a logical progression, starting with broad context-setting inquiries and gradually funnelling down to more specific questions, as suggested by Baumbusch (2010). These questions were intentionally open-ended, neutral, contextually appropriate, and non-leading (DeJonckheere & Vaughn, 2019). The formulation of the questions was informed by prior research interviews and the clinical expertise of the research supervisor and researcher. The questions aimed to prompt a rich description of the participant's experience and thus were an amalgamation of open-ended "who, what, where, when, why and how" questions (Chenail, 2011) and "tell me about…" story-inducing questions

(Baumbusch, 2010). A total of six questions, each accompanied by pre-designed prompts, were included to ensure consistency and thoroughness. The guide included follow-up prompts designed to elicit more detailed information from participants (Kallio et al., 2016) or to redirect participants to the matter being discussed if the conversation had deviated (Baumbusch, 2010; Ryan, 2009). Care was taken to avoid medical jargon, and the language and tone of the questions were carefully considered to facilitate participant comprehension and comfort. Additionally, the interview guide was forward and back-translated to ensure accuracy of translation before being used in the interviews.

2. *Recording device*

The RA recorded the audio of each interview using two separate digital recording devices. Two devices were used in case there was a fault with one of the recorders. Both devices were password-protected with restricted access allowing only the researcher and RA access to the recordings.

Data collection procedures

After approval was obtained from the Faculty of Health Sciences' HREC, the researcher obtained permission from the Department of Health, RCWMCH and MMH, as well as the relevant departments within the hospitals. Recruitment began in May 2023 after all permissions were given. Thereafter, the researcher contacted the onsite SLTs in the neonatal units to discuss the research and ask if they were willing to help identify potential participants who met the inclusion criteria for the study. At RCWMCH, a meeting with the onsite SLT and the researcher was arranged. The researcher explained the study's aims and objectives and the selection criteria for participants for the study. It was explained that it would be best to identify participants once the infants were medically stable and only if they had been at the hospital for more than seven days. The SLTs agreed and informed the research supervisor when there were mothers who fit the criteria to invite them to participate in the study. At MMH, the research supervisor was the onsite SLT and referred potential participants to the RA. Once the SLTs identified potential participants, the RA was informed, approached the mothers and provided them with information about the study. The research was explained, and all benefits and risks were discussed in their preferred language, with the assistance of

the interpreter when necessary. The RA gave the participants 1–2 days to consider the invitation to participate to ensure that they were not placed under pressure to decide. The RA arranged a date and time for the interview with those mothers who agreed to participate and had signed consent forms.

A private room in the facility was used to conduct the interviews. The RA ensured it was a safe and quiet space with no distractions or other patients or hospital staff who could infringe the participant's privacy. The participants were reminded that participation was voluntary (as had been explained when they provided consent), and that they had the right to withdraw at any point. Furthermore, it was explained that the interview was not part of the medical treatment and their participation or withdrawal from the study would not affect the treatment of their infant in any way.

The RA, with the assistance of the interpreter, interviewed participants using the interview guide and encouraged the participants to discuss their experiences. All interviews were conducted in the participants' preferred language of which, 3 interviews were conducted in isiXhosa and 4 were conducted in English. An audio-only recording was made of the interview while the RA made some additional notes. A procedural checklist was created by the researcher to ensure the consistency of the interview procedures. The checklist outlined the order the interview should follow, such as starting with biographical questions and then moving on to the interview guide questions. The guide also included reminders about active listening and recommended phrases to support and reassure the participant. The RA used the procedural checklist during all seven interviews. At the end of each interview, the RA summarised the participant's answers to ensure that the researcher had captured their account accurately. The participant was given an opportunity to confirm whether the interviewer understood their experience and they could correct the interviewer or add additional information. Most participants added to the summary and concurred with the interviewer's synopsis. The interviews were on average between 25–30 minutes except for one interview that lasted for one hour and 17 minutes. When data saturation was reached, recruitment of new participants was suspended, and no new interviews were scheduled. The data collection process was concluded in March 2024, taking approximately ten months in

total. The extended recruitment and data collection period pertained to difficulty finding participants that fit the selection criteria. An amendment was made halfway through the data collection process to expand recruitment to participants not only in the neonatal high-care units but other infant units in the hospital.

Transcription took place after each interview, with the participant's personal information being removed from the data. An interpreter was required for three of the interviews where the participants' home language was isiXhosa. The interpreter assisted with a fourth interview that was conducted in English at the mother's request, but was present to provide the mother with the option of switching languages if she wished to do so. These interviews were transcribed and translated by the interpreter and sent to the researcher, while the English interviews were transcribed solely by the researcher. The transcription and translation of the interviews is discussed further in the Trustworthiness section of the chapter.

Data management

The hardcopies of the completed case history form and interview questions were secured in a locked filing cupboard in an access- controlled office of the research supervisor. Each audio recording and subsequent transcribed file was labelled chronologically as they occurred and with a label indicating the hospital the participant was from, i.e., MMH 1. All digital data were stored on a password protected laptop that had been installed with antivirus software that upheld trusted firewalls. Microsoft Word was used to edit the data and research. All files were kept on a password protected document and stored on the UCT OneDrive storage platform. Once the dissertation was written up, all the data and relevant information were transferred to the research supervisor based at UCT, where it will be stored securely for five years after publication. All information has been removed from the researcher's personal devices and accounts.

Trustworthiness

Trustworthiness in the study was addressed through credibility, dependability, confirmability, and transferability (Connelly, 2016).

Credibility

Credibility is a measure of the accuracy of a study's findings. Techniques that the researcher implemented to ensure credibility included peer-debriefing, verbal member-checking, and reflective journaling (Connelly, 2016). Member-checking in this study was done verbally at the end of the interviews (Stahl & King, 2020). Upon the conclusion of an interview, the RA summarised the information collected in the interview back to the participant. The participant was then asked if the interviewer's information was correct and given an opportunity to add more information, which was also recorded. The inclusion of member-checking reinforced the research credibility as it provided a space for the researcher to assess their interpretations retrospectively (Stahl & King, 2020).

Additionally, peer-debriefing was done frequently throughout the data collection and analysis process. After the interviews were conducted, the RA discussed each one with the researcher, including the findings and topics that commonly came up. During the collection phase, after most of the interviews, the RA, interpreter and research supervisor discussed how they perceived the mothers' feelings and the information brought forward by the participants. Frequent discussions took place between the supervisor and researcher regarding the evolving data analysis process and what the data had shown. Once the researcher and the supervisor had collaboratively decided on the themes to be discussed, the themes and meaning units were sent to the co-supervisor for a fresh perspective on the data, adding another component of peer-debriefing to the study.

The researcher kept a process log showing the dates she re-visited the data and a record of discussions with the research supervisor. Throughout the study, the researcher made use of a reflexive journal. Reflexivity is important for qualitative researchers because they need to frequently self-reflect to consider their preconceptions and biases and how these may affect the research (King, 2022). The researcher maintained a journal and wrote down her thoughts during recruitment, data collection, and data analysis. Self-reflection also took place at the

beginning and end of each section of the study to note how the research, literature and process had influenced her thought processes and ideas about the research.

Dependability

Dependability refers to how consistent and reliable the results of the study are (Connelly, 2016) and how much one can trust the research (Stahl & King, 2020). To ensure dependability, the researcher included an audit trail of process logs and peer debriefing with her supervisors. Process logs include the researcher's notes on all aspects of the decision-making process (Connelly, 2016). The researcher kept a digital log of all meetings and peer debriefings with the supervisors, with all questions and answers that were discussed in the meeting. Moreover, making use of items such as the interview process checklist and interview guide helped enforce dependability and ensure that the same process was followed for each participant and each interview. All drafts of each section of the study were kept and dated with the comments so that the evolution of the study could be followed and all changes in the study could be tracked. Peer debriefing was a crucial method frequently employed during the data collection and analysis of this study. As explained above, peer debriefing took place at almost every step of the process, reinforcing the trustworthiness of the research by maintaining dependability throughout (Stahl & King, 2020).

Confirmability

Confirmability is the degree to which the research findings are consistent and can be repeated (Connelly, 2016). The researcher achieved confirmability by ensuring an audit trail of analysis and methodological processes. Notably, the study made use of a third-party, qualified SLT to conduct the interviews. The same RA was used for all seven interviews. She was not involved in the write-up of the study and was largely impartial to the results, thereby enhancing confirmability of the data collection process (Ahmed, 2024). The RA's notes were discussed during member-checking with the participants on completion of the interview to ensure that the data collected represented the views of the participant and not the RA. Additionally, discussions between the interpreter and RA were held after the interviews and the

information yielded by the interviews was discussed. This component of peer-debriefing is significant to the study's confirmability as the interpreter was a health professional but not an SLT. Thus, she provided a different perspective, which aided the RA and the researcher in minimising their biases when working with participants and the data. In addition, peer debriefing between the researcher and research supervisors was done after each interview. The notes and collected data were discussed to maintain coherence and monitor whether any biased assumptions or presumptions were being made by the researcher. Regarding the transcription and translation of the isiXhosa interviews, immediate discussions were intentionally held after each interview between the interpreter and the RA, as well as in-session with the participant, to ensure that the most accurate version of the information was captured and clarified in real time. This immediate verification is recognised as good practice in qualitative research to enhance the accuracy of data and reduce the risk of misinterpretation (Birt et al., 2016; Connelly, 2016). Conducting these discussions directly after the interviews ensured that contextual nuances were addressed while still fresh in the minds of both the participant and the research team. Consistent communication between the research team members was important to ensure transparency and a coordinated approach within the research team. Lastly, the researcher included verbatim quotes from the participants in the Results and Discussion chapters to enrich the study's confirmability (Stenfors et al., 2020).

Data analysis

Thematic analysis was used to analyse the data. This method of analysis allows for rich and detailed descriptions of the data (Braun & Clarke, 2006) by generating and understanding themes and ultimately creating new insights for the experience being studied (Kiger & Varpio, 2020). The study followed an inductive approach, which allowed the collected data to bring themes forward rather than looking for predetermined meanings in the data (van Rijnsoever, 2017). The researcher and research supervisor employed Braun and Clarke's (2006) framework, which outlines a six-step process. Thereafter, the co-supervisor was presented with the data and themes for input and collaboration on the final analysis.

Step 1: *Familiarising with data*

The researcher and supervisor familiarised themselves with the data before any theme induction began (Braun & Clarke, 2006; Kiger & Varpio, 2020). The data collected were initially verbal, based on the recorded interviews. The interviews were then manually transcribed on Microsoft Word and became written data. Transcribing the interviews involved careful listening to accurately relay the information captured. Thereafter, the transcribed files were revised for spelling errors and read while listening to the recording, checking for any missed information or misheard statements. This step was repeated two or more times depending on the length and clarity of the audio recording. This process allowed the researchers to submerge themselves in the data and familiarise themselves with it before analysis began (Braun & Clarke, 2006; Nowell et al., 2017). With regards to the isiXhosa transcripts, the translated transcripts were read through while listening to the interview, ensuring accurate transcription of the English components and hearing the tone and flow of the interview as added information. Reviewing all the data repeatedly allowed the researcher to identify the topics and experiences that were recurrent. Nowell et al. (2017) explained that it is important for the researcher to repeatedly read the data before they analyse and search for meaning patterns. Thus, this was an imperative step in the process. Once the data had been listened to, transcribed and checked, it was read through once more before codes (meaningful topics) and themes were generated.

Step 2: *Generating initial codes*

After familiarisation, when the researcher was comfortable with the content of the data from the interview, the transcripts were individually analysed, manually on a laptop. In this first step the researcher looked for meaning units from the raw data, creating 'codes' before 'themes' (Kiger & Varpio, 2020). This step included colour-coding certain quotes (which became the meaning units) and roughly grouping the correlating statements. The researcher consulted with the research supervisor after the initial grouping and labelling for input on generating appropriate labels. This process was dynamic and time-consuming as the meaning units were grouped and labelled (e.g., Participant 1: "I was never really told what were the reasons for baby to come before time." This unit was highlighted and colour-coded in blue and labelled 'lack of information'). The labels were the initial codes that were induced. At the

end of the first interview analysis, the initial draft of the codes was listed, colour-coded and stored. This was repeated for all interviews that followed, which were analysed independently.

The researcher's approach was to analyse each interview in isolation and highlight each significant meaning unit. These units could be grouped with the initial codes or a new code could be created, all for later refinement. The names of the codes changed throughout the interviews with certain meaning units correlating or some being moved (i.e., "exposed to mortality around them" $\rightarrow$ 'negative environmental aspects' $\rightarrow$ 'triggering clinical environment'). The researcher did not want any idea to go unheard, and thus each participant's account was thoroughly examined. The researcher allowed the data to generate its own codes, not searching for meaning units to support the existing codes. Whilst the researcher was generating the initial codes, the research supervisor was given transcribed documents of each interview and separately went through the documents highlighting what they thought to be meaningful and what codes they felt were being induced. The supervisor used the interview guide questions to guide her analysis and placed the relevant participant quotes under each question. The quote (now meaning unit) was then highlighted and labelled with the code name it related to. The research supervisor and researcher then met to discuss their separate findings after every third interview was analysed. It was in these meetings that both parties saw and read through the other's analysis and codes. Through this part of the process, the two researchers found that they had mostly highlighted the same meaning units and labelled their codes similarly. Together, refined names were decided for the codes and they then proceeded to analyse the remaining interviews. No codes were abandoned at this stage. Ultimately, all seven interviews were analysed by both the researcher and the research supervisor. The corresponding meaning units and codes were highlighted and tabulated. After all seven interviews were analysed and tabulated, the researcher referred back to the raw transcribed files to analyse the data again to ensure all meaning units had been noted and labelled. Any additional quotes were added to the code table and then given to the research supervisor to discuss the additions.

Step 3: *Searching for themes*

In this step, the researcher sorted the codes and organised them into themes and subthemes. A theme is a collection of captured ideas and experiences that, when put together, outline an important concept (Nowell et al., 2017). As the study used an inductive thematic analysis, the identified codes were then assessed and separated into the themes and subthemes that emerged from the data (Braun & Clarke, 2006). The codes were all weighed of equal importance. However, trends were identified in the data. A thematic network was used to arrange the codes into themes. The researcher and research supervisor outlined three different networks of themes, initially deciding to divide each of them into facilitators, barriers, and support structures (i.e., Knowledge: Facilitators $\rightarrow$ information given; Barriers $\rightarrow$ insufficient information; Support structures $\rightarrow$ helpful staff). After sorting the codes into these themes, the approach was found to be overly repetitive and failed to capture the personal meaning embedded in the codes. The resulting themes appeared detached, which conflicted with the study's aim of exploring the experiences of mothers and doing justice to their accounts. Consequently, this network was abandoned, and a new one was developed. Through extensive analysis, an overarching theme consistently emerged as central to the mothers' experiences and served as the foundation for each code: mothering. The revised network therefore identified 'mothering' as the overarching theme. The decision was made to incorporate facilitators and barriers within each theme, and to integrate improvements and suggestions rather than labelling them each as separate themes. The correlating themes and subthemes that emerged from the data were then labelled and organised under the revised network.

Step 4: *Reviewing themes*

The themes were then refined. The researcher, with the help of her research supervisor, decided what themes had emerged, and which themes correlated and could be grouped as either main themes or subthemes. This step comprised two levels:

$\Rightarrow$ Level 1: Reviewing at the level of the coded data

The data were reread, and the meaning units assigned to codes were checked to ensure that all the data created a well-organised pattern. At this level the researcher assessed whether some data did not fit into certain codes. If so, both the code and the data were reviewed and adapted to be more coherent and represent the data more accurately (King, 2004; Nowell et

al., 2017). This was done by reviewing the meaning units and their codes by tabulating them individually and ensuring that the meaning units from all the individual transcribed drafts were included and had been coded, as shown in Table 2, an excerpt from a thematic table.

Table 1

Excerpt from thematic table in level one of data analysis

What would help? [Improvements]	Involve mothers	Pt 5: Listen to the mother. Don't just assume we know nothing. It is our baby after all. And if they had listened to me, they wouldn't have gone home with the baby like that. Pt 5: So when you are a junior doctor or a doctor, or whatever, listen to the mommy. If the mommy says something's not right, it's not because she's sucking out of her thumb. She's actually watching this baby grow every second, and she can tell what's different, what is not different, what's not normal, what is normal. So you just have to listen to the mommy and follow through. You can rather have a dead end and say, listen here, but there's nothing going on. Pt 7: To my experience, I think they should ask us, also mothers, our concerns for our child. Pt 7: At least if you can have concern, and it would be to them not to take our concern or to take it, but that you just ask us, what do you think?
	Consistency of staff	Pt 1: Yoh. If maybe all the nurses and the doctors were the same. Pt 1: Also, I think that doctors, all the time, they should be friendly and be nice to the patients. Pt 4: but if there could be more, keep who wants to be there as far as nursing staff Pt 4: That also affects the experience because if you're going to have someone who's going to be moaning the whole night, you already stressed yourself. You need someone who's going to be more on the positive or helpful side to sort of make things easier for you.

Multiple codes were generated. However, some could be grouped and labelled under one heading as they were interdependent or explained different aspects of the same experience. The themes and their corresponding meaning units were sent to the research supervisor and co-supervisor for input on generated codes. Together the subthemes were then refined, originally starting with 19 and being reduced to a final seven. It was important that no meaning was lost. However, with careful consideration and organisation, the researcher and research supervisor agreed on final subthemes and themes that fitted the data best. Once all data were correlated with each code, level two commenced.

⇒ Level 2: Reviewing at the level of the themes

The relationship between the codes was assessed and final themes were confirmed with the use of a thematic map. The researcher assessed if the themes accurately highlighted the meaning of the data. Using the guidance of Nowell et al. (2017) and Kiger and Varpio (2020) the identified themes were refined into specific themes that were well-defined but broad enough to capture a set of ideas discussed by multiple text extracts (Nowell et al., 2017). Practically, this meant that the themes needed to be specific in pinpointing a common experience or feeling but, at the same time, sufficiently broad to include the experiences of multiple mothers. The final themes that were decided on were: Knowledge, Environment, Burden of care, Emotional toll, Support structures, and Improvements. The research supervisor was consulted throughout this process to consolidate the labels and organisation.

Once the themes were refined, all the individual tables were collated into one and an infographic of the thematic network was created as a visual representation of the network. Steps 3 and 4 were repeated by the researcher and research supervisor to review themes. Finally, it was felt that all codes and themes had been accounted for and the shared experiences and feelings accurately labelled. The table was then sent to the research co-supervisor who agreed with the final codes and themes. When this phase concluded, the researcher had a good understanding of the themes and the narrative it created to explain the data (Braun & Clarke, 2006; Nowell et al., 2017).

Step 5: *Defining and naming themes*

The researcher aimed to elaborate on the meaning of each identified theme. After discussions with the research supervisor, the themes were renamed to better reflect the participants' stories and emotions. It was agreed that each theme would be labelled with a quote from a participant in that section such as "*Everything on you*" to reflect the theme 'burden of care'. This renaming made the themes more powerful and descriptive of the shared experience. The researcher also assessed how each theme and its story fitted into the overall narrative of the research and decided on the flow of the themes (Braun & Clarke, 2006). The researcher made use of peer debriefing with the supervisor and co-supervisor to ensure the themes were clear and comprehensive, and to potentially identify important aspects of the data that had not been addressed (Nowell et al., 2017). This was done consistently with the research supervisor and researcher sharing multiple working drafts of the theme evolution. The themes and network were sent to the research co-supervisor on completion to allow for a fresh perspective on the analysis. The meaning units, codes and themes were tabulated and sent for review to assess if any data had been overlooked or misinterpreted. The themes were then finalised once the co-supervisor was content and any suggested modifications were made, completing the peer-review at this level. When the researcher felt they could succinctly explain the core of each theme, they proceeded to the next step.

Step 6: *Report production*

In the final stage, the researcher reported on the findings. The data, codes and themes were explained and discussed. To ensure the researcher provided a rich account of the data, a narrative based on the patterns of the summarised themes was created to form an interpretation of the phenomenon and illuminate the broader meaning and implications of the findings. This related to the Results section, where each theme and subtheme is discussed and meaning units are quoted to support the story and experience being illustrated. This section details what each theme meant. In the Discussion section, the results are discussed in relation to existing literature. The researcher attempted to highlight the themes induced by the data and elucidate how they addressed the study's aims and objectives rather than repeating what had been presented in the Results. This meant that the discussion included what the participants felt were the facilitators, barriers and support structures throughout their experiences, and explored these aspects after allowing the results section to narrate the participant stories. Direct quotes from the participants were additionally included to reinforce the point made by the participants (King, 2004; Nowell et al., 2017). The inclusion of the existing literature allowed for comparison and correlation of other lived experiences. This merited the narrative told (Nowell et al., 2017) and further explained why the study was necessary in filling in gaps of contextually relevant research. The researcher aimed to produce a credible discussion. Thus, all the results were included in the discussion to create a valid and trustworthy account (Nowell et al., 2017).

Ethical considerations

Ethical guidelines set out by the Declaration of Helsinki (World Medical Association, 2024) were adhered to and are described in the following sections.

Autonomy and dignity

This principle of respect was adhered to during the research processes. Autonomy is a person's right to make an informed and voluntary decision about whether they want to participate in research (Cosac, 2017). The potential participants were treated with respect

and were provided with all relevant information to make their own informed decisions about participation. Informed consent entailed the RA fully disclosing all aspects of the research including the benefits, risks, and purpose of the study (World Medical Association, 2024). This breakdown was provided in the participants' preferred language and followed by an opportunity to ask questions. The participants were given time to consider the participation invitation and discuss what it would entail. The participants were allowed to withdraw from participation in the research at any time without any repercussions or resistance from the research team nor any negative consequences to the infant's medical management (National Department of Health, 2024).

Beneficence and non-maleficence

This study posed no risk of physical harm to its participants as the involvement of the participants was only by interviews discussing their experiences. There was, however, a risk of psychological harm to mothers reflecting on and discussing their experiences. The risk of the study was that participants may have been upset while they shared their experiences. If the participant became upset during the interview, the interview was paused, and the participants were offered the option to either stop the interview and continue at another time or to withdraw their participation. This occurred only with two participants who asked to pause the interview but chose to continue after a short break, taking a moment for themselves in the interview. All participants reported feeling comfortable to complete their interviews. When a participant indicated being upset by their hospital experience, they were referred to the onsite treating HCPs for additional support, with permission from the participant. No direct benefits were associated with participating in this study; there were no monetary or healthcare treatment benefits for participation, nor would the outcomes of the study directly benefit the participants. However, the results of the study may benefit future mothers of neonates/young infants with FSD, as the information obtained can be used by HCPs to adapt interactions, interventions, and support to benefit the patients and their families in the future.

Vulnerable groups and individuals

The study population of mothers is not specifically vulnerable. However, the participants' neonates/young infants are a highly vulnerable population. This research did not pose any physical risk to the neonates/young infants, and it was considered important to obtain the information from this group to inform appropriate support in future.

Justice (equality)

The principle of justice requires that the risks and benefits of research be balanced between all parties involved in the research (Bošnjak, 2001), in this case, the participants, communities, and South African society at large. In the context of this research, there was a likelihood that the population, which the participants represent, would benefit from the research results. The results from this study will be shared with the research sites. In addition, the results will be shared through presentation and/or publication so that other individuals working in similar settings will also have access to the information, thereby aligning with the principle of equality that states that no portion of the population should be "burdened by the harms of research or denied the benefits of knowledge derived from it" (Department of Health, 2015).

Confidentiality and anonymity

Confidentiality and anonymity are important considerations for protection of the personal information that participants provide to the researcher (World Medical Association, 2013, 2024). All personal information was kept confidential in this study. All electronic documents were password-protected and hard copies were kept securely. The program used to write up the research was Microsoft Word and all documents were stored on OneDrive on password-protected profiles. Any hardcopies were kept locked away and stored securely in a folder in a lockable filing cabinet in the research supervisor's access-controlled office. The laptop used for the research had been loaded with anti-virus software and was password protected. The data were kept private and only accessible to the researcher and supervisors.

Reference codes were implemented to represent the participants and to delink the participants' personal information from the data during analysis and discussions. Participants were referred to numerically in order of their interview, i.e., the first interviewed participant

was called ‘Participant 1’. Participants’ personal information was stored separately from the data collected. Once the dissertation was written, all the data and relevant information were transferred to the research supervisor based at UCT where it will be stored securely for five years after publication. Additionally, the interpreter and RA signed a confidentiality agreement that explained that the contents of the interviews and all other research information may not be discussed or shared with anyone outside of the research team.

End of study considerations

At the end of the study, following examination, the final document (with the results) will be made available to the research sites to share with their staff and patients. The researcher and supervisors plan to publish the results in a scientific journal and/or present the results at relevant conferences or association webinars.

Chapter 3: Results

This chapter details the results of the study, exploring the facilitators, barriers, and support to mothering a neonate or young infant with FSD in a neonatal healthcare context in the Western Cape, South Africa. Through semi-structured, in-depth interviews, the voices of the mothers provide rich insights into their unique experiences. Analysis of the mothers' narratives revealed one overarching theme – mothering – from which seven distinct themes emanated. Each theme is accompanied by corresponding subthemes, illuminating the multifaceted nature of mothering in this challenging context. The mothers also outlined suggestions for the help they would have liked to receive during their experience, with a view to supporting future mothers in their position.

Participant information

A total of seven mothers participated in the study: five participants from MMH and two from RCWMCH. All recruited participants participated in the study, and all completed the interviews without retracting participation. Table 2 provides an overview of the participant demographics in the studied sample.

Table 2

Biographical information of participants

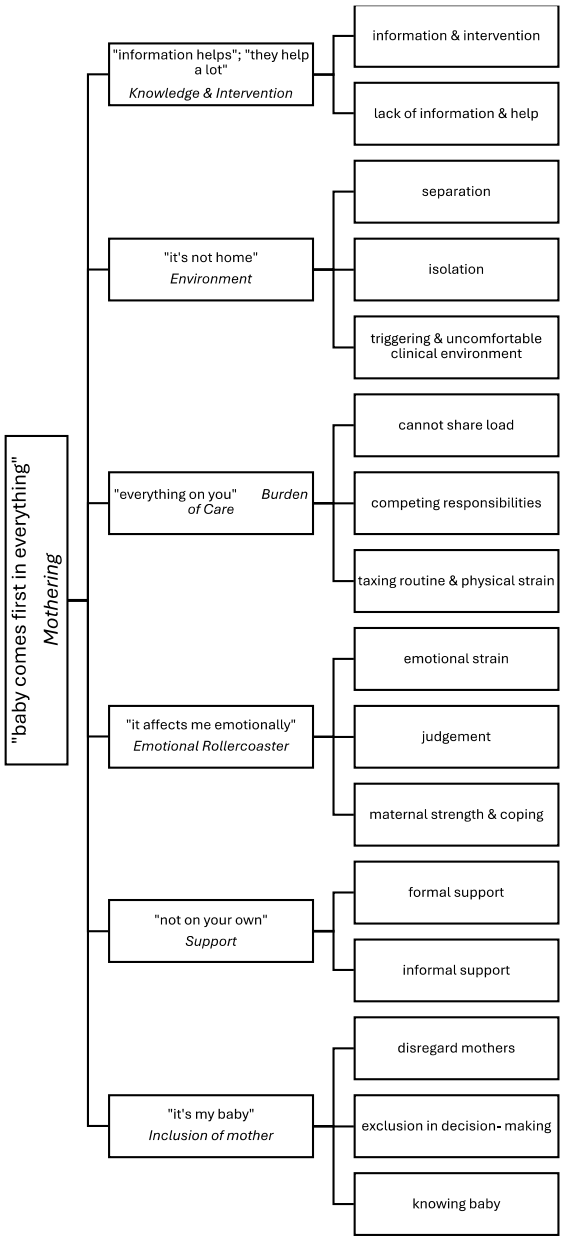
Biographical information	Participant 1	Participant 2	Participant 3	Participant 4	Participant 5	Participant 6	Participant 7
Age (years)	24	25	39	33	29	35	37
Occupation	Lab facilitator	Shoprite worker	Unemployed	Call center agent	Hairdresser	Entrepreneur and stay-at-home mom	Housewife
Home language	English and isiXhosa	isiXhosa	Tumbuka	isiXhosa	English	English	Chichewa and English
Number of children	1	1	3	2	3	4	2
Duration of admission (weeks)	11.5	6	10	12	9	5.5	11

Presentation of key themes and subthemes

Six themes emerged from the overarching theme of ‘Mothering’, described by the quote: “Baby comes first in everything”. Each of the themes is described by a relevant quote: “Information helps; “They help a lot”, “It’s not home”, “Everything on you”, “It affects me emotionally”; “Not on your own” and lastly, “It’s my baby”. The themes and associated subthemes are depicted in Figure 1.

Figure 1

Overview of themes and subthemes



Overarching theme: "Baby comes first in everything" – Mothering

Mothers in this context consistently emphasised the paramount importance of prioritising the wellbeing of their infants above all else, sacrificing personal needs and responsibilities to ensure their infants' needs were met. They described mothering as an unyielding commitment, marked by a dedication to always being present for their infant, regardless of the challenges they faced specifically while admitted in-hospital. This was explained by Participant 1:

> *Mothering is to be making sure that the baby is the first priority that [you] would do anything and must sacrifice anything for them.*

The participants highlighted the all-encompassing nature of mothering, including tasks such as nurturing, feeding, washing, and tending to every need of the infant, especially when the infant is unwell. Participants 6 and 7 described this further in the quotes in Box 1.

Box 1

Participant	**Quote**
Participant 6	"*To me, mothering is being there for the baby, loving the baby, caring for the baby, feeding the baby, teaching the baby*."
Participant 7	"*As a mother, I can say mothering is, like, as a mom, I have to take care of my child and know her wellbeing. If she's doing fine or not, make sure that she has been fed. Yeah, make sure she's in good health. To make sure that I'm taking care of her*."

Despite the demanding nature of these responsibilities, participants expressed a sense of fulfilment and a natural instinct in caring for their infants, driven by an unwavering love. Participant 5 described:

> *Loving your baby is just natural… So we do everything with love.*

Moreover, participants underscored the unique challenges faced in caring for an infant with medical needs or other difficulties (Box 2).

Box 2

Participant	Quote
Participant 6	"*[They] need that and extra.*"
Participant 4 (emphasising the heightened level of attention and care required)	"*It's literally doing everything, taking care, nurturing the child, feeding, washing, doing everything. Especially mother. Mothering a baby, especially a sick baby."*

Regardless of these challenges, participants remained steadfast in their commitment to ensuring the wellbeing of their infants, advocating for their health and providing them with the necessary support and care.

All the themes and subthemes stemmed from this over-arching theme of 'mothering' and are discussed in the following sections.

Theme 1: "Information helps"; "they help a lot" – Knowledge and intervention

Participants shared their experiences of information, intervention, and training received from the HCPs related to their infant's diagnosis and their FSD. Their narratives highlighted the complexities involved in managing infants with FSDs, often compounded by additional health challenges such as infections, prematurity, and other medical complications. Participants described contrasting experiences regarding information, sometimes even within a single participant: some explained that information was provided, and others reported a lack of information and how both impacted their experiences. Several subthemes emerged and are described in greater detail below.

Subtheme: Information and Intervention

All the participants were able to explain the reason for their infant's hospitalisation, and most seemed to be adequately informed about the progress of their infant. The majority of the participants displayed a reasonable understanding of their infant's condition and could elaborate on the intervention/s that they were receiving.

Participant 6 explained the stages of intervention and tools used during the feeding process, exhibiting confidence in the information and an understanding of the effect of the infant's diagnosis on the process:

> *Then if a dummy, as well, to help him stimulate because he has Down syndrome, so it will take him a little longer to adjust to feeding. We started with that while he was on the syringe, on the tube feeding.*

Participant 4 explained that certain HCPs (i.e., the SLT and nurses) made information and intervention very accessible as they created frequent opportunities to ask questions or receive help.

> *We do get a lot of information. If you do have any issue at any point in time, she comes by every day and then she literally just asks, have you had any issue? Do you have any questions? And she would give any advice if she thought she thinks that you may need.*

The participants emphasised the impact of having knowledge on how to help the infant, which allowed them to navigate the challenges of FSD more effectively. Participants appreciated the comprehensive help received, noting the effectiveness of "exercises" prescribed by the SLT in improving their infant's feeding abilities. Participant 4 highlighted:

> *And she does the exercises as well to try and get it [infant to feed orally]. So, she also teaches me to do that. So, I also try those exercises. They do help as well. She opens the mouth at least now.*

The inclusion of specific tools under the guidance of HCPs, the SLT and Ear Nose and Throat (ENT) specialist, proved beneficial in promoting oral motor skills. For instance, Participants 5 and 6 highlighted the positive impact of introducing a pacifier during non-oral feeding and to maintain oral motor skills (Box 3).

Box 3

Participant	Quote
Participant 5	"*We were only allowed a dummy after the ENT saw us. And she said, No, he needs to keep sucking. He needs to keep that motion in the muscles and everything moving. So, from then it was much easier because there was something to suck."*
Participant 6	"*She first showed me how to do the finger-sucking and the dummy-dipping. Okay. Then [with] a dummy as well, to help him stimulate because he has down syndrome, so it will take him a little longer to adjust to feeding."*

The assistance offered by SLT, nurses, and other specialists were instrumental in navigating the challenges encountered during their infant's care journey. SLTs played a pivotal role in assessing FSD and providing solutions or implementing interventions to aid the infant's feeding. Participant 1 expressed gratitude for the efforts of their SLT in exploring various feeding options and patiently guiding them through the process.

> *So [SLT's name] came in, she tried the cup with baby, but she saw it didn't work out. And like, she even, we even tried the syringe, one ml syringe. She had so many options, but baby couldn't take those ones and we were patient.*

Participant 2 highlighted the significant impact of meeting with a specialist SLT, emphasising the valuable assistance received from this intervention.

> *What helped was meeting the specialist, [SLT's name]. So, she helped.*

Participant 4 acknowledged the role of nurses and social workers in facilitating interventions and providing ongoing guidance (Box 4).

Box 4

Participant	Quote
Participant 4	*"The nurses help a lot, but I think the social worker as well..."*
	"There's been ample of support as far as feeding goes I feel. I don't feel like they can be anything more."

The mothers reflected on the training and education they received from HCPs regarding the care and management of their infants. Despite variations in the formality of the training received, participants appreciated the guidance provided, which empowered them to take an active role in their infant's care.

Participant 3 recalled receiving instruction on positioning their infant to prevent vomiting while feeding through a nasogastric tube (Thivierge et al., 2023) during their stay in the intensive care unit (ICU). This informal training equipped them with essential skills for managing feeding-related challenges.

> *Yes, they taught me in the ICU, I should insert it like so, position them so they don't vomit.*

Participant 4 acknowledged the lack of formal training but noted that they were shown the necessary procedures by HCPs, such as administering nasogastric tube feeds. While it was not structured, the demonstrations and explanations enabled them to perform caregiving tasks effectively.

> *I do it myself. We weren't really trained. I was shown the first time if I did it in the… and then yeah just did it on my own. I guess that's informal training that I got.*

Moreover, Participant 1 highlighted the importance of HCPs in teaching them how to administer oral medication to their infant, demonstrating the practical skills necessary for managing their infant's medical needs.

> *[Nurse says] I want to teach you something. We must try to feed baby medication orally. She put baby in a nice position for me also to do it… She would put small drops on baby and would see baby making like this. It's sucking it like a paste. Ever since that day… I never put medication on the milk of baby. I would feed him orally.*

Participant 6 described the learning experience gained from observing and participating in caregiving tasks, such as syringe feeding and oral stimulation techniques taught by the SLT.

> *We did the syringe. We first did the finger-sucking. She first showed me how to do the finger-sucking and the dummy-dipping.*

Participants valued the hands-on training and education provided by HCPs, recognising its role in equipping them with the knowledge and skills necessary for caring for their infants. Despite the informal nature of some training sessions, participants felt empowered to take an active role in their infant's care, contributing to their confidence and competence as caregivers. Participant 6 explained:

> *For me, it teaches me a lot being here. It does. And even with he had diarrhoea a few weeks ago, and then now with the cold as well. So, I pick up a lot of things, what to look out for when I get home and certain things.*

Subtheme: Lack of information and help

In contrast, some participants expressed frustration and challenges stemming from a lack of information and insufficient support from some HCPs during their infant's care journey.

Participant 1 expressed uncertainty about the circumstances leading to their infant's premature birth, highlighting a lack of information received.

> *I would say baby came before time. I was never really told what were the reasons for baby to come before time.*

This feeling was shared by Participant 6, who expressed concern over the lack of guidance provided regarding the premature aspect of their infant's condition, indicating a gap in communication and education from HCPs. This absence of information left them feeling uninformed about their infant's health.

> *I actually had a conversation with one of the mothers the other day. For us, the premature part, the Down Syndrome for me is fine. I can Google that and I can better understand. But the premature side of it. So, we didn't really have someone sit with us as a group and explain to us your child is going to, what it's going to be like in the outside world for the child. Because inside the child is premature.*

Participant 2 voiced concerns about the impact of using a feeding tube on their infant's feeding progress, suggesting a lack of explanation from HCPs regarding the potential benefits of tube feeding.

> *Maybe I feel like using the tube is slowing her down.*

Participant 5 shared frustrations about the restrictions imposed on using a pacifier for their infant, questioning the reason behind such limitations and feeling unsupported in their caregiving decisions especially as later it was explained as an effective tool that would benefit the infant.

> *It was a big adjustment for him because there's no nipple in [his] mouth. We were not allowed to give a dummy. I believe, but some babies are dummy babies, some babies aren't. Why restricting? Why saying no?*

Participant 1 recounted feeling neglected and unsupported by nurses, observing discrepancies in the level of assistance provided to different mothers, notably experiencing this in certain wards.

> *I could see other nurses were helping other mothers. But me, I never got that experience. I had to learn how to do things for myself*.

Participant 3 also expressed dissatisfaction with the communication and support received from nurses, indicating a lack of empathy and effective communication from HCPs.

> *They [nurses] don't speak to me well. I don't get any [support].*

Participant 7 highlighted the absence of a formal support group or adequate support system for mothers in the neonatal/infant care unit, emphasising the importance of peer support and communal resources in navigating the challenges of neonatal care.

> *Since I came here, there's no support group I've met. But we just discuss when we are in the room with other mums. But there's no really another supportive.*

Collectively, participants experienced a lack of comprehensive information and insufficient help from certain HCPs in some wards during their infants' care journey noting the inconsistency of clear explanations and guidance across wards and HCPs.

What would help? Facilitators

Participants shared ideas that they felt would have helped them during their time at the hospital and throughout the experience. Participants expressed that they desired more consistent information and help across the wards and staff.

The mothers explained that they wished to have more opportunities to talk with the HCPs and receive more information regarding their infants. Participant 7 stated:

> *I think it would be best if we can have meetings, to talk with the doctors. I think it will help a lot because like, I'm being affected, emotional, psychological, because of what I've gone through in this hospital.*

Participants explained that they received information regarding certain health conditions (e.g., Down syndrome) but there was a lack of information around others, such as prematurity. They had questions about the cause [as mentioned by Participant 1], differences in feeding, what this means in the long-term, and what life after discharge will look like [as explained above by Participant 6 under the subheading 'Lack of Information and help']. Ultimately, participants wished for more information throughout the experience to alleviate the feelings of uncertainty, as succinctly summarised by Participant 5: *"The information helps because the unknown is not nice."*

Theme 2: "It's not home" – Environment

When a newborn or infant is hospitalised, the environment typically contrasts with that of home. It is within this theme that participants explained the experience of being outside their natural environment. Participants felt significant separation between themselves and their infant, and between themselves and their families at home. Certain participants described how they consequently felt isolated and detached from actively participating in their infant's care. Additionally, the clinical nature of the environment uniquely impacted the mothers and exacerbated their discomfort.

Subtheme: Separation

Participants conveyed the toll of separation – both from their infants and from their families and homes – during their time in hospital. The physical and emotional distance posed significant challenges and impacted their ability to bond with their infants and maintain a sense of normality.

Participant 1 recounted the difficult experience of being unable to comfort their crying infant in the ICU, highlighting how the physical separation barred her from natural caregiving acts.

> *When baby was in ICU, the experience that I did not share with baby, it was when I could see baby's crying, It was when I could see baby's crying, I couldn't pick [them] up. Not because I didn't want to. At that time, baby [they were] not ready to be picked up because he was under ventilation.*

Participant 2 expressed a longing to spend more time with their baby, explaining that the limitations imposed by the hospital setting hindered their ability to be present with their infant: *"I would be staying longer with my baby if I wasn't here."*

Additionally, some mothers described the restrictions imposed by their infant's medical condition, preventing them from breastfeeding, and limiting physical contact, which in turn affected their ability to bond with their infant (Box 5).

Box 5

Participant	**Quote**
Participant 4	*"And I think that also sort of hinders the bond with the child. I mean, I know she's my child and I am the mother, but I don't have the relationship I had with the [first born child] because there's no touching or any contact or limited contact rather."*
Participant 5	*"I think it's difficult because I'm not able to have my baby with me everywhere I am. It's very restricted, obviously for medical reasons, very restricted to one room for your babies. So, I'm not able to be mommy to him."*

The above quotes articulate the challenges of being confined to a single room with their infant, feeling disconnected from the role of a caregiver, and unable to provide the nurturing environment they desired.

Participant 7 shared the distress of being separated from their infant due to her hospital discharge while the infant was still admitted.

> *Since I was not staying in at the hospital. They discharged me. After one week, I was discharged. Then they had to feed the baby through the tube. It was not easy. It was affecting me because… thinking that my child is feeding through a tube while I'm here.*

Participant 3 expressed how the absence of family support in the hospital affected her, highlighting the emotional strain of navigating the infant care journey alone: *"I get stressed out because I don't have a family here."* Similarly, Participant 5 explained:

> *But you're completely out of your comfort zone. Where you can't be like, okay, I have somebody else here that can hold the baby…*

This highlights the challenges of being away from the familiar comforts of home, feeling overwhelmed by the lack of support and the demands of caregiving in an unfamiliar environment.

Participant 4 expressed regret over the inability to engage in typical parental activities, such as dressing up their infant, further highlighting the sense of detachment and loss experienced due to hospitalisation.

> *I think I would have loved to dress her up, which I can't do. She has to be just on nappies.*

In summary, participants grappled with the separation from their infants and their families during their time in the hospital. The physical and emotional distance imposed significant challenges and underlined the importance of support systems during times of separation on both mothers and infants.

Subtheme: Isolation

Participants described feelings of isolation stemming from various factors, including medical precautions and being in a foreign environment, which exacerbated their sense of loneliness and disconnection during their infants' care journey.

Participant 1 recounted how strict contact precautions, due to their infant's medical condition, led people to distance themselves, wearing gloves and aprons when interacting with the baby. This enforced barrier left Participant 1 feeling isolated and disconnected from others.

> *Also, my baby, there was that big prescription, contact precautions. People, they didn't want to come close to baby because they knew they had to wear gloves, they had to wear the apron. Because mos baby, since [baby] had a bug, so they were always strict. Then people, they must wear those stuff. But that didn't make me to feel nice because it was like people, they're isolating themselves to me like that. There's something wrong with my baby and all those things. You could see others [saw] you want assistance, they just dodge it. Or maybe they don't come even at all.*

Similarly, Participant 7 expressed the challenges of being a foreigner without the support of extended family or social networks. This sense of isolation was compounded by the responsibility of managing their infant's care alone.

> *Being a foreigner in a foreign country, and this is not my country. I don't have parents. I don't have any relative. It's only me and my husband. So, I have to do everything alone, myself, me and my husband. So, it has not been easy for us.*

Participants experienced isolation during their infants' care journey, whether due to medical precautions or other external circumstances.

Subtheme: Triggering and uncomfortable clinical environment

Participants described the clinical environment of the neonatal/infant care unit as triggering and emotionally taxing, highlighting the distress caused by witnessing the suffering of other babies, the constant presence of medical equipment, and the lack of comfort. The participants described the toll of witnessing the deaths of other infants in the NICU, acknowledging the fear and anxiety it evoked regarding their own infant's health (Box 6).

Box 6

Participant	**Quote**
Participant 1	*"Because sometimes it was not nice seeing other babies die in front of you because I had that thing it can also happen to my baby and all those stuff, but I just hanged in there."*
Participant 5	*"And then when you hear something like, the baby's gone [deceased]? No. The baby's still here. That's not nice to see a baby go."*

Participant 5 described the environment as presenting with many triggers, particularly for individuals suffering from anxiety (Box 7).

Box 7

Participant	**Quote**
Participant 5	*"Lots of triggers. Especially if you suffer from anxiety".*
	"It's hectic here. The machines drive you nuts."

The nature of the clinical environment and the constant presence and sounds of medical equipment all contributed to an uneasy environment. The discomfort was further explained to be caused by uncomfortable seating arrangements and the restricted movement imposed by medical protocols, adding to the overall stress of the experience. These factors contributed to participants' discomfort, as explained by Participant 5.

> *You're out of your comfort zone. So, when you're out of your comfort zone, they feel everything. So, when you're not in a comfortable place, also the chairs are the worst thing to sit on.*

Theme 3: "Everything on you" – Burden of care

Participants expressed the overwhelming burden of caring for their infants in the hospital setting, highlighting the lack of support compared to being at home where assistance from family members is available. They also described feelings of being torn between caring for their infant and other familial responsibilities and children. Taxing routines and physical strain compounded these difficulties, leaving the mothers feeling a great burden of care.

Subtheme: Cannot share load

Participants emphasised the solitary nature of caregiving in the hospital, noting that despite the presence of nurses and doctors, the responsibility ultimately falls on the mother, which was articulated by Participant 4.

> *I feel when you're a mother in hospital, there are nurses and doctors and so forth, but it's mainly everything on you because you're the only one that can be here with the child.*

Similarly, Participant 5 described the absence of support and comfort of having someone else present to hold the infant while attending to personal needs:

> *But you're completely out of your comfort zone. Where [here] you can't be like, okay, I have somebody else here that can hold the baby, and I can run to the bathroom, grab something to eat.*

The participants contrasted their experience in the hospital with the support available at home, where assistance from family members can alleviate the caregiving load and the weight of sole responsibility.

Subtheme: Competing responsibilities

Participants described the challenge of balancing the care needs of their infant in hospital with their responsibilities to other family members and personal commitments at home and outside of the hospital, highlighting the strain of divided attention and resources.

Participant 5 highlighted the perpetual cycle of attending to their infant's needs in the hospital while also fulfilling their other familial obligations. Participant 7 echoed this sentiment, emphasising the struggle of sharing time between their infant in the hospital and their other child at home. They explained being torn between their roles as a hospital caregiver and a parent at home, resulting in a constant sense of being spread too thin (Box 8).

Box 8

Participant	**Quote**
Participant 5	*"The second part is because you've got other kids, you have to stretch yourself further than normal."*
Participant 7	*"It has not been easy because I have to share my time [with] home. I have to take care of another child at home, and here at the hospital at the same time. So, they all need my time. So, it has not been easy for me."*

The participants described the financial and emotional toll of commuting between home and the hospital, and the impact on their ability to maintain other aspects of their life, such as small businesses, as in the case of Participant 5.

> *It hasn't been easy because of transport. I have to spend money every day and time. And most of the things that I do, I've stopped. I do small businesses. I've stopped just because I need time to be here with the child every day.*

The participants struggled with the challenge of managing competing responsibilities while caring for their infants in the hospital. The strain of dividing time and attention, and the

financial and emotional toll of commuting between home and the hospital, all highlight the complexity of their caregiving roles.

Subtheme: Taxing routine and physical strain

Participants highlighted the demanding nature of the caregiving routine in the hospital setting, emphasising the physical strain caused by the rigorous schedule and adherence to hospital protocols. They noted the requirement to feed every two to three hours around the clock, which led to the physical toll of significant sleep deprivation and frustration at the disruption to their usual feeding and sleeping patterns. Participant 3 noted:

> *I don't have a choice, it's my baby. At night I don't sleep, after 2 hours I must feed.*

Participant 7 reinforced this view, emphasising the significant time commitment. They also noted the logistics of navigating the hospital environment, including having to go to the nursery every two hours to feed their infant, as they were staying in different wards, making it more taxing than if their infant was with them at home (Box 9).

Box 9

Participant	**Quote**
Participant 7	*"Yeah, it's a lot of time. Not much sleep."*
	"Because here at the hospital, we are following the rules of the hospital to take care of the child. But at home, I take care of my child the way I want."

Overall, participants in the study revealed a burden of caring for their infants in the hospital environment that was exacerbated by disrupted sleep patterns, structured feeding schedules, and adherence to hospital rules and protocols. Collectively, these findings underscore the multifaceted and laborious nature of caregiving for infants in the hospital setting.

Theme 4: "It affects me emotionally" – Emotional rollercoaster

Mothers explained the feelings and emotions associated with their caring journey that accompanied both positive and negative moments. The participants felt a great deal during their infant's stay resulting in a sort of emotional rollercoaster. Feelings of sadness, stress, and guilt were all commonly felt and placed emotional strain on them. Some participants

explained feelings of helplessness at times and even judgement from some HCPs. These times of difficulty were met with the mothers' patience and hopefulness. However, what ultimately prevailed was the strength of the mother. These feelings are explored in greater detail because they give insight into how the mothers coped.

Subtheme: Emotional strain

Sadness

Sadness was described by the mothers at the sight of seeing their infants cry from discomfort. The mothers described feeling that pain personally, especially when they were unable to hold and comfort their babies. Some participants explained that some sadness stemmed from the turbulent health of their infant and being unable to take them home, knowing they needed to remain in hospital for them to receive the necessary intervention (Box 10).

Box 10

Participant	**Quote**
Participant 1	*"… I could see baby's crying, I couldn't pick him up. Not because I didn't want to. At that time, baby… he was not ready to be picked up because he was under ventilation. I felt sad because I would see other mothers carrying their babies."*
	"Sometimes [I] would cry. I would feel sad that I couldn't take him."

Stress

Participants expressed stress related to several aspects of their emotional journey, and it seemed to underpin many of the emotions they experienced. Mothers described stress related to worrying about their infant's wellbeing and whether they would ever go home, as well as medical procedures being traumatic for the infant and, as a result, for the mother too (Box 11).

Box 11

Participant	**Quote**
Participant 4	*"Obviously it's stressful because she's very sick. She's not like sick oh I'm going home in two weeks' time. She's sick. Are you going home or not?"*
Participant 5	*"So, we go through the trauma."*

Moreover, factors already mentioned such as the burden of care and the foreign environment of the NICU also contributed to the stress the mothers experienced (Box 12).

Box 12

Participant	Quote
Participant 3	*"I get stressed out because I don't have a family here."*
	"It's not the same [as caring for infant at home]. I'm stressed, I'm struggling."

In some cases, the participants worried about being able to adjust to the special needs of their unwell infant and how capable they are to care for their child in the unit and eventually after discharge. Participant 6 noted:

> *Big adjustment. Not for me, but for most of the mothers. Because my child is quite big [requires a lot] for the different needs.*

<u>Guilt</u>

Mothers explained feeling guilty. They described feeling responsible for their infant's illness and difficulties. Participant 4 asked herself:

> *Is it me? Is she just sick because she's sick? Could I have done something different?*

Moreover, some infants' FSD hindered them from being able to breastfeed, and the mothers grappled with the guilt of being unable to fulfil that basic need. Participant 2 reflected:

> *Since she couldn't latch on my breast. I was not okay about that.*

Additionally, as certain mothers experienced competing responsibilities, they felt guilty for either having to leave their hospitalised child to care for their family at home – and vice versa when at the hospital (Box 13).

Box 13

Participant	Quote
Participant 7	*"I don't have time also to spend with the other child at home. I'm always busy coming here. I don't have time, enough time with the other child at home. It has affected me a lot."*
Participant 5	*"So that's hard because it's not easy to just... I feel like I chuck him away sometimes. I feel like I'm putting your down in. I'm like, Oh, okay, forget about it for a few hours, and then you remember you have me again. So that's hard."*

Helplessness

Some participants noted feeling helpless while caring for their infant in hospital. This is best described by Participant 5 who said:

> *I think, okay, so the hardest part about when your baby's in the hospital is you can't fix it.*

While mothers play a crucial role in caring for the infant, while in hospital the mother needs to follow hospital protocols and allow the HCPs to take the lead in 'helping' the infant. Participant 7 explained:

> *But I can't tell them what to do. They have to follow the rules and do it at the right time.*

Subtheme: Judgement

Some participants explained that they felt judged by some of the HCPs, and others felt that some HCPs had preconceived ideas about them. The mothers reported that they were talked down to or blamed (Box 14).

Box 14

Participant	Quote
Participant 1	*"She [social worker] quickly judged me and said that I have anxiety, that I'm obsessed with the baby and all those stuff. I saw that she's not the kind of person for me. I said to her that I won't come back to her office."*
	"On the conditions of babies, doctors shouldn't always find the person to blame because sometimes situations that happen to our babies is not our fault."
Participant 5	*"Do not treat the mother like they are stupid."*
	"Don't just assume we know nothing."

Subtheme: Maternal strength and coping

Despite the stress and emotional strain experienced by the mothers, they demonstrated coping strategies that included adapting to the situation and finding the positives through remaining patient and hopeful.

<u>Adapting</u>

Participant 2 observed: *"I'm satisfied. It's not easy but you have to be strong."* This explains that through their stressful moments, they tried to remain composed to help their infant as best as they could. Participant 6 elaborated on how mothers eventually adapt to the hospital and care for an unwell infant after a long enough time of being admitted. It was explained that although the situation remains challenging, your trust grows in the HCPs and the system. Mothers hold the greater picture in mind: of being discharged with their infant.

> *You adapt to it eventually. When you [are] here this long, it doesn't faze you as much. Because you know what your purpose is. Your purpose is to be with the baby so that you can eventually go home.*

Another mother, Participant 5, highlighted her initial shock at the overwhelming information about their infant's situation. However, once she had processed it, she was able to move forward and do her part. She noted: *"If you get over the shock now… you can move forward."*

Patience/hopefulness

The pivotal emotions that most mothers displayed were patience and hopefulness, exhibiting their resilience. The participants often showed that they tried to remain patient during the process and keep hope that their infant will eventually go home.

Participant 6 gave an example of a time when her infant had a "downfall." Nonetheless, they continued with intervention and she practiced the various strategies explained to her, eventually seeing that the infant had retained abilities, such as sucking during non-oral feeding, after the setback.

> *But she [the SLT] started him on 1.5ml, and then eventually we got to 6mls with the bottle. So, it's a process. It made me feel very good. And we had the downfall. But we continue with the sucking and the dummy so that we can know that. Because actually the next day, we knew that I had to have a feed with the bottle. He was laying with the tubes in, and he was laid on his bed, and he was actually, he was making with a mouth, that I need my bottle.*

A similar experience was shared by participant 7 when she said:

> *Last week, this week, she's drinking. I can say she's learning very good, very well. She's getting there.*

It was evident that a range of emotions were felt by the mothers during this time. These emotions ranged from negative feelings such as sadness and guilt, to positive feelings and emotions, such as hopefulness, reflecting their resilience and coping.

Faith and culture

One participant explained how having faith guided her throughout this journey. This was a divergent case as it was only explicitly explained by Participant 1 as being a core coping component. The participant outlined how she had found cultural guidance through a staff member of the hospital that encouraged her and reaffirmed her cultural beliefs, thus helping her throughout the process. Ultimately, Participant 1 stressed that there were times they were given very difficult news and the only thing giving her strength was her faith. This participant believed that the challenges she faced were manageable because of this strength and was hopeful that her infant would be well enough to go home with her eventually.

But I just had hope that the doctors they will do their part, but as the mom of the baby, I'll do my part. I just had faith. I kept on praying. But most of them wondered why I never cried or what. But I just told myself, It's fine. If God wants it, He's going to take baby. If He doesn't want, He won't take baby. But I had that faith that God cannot give you a burden that you cannot handle.

Theme 5: "Not on your own" – Support

The mothers described feeling supported both formally, by healthcare workers, and informally, by family and other mothers in the unit.

Subtheme: Formal support

Participant 7 recounted that the hospital had very supportive staff on-hand ranging from the nurses, doctors to even the kitchen staff who showed empathy with their situation and helped in any capacity they could. A few participants described that they felt encouraged by the staff when given an opportunity to express their feelings. This aided the mothers' wellbeing and thereby helped the infant. Participants highlighted these aspects through the quotes in Box 15.

Box 15

Participant	**Quote**
Participant 4	*"The palliative care champion [social worker]. They help a lot, because then it's not just only about the physical doing of things. It's also the emotional part of dealing with having a sick child."*
Participant 7	*"I can say that here in the hospital, every staff is being supportive to us, to me. Because from doctors, nurses, cleaners, the kitchen staff, they are all doing a lot of work."*

Participants recalled that at one of the hospitals, a formal music group was established as a support group for mothers with children in the nursery section. It was explained as a fun outlet of emotions that was coupled with comforting conversations when they were given time to talk about their experiences and their children.

Moreover, it was recollected that some HCPs would go "the extra mile" when providing intervention for their infant. Some HCPs would try their best to include the mother in the

caring of the infant, and some nurses gave the mothers ways of assisting them as an added opportunity to bond and care for the infant when their medical state restricted their interactions. Participant 1 retold:

> *They would say to me, just lift up baby [when working with the infant]. Just to give me that closure because they saw I wanted to carry baby…*

Most participants trusted the HCPs, which consequently allowed the mothers to feel confident in the care that their infants were receiving. Mothers highlighted that they felt comfortable with the staff and trusted them with their infants.

Trust was crucial for mothers who could not stay with their infants and had to be at home in the evenings. Not being present for their infants was explained to be very challenging. However, given their trust in the hospital and their staff, they had some peace of mind in their absence. This was best relayed by Participant 5:

> *But the staff here make your stay just a little bit more comfortable. They obviously can't make it completely better. But I think it's just the type of people that are here at [hospital name]. They just have a love for your child. So you going home knowing your child is taken care of, it's not just a number. It's not just going to lay there and they're going to be like, oh well, we feed you and that's all you need. So you put more at peace when you walk out. Even though you come in the next day or a few hours' time, like I do, mornings and then evenings, it just give you a little bit more peace. But it's hard here. It's not easy.*

Mothers explained that they understood they didn't have the medical expertise to treat the babies and thus had faith in the HCPs to do their job while they fulfilled their role as a mother. Participant 1 said:

> *We're meeting each other half of the way for the sake of baby. They do their role, I do my part. As a mother, I do my part because also I'm here all the time. I know what's happening with baby.*

This shows the interdependent relationship between caregiver and health care worker and how finding a balance in roles can occur when there is trust.

Subtheme: Informal support

As previously discussed, the participants experienced separation from their loved ones and personal support systems when they were caring for their infant in hospital. However, participants explained that despite the physical distance, family members and their partners supported them through the process. Some participants, such as Participant 1, explained that their significant others would visit often and keep them motivated when challenges arose.

> *The other person who's been supporting me that each and every day, would keep me going too… my baby daddy. Like he is very supportive and all those stuff.*

Additionally, other participants, such as Participant 4, explained that their mothers and family members tried to be present often to provide a helping hand.

> *My family is very supportive. My mother's close by. The baby's father is also, he is supportive. He is hands on. He comes every day, he checks out.*

At the hospital, the participants spent the most time with other mothers in the unit. Their shared circumstances provided a great deal of support as they made each other feel heard, understood, and comforted (Box 16).

Box 16

Participant	**Quote**
Participant 4	*"And I think maybe it also helps that you in a room, not on your own, but also other mothers going through the same thing as you, because then you talk and then someone else is experiencing something similar to you. So, it does make it a bit better or does put off the load a bit off your shoulders."*
Participant 5	*"There's nice moms. You meet moms as you come and go, obviously. Like the mom next to me, that's also coming, we've been talking. So, talking helps you."*

Some mothers felt that certain HCPs went beyond their duty and bonded with the mothers on a personal level. They highlighted that they developed what they would call a friendship with the HCPs who were very invested in the mother's and infant's wellbeing and surpassed what was expected to become a support system for the mothers (Box 17).

Box 17

Participant	Quote
Participant 6	*"Some nurses are very good with helping me with baby. There are a few nurses that I got to know on a personal level. Doctors as well."*
Participant 1	*"She, I could put it in a way, I could put it in a way like she's not only just a Speech Therapist, according to me. She's like a mother."*

These relationships allowed mothers to have more honest conversations with the HCPs and ensured they felt more included in the care provided for their infant. The mothers additionally described frequent conversations that allowed them to express their concern, resulting in a calmer experience. Participant 6 explained:

> *I have three different sit-outs with three different doctors with one-on-one conversations also.*

What would help? Staff attitude

Some inconsistencies in how the hospital staff treated the mothers during their hospitalisation was noted. Despite a large portion of the participants being pleased with the HCPs that they worked with, some mothers expressed a lack of consistency among the staff, explaining the need for improvements to better their experience. One example was that some mothers felt as if certain nurses did not wish to be working with young infants and thus lacked a caring attitude towards the mothers and the babies. Participant 4 expressed:

> *That also affects the experience because if you're going to have someone who's going to be moaning the whole night, you already stressed yourself. You need someone who's going to be more on the positive or helpful side to sort of make things easier for you.*

Participant 4 suggested that by allowing staff to work with the population of their choice, patient and staff satisfaction would be improved.

> *Maybe, I don't know, nothing to do specifically with speech therapy or the child not feeding, but if there could be more… keep who wants to be there as far as nursing staff, because experience for that day is different. Depending on who comes, you might get someone who's going to complain like we've been getting the two years the whole time about how they don't want to be there. You might get someone the next day who is very hands on, involved in help and is giving you advice and is literally doing their best to assist. So, if they just had a system*

> *of maybe just keeping who wants to be there and then who doesn't? Because I noticed a lot with the change.*

The participants noted a fluctuation in staff attitude with the rotations of the staff, which affected the participants. Participant 1 highlighted:

> *Also, I think that doctors, all the time, they should be friendly and be nice to the patients.*

The mothers felt that being treated with respect and empathy was important. Participant 5 considered that they should be treated as equals and not "spoken down to".

> *It would be great if doctors never spoke down on you. You're already in this emotional state because this is your baby... So now you've got this mountain of information that's spoken to you as if you are a medical professional or as if you have no feelings, as if you are just this brick wall that you can just keep putting little sticky tapes on. So that part has to change. Not all doctors have very good bedside manners, as they say. So, they need to change that because that's moms. Moms are already emotional.*

This also related to how information is shared. It was explained that some HCPs lacked compassion and empathy towards the mother, especially when the infants were initially admitted – a very emotional and overwhelming event. The mothers wish for a balance between being told all the relevant medical information and it being explained with compassion. Daily events that are routine for HCPs are alien and daunting for mothers. Participant 5 further explained:

> *But I mean, it just needs to have more compassion. The compassion part in the beginning helps a lot, nurturing you into this whole process of this new rhythm that you're going to have, a new world that you're now entering. Just for a small period of time.*

Theme 6: "It's my baby" – Inclusion of mother

Mothers expressed feeling disregarded either during decision-making processes or when information was given but not explained, under the presumption that they would not understand. The participants agreed that this not only offended the mothers but also kept them at a distance from their infant's medical treatment of which they should be an integral

part. The mothers acknowledged that they may not have any medical background. However, they know their infant and feel as if they should be heard and included.

Subtheme: Disregard mothers

Participants described feeling unheard by some HCPs after voicing concerns about their infants. Some felt that certain HCPs had a curt attitude when talking to them about their infant's health. Participant 5's infant had a rare condition that was initially overlooked and only identified after subsequent feeding complications emerged. The mother expressed that if her concerns had not been initially dismissed, earlier diagnosis and treatment could have reduced the risk to the child (Box 18).

Box 18

Participant	**Quote**
Participant 5	*"It is almost like he was breathing his own phlegm constantly. And the more I tell you this is not normal, the more you tell me, I don't know what I'm talking about. And had that not have happened, we probably would have stayed in the hospital and got an answer sooner than later."*
Participant 1	*"I don't need the doctor to have an attitude to me when I'm asking about my baby because at the end of the day, this is my baby."*

Subtheme: Exclusion in decision-making

Participants shared similar experiences in that they felt excluded in the decision-making process when it came to their infants' health. Mothers explained that they desire to be included in the process of caring for their infant and, importantly, to be part of key decisions that may or may not align with their beliefs (Box 19).

Box 19

Participant	Quote
Participant 1	*"I'm the kind of mother that each and every thing that has been done on my baby, I want to know. I don't want to be sidelined. That's one of the things that I told him, that you see when you're taking a decision about my baby, tell me each and every thing. Because some other things that you're going to do with my baby, maybe my religion does not support that thing."*
Participant 7	*"For example, I know that the baby can suck but they are saying, you have to wait. She's too young, she can't suck. You see? For example, the likes of the feeding with the bottle. It's the one thing that I've been thinking from the start, that what if we train her the bottle since he don't want to take a cup. But I had to wait for them to tell me what to do, of which I was right in my mind."*

Subtheme: Knowing baby

Frequently the mothers expressed that they have learnt about their infant throughout the process but also as the person who spends the most time with the infant and knows them best. They explained that after spending many hours with their infant, they could recognise their cues and when something was required, i.e., more warmth or when they were satiated. During their healthcare journey the mothers patiently implement intervention, observe their infant's progress and could identify when there was an issue in that regard as well (Box 20).

Box 20

Participant	Quote
Participant 5	*"[Referring to herself, the mother] actually watching this baby grow every second, and she can tell what's different, what is not different, what's not normal, what is normal".*
Participant 1	*"Because since I'm here in hospital, I'm also learning baby because I'm a new mommy, so I learn a lot of things. I know my baby now."*
Participant 7	*"But with our common sense as mothers, we also know that if they do this way, it can help the child."*

Ultimately, the mothers are integral to the health and recovery of their infants, and they feel that they should be considered as a key element of the team.

What would help? Involve mothers

Mothers provided suggestions for changes that could be implemented to improve the mothering experience in hospital. The participants outlined that they would like to be involved with the decision-making related to their infants, as Participant 7 suggested:

> *To my experience, I think they should ask us, also mothers, our concerns for our child.*

Thus, participants explained that they felt that they were not given an opportunity to discuss their concerns with the appropriate HCPs, solidifying the need for mothers to be more included throughout the journey.

Similarly, participants explained the mothers should be heard because their involvement could contribute to discovering information about the infant such as any new symptoms or the overall progress of the patient (Box 21).

Box 21

Participant	**Quote**
Participant 7	*"It is our baby after all. And if they had listened to me, they wouldn't have gone home with the baby like that."*
Participant 5	*"So when you are a junior doctor or a doctor, or whatever, listen to the mommy. If the mommy says something's not right, it's not because she's sucking out of her thumb."*
	"At least if you can have concern and it would be [up] to them not to take our concern or to take it, but that you just ask us, what do you think?"

The statements above emphasise the valuable insights mothers have gained through their experiences with their infants in these units. Their views reinforce the notion that, although the infants are under the care of the HCPs, they are foremost the mother's child. This underscores the need to involve mothers in treatment approaches, recognising that their first-hand knowledge is crucial and that their concerns should be heard.

Summary and conclusion

The exploration into the experiences of mothering a neonate or infant with FSD within a hospital setting revealed strengths and challenges in the environment and throughout the experience. The study identified the presence of highly dedicated staff members, effective interventions, and several support systems that contribute positively to the mothering experience. However, these positive aspects are contrasted with significant gaps, including inadequate information, inconsistent support, and an expressed need for additional resources. The themes that emerged were complex and multifaceted, with interconnected subthemes that, upon further discussion, will illuminate the facilitators, barriers, and support structures relevant to this context.

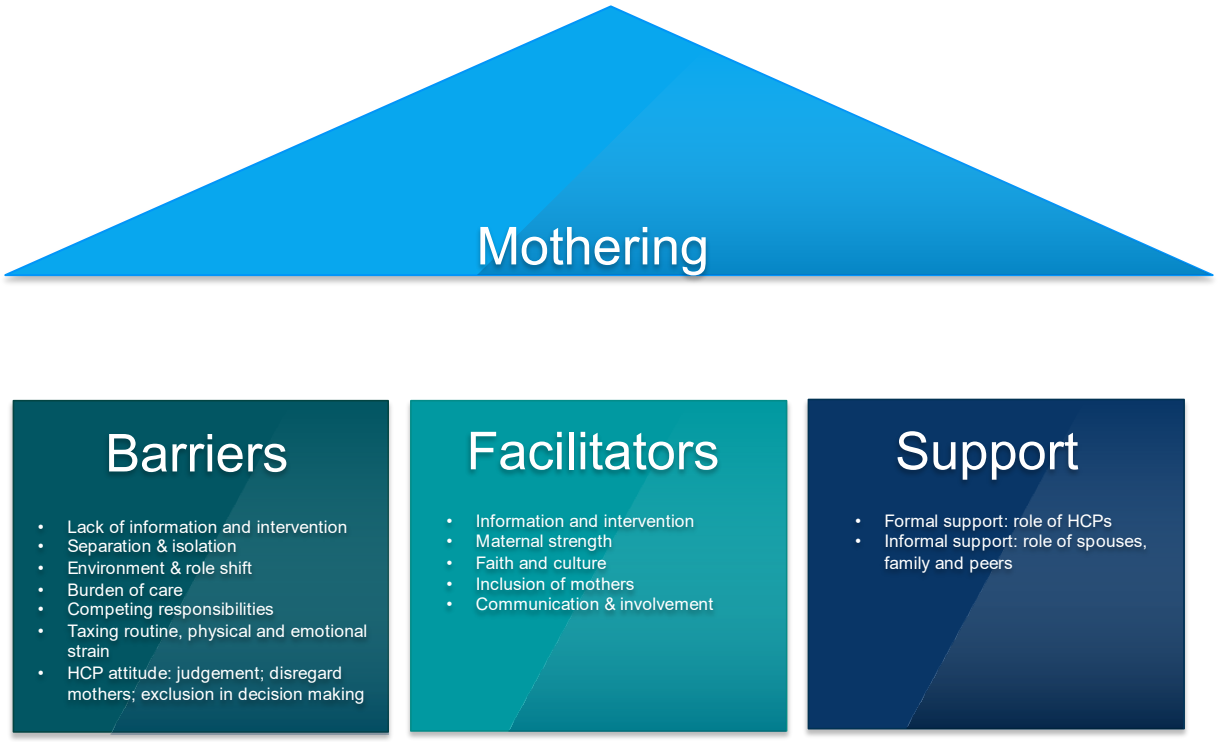
These findings underscore the dedication and resilience of mothers in navigating the challenges of caring for infants with FSD, while also highlighting the intricate and often dichotomous realities they face in the hospital setting. This duality offers a foundation for discussion to understand the mothers' experience and ultimately improve the overall care experience for both mothers and their infants.

Chapter 4: Discussion

Building on studies that explore mothering in NICU and similar settings, this research provides insights into the challenges and support mechanisms encountered by mothers of infants with FSD, a population that remains understudied, particularly in LMICs such as South Africa. Exploring mothering an infant with FSD in neonatal hospital settings is important to advance understanding of the barriers and facilitators to mothering, and the structures available to support such mothers. This information can be used to guide HCPs working with hospitalised young infants with FSD and their families to develop or ensure a supportive environment for both the infant and caregivers, thereby facilitating mothering and optimal outcomes. The results of this study outlined key barriers, facilitators, and support structures to mothering a young infant with FSD in a South African hospital context, as described by mothers' personal experiences, and summarised in Figure 2.

Figure 2

Mothering a neonate/infant with feeding and swallowing difficulties: barriers, facilitators, and support structures



Mothering

In this study, the participants consistently emphasised a view of mothering that centres on self-sacrifice, prioritising the wellbeing of their infants above all else. This perspective reflects a deeply entrenched belief in 'intensive mothering', where mothers assume full responsibility for the physical and emotional care of their infants, often at the expense of their own needs (Williamson et al., 2023). This framework resonates with an essentialist view of motherhood that positions caregiving as an innate, biologically driven role (Gaunt & Deutsch, 2024). As described in the Results chapter, mothering in the neonatal unit context involved an unrelenting commitment to the infant's health and wellbeing, with participants repeatedly highlighting that their role required constant presence, care, and attention, especially when their infant was unwell. This aligns with the 'good mother' ideology that emphasises maternal selflessness, where the infant's needs are always prioritised (Williamson et al., 2023).

The participants described mothering as a natural and fulfilling act driven by love, which suggests a strong emotional dimension to their caregiving experience, aligning with attachment theory (Cassidy et al., 2013). Attachment theory highlights the importance of a mother's responsiveness and sensitivity in fostering secure attachments that are critical for the infant's development (Benoit, 2004). Yet, in the context of neonatal care, where infants may be too fragile for regular physical contact, the traditional forms of bonding (e.g., breastfeeding or 1:1 feeding, rooming-in, physical touch) described in attachment theory are disrupted or delayed, potentially due to contact precautions, equipment, or health needs complicating the mothering role. Fear of handling the infant or uncertainty about their chance of survival affects their interaction and influences the nature of mothering in this context (Ncube et al., 2016; Spinelli et al., 2016; Steyn et al., 2017).

The participants' narratives reveal a nuanced understanding of mothering medically fragile infants. While the foundational elements of nurturing and caregiving remain central, the added component of medical needs required mothers to adapt and expand their role to include medical caregiving tasks. For instance, one participant highlighted that their infant needed more of her mothering, a sentiment that underscores the added emotional and physical toll of mothering a sick infant. Mothers in this study explained they needed to learn

how to give their infants medication, how to feed them, and monitor how they are coping with the feeding mode and intake, among other components. Mothering in this context is accompanied by additional strain placed on mothers of children with complex medical needs (O'Reilly, 2010). Mothers in a study investigating mothering preterm infants regularly described their experience as being “difficult” and “overwhelming” (Buys, 2020). Mothers in other similar studies articulated that it was challenging to step into their expected mothering role with their vulnerable infant (Ncube et al., 2016).

The view of mothering as an unyielding and self-sacrificing commitment also raises critical questions when contrasted with social constructionist theories, which frame mothering as a socially constructed role rather than an innate biological function (du Toit, 2017). These theories suggest that mothering practices are shaped by societal expectations and norms (Lumby & Azaola, 2014). In this sense, the participants’ narratives reflect not only their personal commitment to their infants but also broader societal expectations of what it means to be a ‘good’ mother, particularly in high-stress, hospital settings where maternal involvement is often emphasised. Mothers in Steyn et al.’s (2017) study explained that they felt it was important for them to be seen as “competent and coping” by the other mothers in the unit with them. Certain narratives label breastfeeding as core to ‘good mothering’ and this is an idea that is internalised by many mothers (Carter & Anthony, 2015). Carter and Anthony’s (2015) study explored the narratives mothers hold regarding feeding and breastfeeding, and found that a third of their participants believed that breastfeeding is necessary to be a ‘good mother.’ Two-thirds of their participants identified ‘extraordinary mothering’ as encompassing breastfeeding, tireless commitment, personal selflessness, and devoted care. This internalised expectation places an immense emotional load on the mother and was expressed by one of this study’s participants who explained that they were “not okay” when their infant could not breastfeed.

The participants’ perspectives on mothering, as revealed in this study, align with traditional views of maternal sacrifice and devotion, but also reflect the added complexity of mothering in medical contexts. The commitment to prioritising their infant’s wellbeing, despite significant personal and emotional challenges, underscores the intricate balance between societal expectations, personal instinct, and the unique demands of caring for an infant with

medical difficulties. This finding suggests that healthcare systems must recognise the toll of this intensive mothering model and offer support to help alleviate the burden faced by mothers or implement structures to facilitate mothering that considers both the infant and the mother.

Barriers

Mothers encounter a range of barriers that challenge their caregiving role in the context of mothering infants with FSD in hospital settings. These obstacles can influence both the physical and emotional aspects of mothering, often complicating mothers' ability to provide care as they would out of the hospital and in typical situations.

Lack of information and communication delivery

Participants reported significant challenges related to inconsistent or inadequate communication from HCPs. This lack of clear and consistent information left mothers feeling confused, unsure, and even at times neglected. This aligns with existing literature that identifies inconsistent communication as a critical barrier for mothers in NICU and similar environments (Crowe et al., 2011; Ncube et al., 2016; Robinson, 2014; Steyn et al., 2017; Williams et al., 2018). Williams et al. (2018) explained that particular importance is placed on communication between HCPs and caregivers, which was found in their study to be fundamental to the mother's experience in the NICU. This communicative relationship can be notably beneficial when clearly established and maintained, but is conversely a point of particular stress if not. The current study's results demonstrate that the mothers who lacked sufficient information about their infant's condition, treatment, or prognosis experienced feelings of uncertainty, which contributed to their emotional strain.

Mothers require effective and regular communication from HCPs working with their infant – for their wellbeing and for the care of the infant (Kim, 2020; Ncube et al., 2016; Weiss et al., 2010; Williams et al., 2018). Mothers who are well informed about their infant's progress and care additionally gain self-assurance when caring for their infant (Ncube et al., 2016; Yilmaz & Küçük Alemdar, 2022). Weiss et al. (2010) investigated HCP communication interventions and their influence on caregiver satisfaction, finding that interventions such as educating

HCPs on communicating with caregivers of infants in the NICU were associated with increased caregiver satisfaction. Mothers who have received education on their environment and their infant have been shown to have decreased stress levels (Abdeyazdan et al., 2014; Goral & Geçkil, 2022; Yilmaz & Küçük Alemdar, 2022). Moreover, strategies such as introducing contact cards and exhibiting posters that provide the name and role of staff members working in the unit were all perceived to improve the HCP's availability and communication with the caregivers (Weiss et al., 2010; Williams et al., 2018). In other research, mothers reported that they experienced fear and uncertainty in the neonatal units due to the fragility of the infants and the overwhelming environment (Fernández Medina et al., 2018; Trombini et al., 2008). However, caregivers find the infant's appearance and behaviour less distressing when HCPs discuss their infant's atypical presentation (Goral & Geçkil, 2022; Miles et al., 1992; Trombini et al., 2008), highlighting the importance of communication. It was ultimately found that communication plays a central role for the caregivers and should be a primary component in staff education and training (Kwame & Petrucka, 2021; Malenfant et al., 2022; Williams et al., 2018).

Participants expressed dissatisfaction with the communication and support received from certain HCPs, indicating a lack of empathy and effective communication from some. In particular, the lack of compassion during the early stages of hospitalisation left mothers feeling emotionally unsupported. Steyn et al.'s (2017) South African study on the lived experiences of caregivers of premature infants in the intensive care unit reported that some caregivers felt frustration, anger, and helplessness, and perceived their infant's doctor to be unsupportive and indifferent when their infant was in pain. One participant in the current study highlighted the need for a balance between receiving essential medical information and having it delivered with empathy, especially during the emotionally overwhelming initial stages of admission. Although the information provided may be overwhelming, caregivers experience greater anxiety when they are not fully informed (Ncube et al., 2016). Ultimately participants in the studies by Phiri et al. (2020) and Kim (2020) – and in the present study – wished for more compassionate, clear, and consistent communication throughout the experience to alleviate their feelings of uncertainty, reduce stress, and promote maternal engagement. However, consistent and compassionate communication to all mothers can be challenging for medical staff whose primary responsibility is often perceived to be managing

the health care of the vulnerable infant (Ncube et al., 2016). In a study by Negarandeh et al. (2021), nurses attributed their inability to fulfil the maternal support needs being due to understaffing. The heavy patient loads resulted in a lack of time to provide meaningful communication with caregivers (Aein et al., 2009; Negarandeh et al., 2021).

While the two hospitals where the research was conducted strive towards an FCC framework, its functional implementation is difficult. One of the most critical challenges in implementing FCC in low-resourced settings is the shortage of healthcare staff and resources. Overcrowded hospitals and understaffed units limit the ability of HCPs to provide the necessary support to families (Hoffman et al., 2012). In many cases, healthcare workers are overwhelmed by the sheer volume of patients, making it difficult to involve parents meaningfully in their infant's care (Hoffman et al., 2012; Mirlashari et al., 2020). The participants in this study echoed these concerns, describing how the inconsistent availability of staff, and the variability in care from one nurse to another, affected their experience of support in the hospital. Some participants pointed out the negative impact of a lack of consistency in the attitudes of nurses and how it could make an already stressful situation even more challenging.

The limited infrastructure and support systems available further complicate the implementation of FCC. Without adequate facilities to accommodate family involvement, such as designated spaces for parents in neonatal units, or regular family meetings with HCPs, FCC becomes difficult to execute (Malepe et al., 2022). Participants in the current study expressed a desire for more consistent and structured communication with HCPs. They noted the lack of information about certain health conditions, such as prematurity, which contributed to feelings of uncertainty and stress. This lack of infrastructure for communication and support not only impedes the implementation of FCC but also adds to the emotional burden faced by mothers in these settings (Wang et al., 2021).

Hospital environment and role shift

Mothers described the hospital environment as clinical, overwhelming, and alienating. The results highlight that mothers felt out of their comfort zones while they were 'living' in the hospital, caring for their infants. The clinical nature of the environment did not have many comforts, was filled with loud and emotionally-triggering equipment, and mothers had to face

mortality of infants around them, all of which is in stark contrast to caring for their infants at home. Mothers in similar studies described the clinical hospital environment as intimidating and frightening (Leonard, 2008; Pascoe et al., 2016; Trombini et al., 2008). In previous studies, mothers noted that the presence of medical equipment acted as a visual reinforcement of their infants' vulnerability (Buys, 2020). In the current study, the sound of the equipment triggered overwhelming stress for mothers. Williams et al. (2018) investigated the environmental stressors and supports in the NICU, finding that maternal stress was significantly reduced when comprehensive explanations of the machinery, equipment, sounds of the alarms and alerts were provided to the mothers of infants. This highlights the importance of communicating medical information and explaining the environment to the caregivers to alleviate preventable stress. Mothers in the current study further commented on the physical discomfort of the furniture and layouts of the room, explaining that it is difficult to 'live' in the space as the facilities are not conducive for caregiving or caregivers.

Mothers felt disconnected from their infants, both physically due to medical restrictions and emotionally, as the clinical environment made bonding difficult. Some mothers expressed that being present in the environment, with its protocols and setup, decreased bonding opportunities, negatively affecting the bond between the mother-infant dyad. Mothers in our study reported that their feelings of separation were elicited by the hospital routines, protocols, and their infant's condition, which limited physical contact. The restrictive environment made mothers feel unable to mother their infants. They conveyed the toll that separation – due to unit schedules, sleeping facilities, or equipment – placed on their caregiving role. The rules and protocols of hospital units have been a notable point of frustration for caregivers previously (Baird et al., 2015; Kim, 2020; Williams et al., 2018). One participant reported that she felt exhausted by the schedule of the hospital, noting that it was significantly different to the caregiving routine she would have established for her infant at home. Another mother explained that the dyad's bond was harder to create with her ill and hospitalised infant due to the medical equipment that was attached to her infant in combination with the nature of the infant's disease. This was a shared experience with the mother in the case study by Pascoe et al. (2016) where the mother could only hold her infant weeks after birth as they needed to wait for the removal of respiratory support devices. That study reported that even once the devices were removed, the infant had an aversion to her

mother's touch, making KMC and bonding challenging (Pascoe et al., 2016). The literature frequently highlights how separation between mothers and infants during critical early days of neonatal care leads to maternal stress, anxiety, and emotional distress (Flacking et al., 2012; Kim, 2020; Spinelli et al., 2016). Participants in the present study expressed the same sentiments. Previous studies explained that barriers such as incubators and contact restrictions compounded the perception of the dyad's separation (Ncube et al., 2016; Wang et al., 2021).

Both settings in the current study encouraged KMC. At MMH, mothers of infants that were incubated were encouraged to use KMC for extended periods throughout the day until infants were transferred to the KMC units, where skin-to-skin close contact was primarily used. This practice may explain why mothers in the current study did not perceive incubators to elicit feelings of separation but associated them rather with stress.

The shift from home-based caregiving to clinical caregiving alters the mother-infant dynamic, often reducing mothers to 'observers' instead of active participants in their infant's care (Carter et al., 2007). Carton et al. (2020) described how the role shift led to feelings of inadequacy and loss of maternal identity, as mothers are unable to fulfil what they see as their primary role in caring for their infants. Removing the mothers from their daily caring tasks makes them feel out of place and disconnected from their usual nurturing roles (Ncube et al., 2016). This was seen in the current study as some mothers explained that they felt helpless when caring for their infant because they could not tell the HCPs what to do and had to follow the rules of the hospital, thus reducing or removing them from actively participating in care. Although mothers in the current study did not mention feeling inadequate, some mothers did explain that the hardest part of caring for their infant in the hospital was not being able to "fix it" (improve their infant's medical condition), highlighting that the mothers felt somewhat responsible for their condition and disconnected from their infant's care. Certain participants described how they consequently felt isolated and detached from actively participating in their infant's care.

In other instances, when mothers are involved with the care of their hospitalised infant, their traditional maternal role still changes. Some mothers caring for their infants had the added daily responsibility of administering medication, and monitoring their symptoms, feeding

mode and intake, thus adding clinical components to their role. One mother reported that she needed to advocate for her infant regularly to ensure the child was not subjected to unnecessary procedures, results were followed up, and the medical staff remained compliant with her cultural beliefs. Caregivers in other studies emphasised their roles as advocates and highlighted the importance of closely monitoring and communicating any changes to the medical staff (Hoffman et al., 2012; Rossman et al., 2017). Rossman et al.'s (2017) study further explained that mothers becoming advocates for their infants is also a coping strategy because advocacy is an act of meaning-making.

Staff disposition

The inconsistency in healthcare staff attitudes emerged as a barrier in the hospital experience of the mothers. While many participants had positive interactions with some HCPs, others described frustration over the lack of empathy shown by certain staff members. Several participants emphasised emotional strain related to interacting with staff who seemed disengaged or disinterested in their work, particularly during high-stress moments. This inconsistency reflects broader challenges in neonatal and infant units where burnout and mismatched staff roles may impact the quality of care (Adama et al., 2022). Aligning staff with their preferred populations, as suggested by one participant, could improve both staff satisfaction and patient care, a finding supported by research on healthcare worker engagement (Wang et al., 2021). However, this simple solution can be difficult to implement in South Africa where the public health sector is understaffed and under-resourced (Maphumulo & Bhengu, 2019).

South Africa's healthcare system is greatly dependent on nurses, thus making the staff shortages of nurses heavily impactful (Maphumulo & Bhengu, 2019). In addition to being understaffed, South Africa's Department of Health implementation of staffing moratoria has increased workloads. Medical staff often have to include non-medical jobs in their day due to the absence of previous administrative staff. According to the respondents in Ndebele and Ndlovu's (2023) study, understaffing results in increased waiting times between patients, a perceived increase in errors by HCPs, greater work pressure, and an increase in patient mortality. These are important factors to note because it may not always be feasible for hospitals to match the available nurses to their preferred units. Overworked staff may come

across as lacking empathy due to their substantial workload, thus creating a vicious cycle for both patient and healthcare worker. HCPs frequently face significant stress in their units due to heavy patient workloads, tight schedules, and the critical nature of their responsibilities (Williams et al., 2018). Additionally, heavy workloads, job dissatisfaction, exposure to trauma and empathetic connections to patients can all contribute to compassion fatigue, which negatively affects the quality of care provided (Pakdaman et al., 2024; Weintraub et al., 2016). Despite these challenges, Williams et al. (2018), Malepe et al. (2022), and this study's participants emphasise the importance of nurses and other HCPs being more supportive to mothers when engaging in care of their infants.

In this study, mothers noted that the quality of interaction varied depending on the healthcare providers on duty, with some participants stressing the need for consistent friendliness and empathy from doctors. Some mothers felt "spoken down to" by doctors, which undermined their confidence and trust in the HCPs. Similar negative outcomes were reported by mothers when communication was overly clinical and neglected the emotional needs of the family (Steyn et al., 2017; Williams et al., 2018).

Emotional isolation and impact

Having an ill infant with FSD and caring for their infant in hospital elicited a range of emotions in mothers. Studies identified negative emotions like fear (Steyn et al., 2017; Wang et al., 2021), helplessness and incapability (Ncube et al., 2016; Steyn et al., 2017; Wright, 2011), and sadness (Steyn et al., 2017). The emotional strain faced by mothers in the current study emerged throughout their experience. Their emotions encompassed an interplay of sadness, stress, guilt, helplessness, and feelings of being judged. One mother reported that her sadness stemmed from witnessing her infant in discomfort and being unable to physically comfort them.

In the current study, stress was another emotion tied to maternal concerns about their infants' health outcomes and trauma associated with medical procedures. Many of the mothers experienced guilt, blaming themselves for their infants' condition/s or feeling inadequate to fulfil traditional caregiving roles, such as breastfeeding. The unfamiliar hospital environment, separation from their families, and anxiety about meeting their infants'

specialised needs added to this emotional challenge. The distance from their families and other responsibilities felt by mothers who were admitted and/or sleeping in contributed to feelings of being overwhelmed and exhausted. Many of the mothers explained that for them, their perception of being a mother was to constantly be present for the infant and take on all their care needs. However, this internal belief of needing to be there constantly left them with feelings of either neglecting their children and responsibilities at home or neglecting the hospitalised infant by needing to return home to attend to competing responsibilities. With nearly half of South African households led by women – who are noted to be managing work, running households, and caregiving – mothers are overwhelmed with responsibility (Rabe, 2017; Robinson, 2014; Statistics South Africa, 2022). One mother in the current study explained how being in-hospital and caring for her infant meant she was not able to attend to her business causing financial strain and worry.

Mothers who were separated from their families while in the hospital further experienced feelings of loneliness (Gibson et al., 2021). In our study, though many mothers had supportive partners or parents, many felt that the burden of care fell on them as they needed to care full-time for their infant in the hospital, alone. Feelings of helplessness were frequently reported, as mothers found themselves unable to "fix" their infant's conditions and had to rely on HCPs. Adherence to hospital protocols often left them feeling sidelined in their role as primary caregivers. Additionally, some participants noted experiencing judgement from HCPs, which intensified their emotional strain. Collectively, these findings highlight the emotional toll of the hospital experience, underscoring the need for supportive interventions that validate mothers' feelings, empower them in caregiving roles, and foster a more compassionate and inclusive environment (Kim, 2020).

The impact of separation goes beyond emotional distress. Prolonged separation can affect breastfeeding initiation and feeding practices, which are critical for infants with FSD (Carter et al., 2007; Palmquist et al., 2020). Some mothers in the current study explained that they struggled with being unable to breastfeed their infants or not being able to feed them in the way the mothers believed their infants should be fed. Palmquist et al. (2020) state that a large portion of mothers who give birth prematurely have delayed or affected breastmilk production due to maternal stress and premature birth. These stressors, in addition to the

stress of having a medically vulnerable infant, the stress of survival and needing to learn and adapt to the environment and caring for an infant with medical needs all further exacerbate the emotional load of the mother, ultimately affecting her breastmilk. Separation from the infant and not being able to physically touch the infant are additional barriers to lactation (Jackson et al., 2022; Li et al., 2024; Palmquist et al., 2020). As previously noted, many mothers highly value breastfeeding. Being unable to breastfeed due to their infant's condition/FSD or if they cannot provide breastmilk through alternative methods significantly increases their stress and feelings of overwhelm and failure (Jackson et al., 2022).

Feeding is a very complex function that is impacted by multiple physical and psychosocial components (Arvedson et al., 2020). Thus, barriers to mothering may also act as indirect barriers to feeding. This emphasises the importance of the environment, and the involvement and wellbeing of the mother. Thus, it is essential to consider the factors impacting the mother, as these directly influence the infant's feeding patterns and can either facilitate or hinder the treatment and recovery process for FSD.

Facilitators

Mothers of hospitalised infants with FSD identified a range of components that encouraged mothering and facilitated caregiving. These positive aspects enabled mothering and bonding between the infant-mother dyad.

Access to knowledge and training

One of the primary facilitators to mothering infants with FSD in hospital settings was the access to information and interventions provided by HCPs. Mothers in the current study emphasised that having clear information about their infant's condition/s and treatment empowered them to manage those needs better, aligning with the literature that highlights the importance of caregiver education in reducing anxiety and promoting effective caregiving (Ericson & Palmér, 2019; Kim, 2020; Ncube et al., 2016).

Some mothers in this study who could confidently explain their infants' medical interventions and needs represented how informed caregivers were better equipped to navigate the

complexities of hospital care. This sense of empowerment is crucial, as parental involvement and understanding were found to foster confidence and improve the caregiving experience (Gómez-Cantarino et al., 2020). When HCPs in the current study provided accessible information and regular opportunities for questions, as reported by participants, it facilitated mothering and increased the sense of involvement in their infants' care. Steyn et al. (2017) explain the significant psychological benefits of clear communication and guidance from the healthcare team.

The provision of practical interventions in the current study, such as feeding strategies and tools, proved valuable for the mothers. SLTs played a pivotal role in assessing FSD and providing solutions or implementing interventions to aid the infants' feeding. Mothers noted that the SLT in their unit was "like a mother" to some, giving guidance and assurance to the mothers. The SLT in the current study was referenced as a source of hope for the mothers due to her perseverance at times when their infants were not showing improvement. Another mother explained that she noticed how the use of certain feeding techniques and stimulation provided by the SLT helped maintain oral motor skills and improve the feeding outcome of her infant. This is reinforced by Wang et al.'s (2021) study that described how practical skills training, such as syringe feeding or oral stimulation, helped alleviate maternal anxiety and boosted confidence. The role of the SLT is wide in the NICU and their involvement has been seen to aid in promoting feeding outcomes in infants and in supporting mothers through their experience (Murphy et al., 2021).

The informal training provided by nurses and therapists in the current study, though not always structured, was appreciated by mothers and contributed to their confidence and competence in caregiving tasks. This type of hands-on education, whether it involved administering nasogastric tube feeds or learning how to orally feed the infants medication, reinforced maternal agency. Studies explain that empowering caregivers through education is critical to enhancing their capabilities, promoting confidence in their skills and reducing the emotional burden of caring for a hospitalised infant (Abdeyazdan et al., 2014; Ericson & Palmér, 2019; Johnson, 2008; Steyn et al., 2017).

Inclusion in care and decision-making

Mothers who were actively involved in their infants' care and medical decision-making reported feeling more connected to their infants and more competent as caregivers. The principles of FCC emphasise the importance of including caregivers in all aspects of the infant's care, and this study found that mothers valued such inclusion (Banerjee et al., 2017). This was seen in our results where small instances of involvement such as being able to lift their infant while their incubators were being cleaned or changing their diapers while they could not be held was noted as meaningful to the mothers. Some studies suggest that empowering mothers with practical caregiving skills not only enhances their confidence but also improves infant health outcomes by promoting active maternal involvement (Ashcraft et al., 2019; Umberger et al., 2018).

The results of this study highlight the importance of giving mothers opportunities to collaborate with HCPs and be part of the decision-making process, to allow them to feel a greater sense of agency in their infants' care. Multiple participants wished to be more involved in the process and did not want to be "sidelined." Mothers in this study reported that they too could detect concerning signs and symptoms in their infant or identify what may benefit their infant. If mothers are not actively involved in the decision-making process, they cannot contribute and help their infants. Mothers in the current study requested greater inclusion, which is a core pillar of FCC. FCC advocates for familial involvement in the care process, which is known to result in improved maternal and infant outcomes (Gómez-Cantarino et al., 2020; Umberger et al., 2018). However, cultural factors and varying expectations of healthcare roles can complicate the implementation of FCC in low-resource settings. In many LMICs, where traditional hierarchical structures in healthcare prevail, the involvement of families in decision-making may not be fully embraced by HCPs (Phiri et al., 2020). Some participants in this study described how their input was sometimes overlooked or undervalued by HCPs, leading to feelings of exclusion. If such hierarchies and opinions are supported by HCPs in these contexts, obtaining HCP buy-in for the FCC framework and its implementation may be a challenge.

Maternal strength

The adaptability demonstrated by mothers in this study aligns with findings in maternal strength and coping mechanisms, such as problem-focused and emotion-focused coping strategies (Folkman & Moskowitz, 2004).

Adapting to hospital challenges

Mothers' ability to adapt to their circumstances emerged as a significant coping mechanism in the current study. Mothers gradually adjusted to the hospital environment and the demands of caring for an unwell infant. Some mothers explained that although it was not easy, they found strength by remaining composed to help their infants. Emotion-focused coping is a strategy employed by mothers in the present study and previous similar studies where mothers manage their distress to endure the barriers of the experience and maintain focus on their infant (Alinejad-Naeini et al., 2021; Rossman et al., 2017). Other mothers in the current study described how prolonged exposure to the hospital environment allowed them to develop trust in the HCPs and the treatment process, demonstrating the importance of building trust between caregivers and medical staff (Feeley et al., 2013). Trust in the hospital system and HCPs allows mothers to feel more secure in their ability to care for their infant, fostering a sense of control and competence despite the challenging environment (Carton et al., 2020). Adapting to the environment can, however, also be seen as problem-focused, as some mothers in this study explained that adapting to the environment also included changing their routine to minimise environmentally induced anxiety. One mother noted that she found ward-rounds extremely stressful. Thus, she avoided being present during those times, preferring to engage privately with HCPs to discuss her infant.

Patience and hopefulness

Patience and hope were central to the mothers' resilience. These emotional traits, widely discussed in maternal coping (Hewetson & Singh, 2009), played a pivotal role in helping mothers remain positive throughout their infants' treatment. Mothers in a previous study by Rossman et al. (2017) maintained a positive attitude and wanted to be resilient for the wellbeing of their infant. Several emotion-focused coping strategies were used by the

mothers in the current study, such as reframing, meaning-making, and prayer. Some mothers view the hospital as a learning environment (e.g., learning how to care for their infant, and expanding special need awareness), displaying how mothers choose to reframe their environment and perspective. This is a prime example of an emotion-focused coping strategy (Folkman & Moskowitz, 2004). Mothers in this study further expressed how they practised patience, even during setbacks. This was seen in instances such as mothers continuing to believe in and implement feeding interventions even when their infant was not progressing as they had hoped. In an Iranian study detailing coping strategies and the maternal role of mothers with preterm neonates, hope creation was a key strategy employed by mothers to expand their self-hope (Alinejad-Naeini et al., 2021). Mothers in that study would rejoice at their infants' health improvements and create positive experiences that involved close proximity and caregiving acts to facilitate hope creation and a positive outlook (Alinejad-Naeini et al., 2021). A South African study by Sih et al. (2019) that looked at coping strategies in mothers of premature infants agreed. The authors described how bonding and being near to and involved with their infant allowed mothers to cope. Emotional traits of maintaining hope and patience have been found to be central to caregivers facing prolonged periods of uncertainty regarding their infants' health (Steyn et al., 2017). The ability to remain hopeful, as described by one of the mothers in the current study, was a personal emotion-based coping mechanism that was also felt to have positive implications for the mother-infant relationship. Published findings suggest that when mothers remain hopeful, they are better able to engage with their infants and take an active role in their recovery process (Gómez-Cantarino et al., 2020).

Faith and cultural beliefs

Faith and cultural practices also played a role in helping one mother in the current study cope. One participant found strength through her faith, believing that it helped her manage the uncertainty surrounding her infant's health and giving her strength to withstand this journey with her infant. Spjeldnæs (2021) highlighted the role of spirituality in providing emotional support to mothers in hospital settings. In other studies, mothers who followed faith-based practices, sought spiritual assistance through prayer, finding meaning or asking for strength (Alinejad-Naeini et al., 2021; Sih et al., 2019).

Coping strategies as facilitators

The combination of adaptability, hope, patience, faith, and cultural supports highlights the complex strategies mothers use to cope in stressful hospital settings, both problem- and emotion-focused. This study underscores the need for healthcare systems to recognise and support these internal emotional resources alongside medical care to ensure both mother and infant cope during the hospital experience. By understanding what helped these mothers cope, interventions can be designed to meet their emotional needs through counselling, spiritual support, and hope-building activities, and empower them with practical tools, education, and support networks. These interventions could improve both maternal wellbeing and caregiving effectiveness, ultimately leading to better outcomes for infants with FSD.

Participant suggested facilitators

A desired facilitator discussed was greater involvement in decision-making regarding their infant's care. Participants expressed frustration over not being consulted enough, emphasising that mothers should be actively included in discussions about their children's health and progress. Mothers in previous studies also expressed frustration due to exclusion from key decisions or lacking detailed information about their infant's health (Robinson, 2014; Steyn et al., 2017). Mothers have described being dismissed by HCPs regarding decisions on their infant's feeding such as ignoring the mother's request to breastfeed if possible (Palmquist et al., 2020). This was a poignant finding in the present study as mothers explained they felt as if they 'know' their infant and can contribute to their treatment. One participant shared frustrations about the restrictions imposed on using a pacifier for their neonate, questioning the reason behind such limitations and feeling unsupported in their caregiving decisions – especially as it was later explained that a pacifier could benefit the oral-motor development of the infant. Participants felt they could identify concerns with their infant's feeding, notice when they are not coping with quantity during feeds or when they are ready for more, or when a different mode of feeding is needed. A study by Kapti et al. (2023) supports this notion: after a coping intervention, mothers were able to promote infant nutritional intake, identify concerning signs or symptoms in infants, and even decrease HCP workload. However, mothers in the current study felt unable to voice their observations

because they were not asked or, if heard, their concerns were not followed through. Involving mothers in decision-making has been noted to improve accurate information sharing, such as identifying new symptoms, and tracking infant development, which ultimately improves infant health (Franck et al., 2023; Hoffman et al., 2012; Steyn et al., 2017). FCC approaches, where parents are partners in caregiving, have been shown to promote maternal empowerment and improve both maternal and infant health outcomes (Banerjee et al., 2017; Umberger et al., 2018).

One mother in the current study gave an account of the collaborative relationship between caregivers and HCPs, highlighting how inclusion in caregiving tasks, even when physical contact is limited, promotes maternal confidence. This partnership between parents and professionals fosters emotional wellbeing, as seen in FCC models where shared responsibility leads to better coping with hospitalisation challenges (Gómez-Cantarino et al., 2020; Wang et al., 2021). These personal bonds helped mothers feel more integrated into the care process and less like bystanders.

Trust in hospital staff emerged as key in the caregiving journey. Mothers in the current study expressed that trusting the HCPs reassured them that their infant was receiving optimal care, even when they had to leave their infants overnight. This finding echoes the importance of trust in FCC, where caregiver confidence and empowerment stem from a strong relationship with HCPs (Gómez-Cantarino et al., 2020). Trust is crucial not only during hospitalisation but after discharge too as it enables smoother transitions to post-hospital care and compliance with treatment plans (Mirlashari et al., 2020).

The above recommendations all align with the FCC framework. FCC has been frequently cited across multiple studies as the model framework for including caregivers in the healthcare setting (Gómez-Cantarino et al., 2020; Kestler-Peleg et al., 2022; Malepe et al., 2022; Mirlashari et al., 2020; Umberger et al., 2018). Effectively implementing the principles of FCC will greatly benefit the infants, mothers, and HCPs. The reality is that both research facilities in the current study strive to uphold FCC principles. However, the clinical implementation of this framework is challenging in the public health sector of South Africa.

The implementation of FCC in low-resource settings such as South Africa presents significant challenges despite its proven benefits for improving maternal and infant health outcomes. FCC emphasises the involvement of families in the care of their infants, recognising them as essential partners in decision-making and caregiving (Kestler-Peleg et al., 2022; Mirlashari et al., 2020). In higher-resource settings, this model has been widely praised for enhancing maternal confidence, promoting bonding, and improving infant health outcomes, particularly in NICUs and similar settings (Banerjee et al., 2017). However, in resource-limited countries like South Africa, the practical application of FCC is hindered by several factors such as the lack of training for HCPs in FCC principles. Effective implementation of FCC requires that HCPs are skilled in their clinical roles and also trained to provide psychosocial support to families, particularly in emotionally charged situations like caring for a critically ill infant (Carton et al., 2020; Mirlashari et al., 2020). In resource-constrained settings, training programs are often limited, and healthcare workers may prioritise the infant's immediate medical needs over family involvement (Malepe et al., 2022) further distancing parents from their infant's care (Mirlashari et al., 2020). The findings from the current study indicate that some participants had positive interactions with HCPs who made efforts to involve them. However, these experiences were not consistent across wards or providers. Despite these challenges, FCC remains a valuable model for improving health outcomes in neonatal and infant care (Kestler-Peleg et al., 2022), even in low-resource settings. The desire expressed by participants for more structured support, better communication, and involvement in decision-making highlights the potential benefits of FCC if these barriers are addressed.

Support structures

Support structures are vital to aid and equip mothers to care for their hospitalised infants and to manage their external responsibilities. By evaluating the support structures used by mothers we can analyse the effectiveness of the available frameworks and identify existing gaps within these systems.

Healthcare professionals' support

HCPs, particularly SLTs, social workers, doctors, and nurses, played a critical role in providing emotional and practical support to the mothers in this study. The support received from these

professionals helped mothers navigate the complexities of their infants' medical conditions and provided reassurance during difficult times. The benefits of that support were evident in this study and have been previously reported (Kestler-Peleg et al., 2022).

Participants in the current study highlighted the critical role that hospital staff played in providing both formal and informal support during their time caring for infants with FSD. Formal support is typically defined as medical intervention, established groups, or workshops, whereas informal support relates to peers and family (Kestler-Peleg et al., 2022). Support to mothers was both formal and informal, and nuanced by the nature of individuals. Mothers acknowledged the empathetic and supportive nature of the nurses and doctors, and other staff members such as cleaners and kitchen staff. This comprehensive support system contributed to the mothers' wellbeing, positively impacting their ability to care for their infants. HCPs are known to be able to alleviate maternal stress and foster emotional stability, which is essential for both maternal and infant outcomes (Ericson & Palmér, 2019; Steyn et al., 2017; Williams et al., 2018).

Some mothers in the current study emphasised the role of the social worker or SLT, explaining that, in their experience, their support was immeasurable in addressing the emotional toll of having a sick infant. This aligns with the findings of Banerjee et al. (2017), where holistic support, including emotional guidance, enhanced parental involvement and reduced stress. Formal support from HCPs is crucial in the NICU where the emotional and psychological strain on caregivers can be significant (Mirlashari et al., 2020; Thomson et al., 2023).

Certain mothers in the current study formed close relationships with the HCPs, describing how certain staff members went beyond their clinical roles to provide emotional support. The guidance of HCPs filled the gap left by absent family members or friends (Steyn et al., 2017). Research highlights the importance of compassionate care and emotional engagement from HCPs in fostering trust and reducing maternal anxiety (Banerjee et al., 2017; Kim, 2020). A mother in the current study noted how these relationships facilitated more open and honest conversations, allowing the mothers to express their concerns freely and feel more at ease.

Peer and family support networks

In addition to HCP support structures, peer-based support systems were important for mothers in navigating the challenges of hospitalisation. Participants reported receiving significant emotional and practical support from family members, partners, and fellow mothers in the neonatal unit. This informal support helped mitigate the sense of isolation they felt due to separation from their loved ones during their infant's hospital stay. Family members, particularly partners and mothers, were mentioned as being integral to maintaining the participants' emotional resilience. This corroborates findings in previous studies where family support is seen as a vital resource for mothers of hospitalised infants, helping them cope with the stress of caregiving (Carter et al., 2007; Eduku et al., 2024; Kestler-Peleg et al., 2020, 2022; Steyn et al., 2017).

Mothers shared that their partners frequently visited and provided much-needed encouragement during difficult moments. This reflects the essential role of emotional support from partners in reducing caregiver stress, as identified in previous research (Feeley et al., 2013; Kestler-Peleg et al., 2020). Similarly, mothers mentioned how their own mothers and infant's father played active roles in caregiving, reinforcing the importance of extended family in supporting maternal wellbeing. Family involvement is highlighted as a critical buffer against the emotional strain experienced by mothers in neonatal care environments (Ncube et al., 2016; Steyn et al., 2017; Wang et al., 2021).

Beyond family, peer support from other mothers in the unit was a valuable source of support. Mothers described how talking to other mothers going through similar experiences provided a sense of understanding and comfort. A shared connection created a sense of community, as seen in Rossman et al.'s (2017) study, which helped alleviate feelings of isolation. Peer support was a significant source of emotional resilience for mothers, as they could share their experiences, frustrations, and coping strategies with others who truly understood their situation. A sense of community has been noted to help mitigate loneliness and anxiety (Buys, 2020). Ericson and Palmér (2019) highlight that informal peer support in NICU settings can reduce maternal stress and promote a sense of belonging because mothers feel validated by those who are going through similar experiences.

The inclusion of support groups, such as the music therapy group mentioned, provided an outlet for emotional expression and community-building among mothers. These support groups align with research noting that peer-based support systems in hospital settings foster a sense of solidarity and mutual understanding, which can significantly improve maternal wellbeing and coping mechanisms (Mirlashari et al., 2020). Peer-based interventions help caregivers cope by offering emotional comfort and shared resources (Carter et al., 2007; Hall et al., 2015). However, few formal support groups were available to mothers or, if there were, mothers were not well informed about the available groups and resources. When mothers were asked what additional support they would like, few mentioned they desired more support groups. This may be due to them being unaware of the value of such support structures, or mothers feeling that improvements in other areas (i.e., inclusion in decision-making and more communication) are more important.

Overall, informal support from family, peers, and HCPs played a crucial role in aiding mothers through their caregiving journey. This highlights the need for healthcare systems to encourage and integrate these informal support structures into the caregiving environment, given their role in significantly enhancing maternal and infant outcomes (Eduku et al., 2024).

The outcomes of this study highlight the intricate experience of mothers caring for infants with FSD in South Africa. Their journey is shaped by feeding challenges, and emotional, social, and systemic factors, with barriers such as separation, inadequate communication, and inconsistent support compounding stress and guilt. However, facilitators like access to knowledge, inclusion in decision-making, and practical and emotional support from HCPs, family, and peer networks empower mothers and alleviate mothering challenges. Maternal resilience is illuminated by the accounts of the mothers, and their needs should be considered to improve healthcare provision in this context. The findings emphasise the importance of holistic FCC that addresses both maternal and infant needs, fostering maternal wellbeing, enhancing mother-infant bonding, and improving feeding outcomes essential for infant recovery and development.

Limitations

A main consideration when evaluating the findings of this study is the recognition of limitations that may have impacted the results. While this in-depth qualitative study aimed to explore the experiences of mothers in neonatal and infant hospital settings, several limitations must be acknowledged that may have influenced the depth and scope of the findings.

The first limitation pertains to the research sites, which included MMH and RCWMCH in the Western Cape, South Africa. The institutions serve as secondary and tertiary hospitals, respectively, within the public healthcare sector. MMH, as a secondary-level facility, provides specialised maternal and newborn care, offering tailored support to this specific population (Mowbray Maternity Hospital, 2022). RCWMCH, a tertiary hospital, offers highly specialised care, benefitting from a range of advanced equipment and specialised interventionists, making it more resource-rich compared to other public hospitals that serve at lower levels (Red Cross War Memorial Children's Hospital, 2022). Consequently, the experiences of mothers in these settings may not fully reflect the broader range of experiences encountered by mothers in district hospitals or other public healthcare facilities with fewer resources and specialised care. This limits the transferability of results to other settings within the public healthcare sector across various cities and provinces around the country.

A second limitation is that only mothers of medically stable infants were included in the study, providing a limited representation of mothers of other infants with FSD in these units. This criterion was established out of respect for the mothers, to avoid additional stress, or emotional distress that participating may cause.

Third, some interviews in this study were conducted in isiXhosa and later transcribed and translated. While this process was carried out by a first-language speaker and professional translator to ensure accuracy, certain nuances, cultural expressions, or contextual meanings may not have been fully captured in translation. This could have led to a slight loss of depth in participant responses, which could have influenced data analysis and interpretation.

Future research

This study highlights some gaps in current research on mothering experiences of infants with FSD in hospital settings. Despite FCC being emphasised in literature as a standard of care, a gap remains in ensuring that recommended interventions and information are consistently implemented across all healthcare levels, particularly in lower-resource settings. Mothers in this study frequently mentioned inconsistency in the level of support and information received, revealing a need for improved care coordination and communication. Future research could focus on developing quality improvement strategies that ensure consistent implementation of FCC, along with appropriate training, resource allocation, and policy reformation in hospitals of varying levels to improve the support systems for mothers of infants with FSD. Future research could include studies exploring mothering infants with FSD across multiple healthcare centres or in units across various levels of care.

Additionally, this study underscores the evolving role of mothers in infant care settings when caring for an infant who presents with FSD. As frameworks and mothers encourage greater maternal involvement in interventions, there is a role shift in which mothers are not passive caregivers but active participants in their infants' medical journeys. With this shift, research should highlight how this expanded role impacts maternal wellbeing, mental health, and caregiving capacity. Future research could explore how mothers perceive this role shift and develop strategies that better equip them to manage the added responsibilities, particularly in resource-constrained environments where professional support may be less consistent.

Clinical implications

This study has outlined the barriers, facilitators, and support structures available to the mothers of infants with FSD in two hospital settings. To mitigate barriers and improve facilitators to mothering, hospitals need to incorporate the mothers, acknowledge their needs, and consider implementing their recommendations. This study highlighted the need to include mothers in their infants' care and improve communication between HCPs and mothers.

Healthcare facilities must recognise the need for training of both HCPs and mothers. HCPs need to consider their role in supporting mothers and offering counselling in hospital environments. Improving their skills to better care for mothers would ultimately support better infant care. HCPs should be educated on the importance of compassion during engagements and given tools regarding ways to remain considerate of mothers' emotions while delivering consistent communication (Malenfant et al., 2022; Malepe et al., 2022). HCPs should prioritise effective communication to address maternal anxiety and promote resilience (Eduku et al., 2024).

Furthermore, HCPs are encouraged to participate in daily multi-disciplinary staff meetings to discuss updates, goals, and schedules where mothers are included to ensure alignment and a shared understanding. Mothers should also be encouraged to join ward-rounds and the care processes as they are contributing members of the care team. Mothers require regular opportunities to discuss their concerns and ideas with the HCPs. In turn, HCPs could train mothers to monitor their infants for abnormal signs and red flags that should be reported to the HCP team. Lastly, HCPs are encouraged to share care responsibility by involving parents in caregiving and basic medical tasks such as administering medication. Training caregivers is beneficial to all parties as it has been shown to alleviate HCP workload, improve maternal confidence, and improve infant health by stimulating development and promoting nutritional intake (Kapti et al., 2023).

Mothers of hospitalised infants are recommended to undergo NICU and similar environment training/education. This training would provide education about the environment (i.e., machinery, routines, neonatal care, feeding, bonding, and explanations of infant conditions and typical treatment). Education on these topics has been shown to reduce maternal stress, promote maternal-infant bonding, and improve maternal beliefs that aid maternal coping in environments such as the NICU (Abdeyazdan et al., 2014; Goral & Geçkil, 2022; Yilmaz & Küçük Alemdar, 2022). Additionally, mothers should be provided with demonstrations on how to administer permitted care acts, how to hold their infant to encourage touch and bonding, and education on feeding practices (Eduku et al., 2024).

Effectively implementing the principles of FCC would greatly benefit the infants, mothers, and HCPs. If facilities in South Africa wish to provide effective FCC in their units, the facilities

should ensure that their training enables that. Hospitals should consider providing more comprehensive staff training on FCC and ways for HCPs to implement FCC within their role (Malepe et al., 2022). Units should foster a more collaborative healthcare culture because improving hospital infrastructure could help bridge the gap between the ideals of FCC and the realities of its implementation in a low-resource environment. The effective implementation of the FCC framework could greatly improve mothering and overall care in these units.

Conclusion

This study highlighted the multifaceted experiences of mothers caring for infants with FSD in neonatal and infant hospital settings in South Africa, emphasising the complex interplay of physical, emotional, and systemic factors that shape their journey. At the core of the mothers' experiences lies a deep commitment to their infants' wellbeing and feeding, a hallmark of mothering influenced by personal values and societal expectations. However, this experience goes beyond feeding challenges alone. Rather, it encompasses a broader amalgamation of factors that act as barriers and facilitators to mothering.

The findings revealed a range of barriers that mothers face, including the emotional toll of separation, inadequate communication, the alienating hospital environment, and inconsistent support from HCPs. These challenges not only hinder the caregiving role but also compound maternal stress and guilt, underscoring the need for holistic interventions that address both physical and emotional needs. Mothers highlighted the importance of being involved in their infants' care, having access to clear and compassionate communication, and being supported in navigating the clinical caregiving environment.

Conversely, facilitators such as access to knowledge, training, and inclusion in decision-making were pivotal in empowering mothers and gave them a sense of agency. Practical support by HCPs, including SLTs and nurses for example, helped mothers adapt to the complex needs of their infants, while peer and family support networks helped alleviate feelings of isolation and the stress of caregiving. The study also revealed mothers' adaptability and strength, with participants often drawing on internal coping mechanisms such as hope and patience to manage the challenges they face.

This study underscores that mothering an infant with FSD in hospital units is not solely defined by feeding challenges but shaped by a broader interplay of factors, including emotional, social, and institutional barriers and facilitators. The experience of mothering is a combination of these elements that affect the mothers' ability to care for their infants and their emotional wellbeing and sense of identity as caregivers. FSD is intrinsically linked to these broader factors, reinforcing the importance of addressing the environment and systemic supports to ensure optimal outcomes for both mothers and infants. These support structures are essential for alleviating maternal stress, promoting mother-infant bonding, and improving feeding outcomes, all of which are central to recovery and development in infants with FSD.

To promote maternal and infant wellbeing, healthcare systems must adopt a more inclusive and family-centred approach, addressing the structural and emotional needs of mothers alongside the clinical care of their infants. Such an approach includes improving communication, fostering a culture of empathy and respect, and ensuring that mothers are valued partners in their infants' care.

Ultimately, this study emphasises that caregiving in infant hospital units is a shared journey. It requires a collective effort from HCPs, families, and facility structures to create an environment that supports the medical recovery of infants and the holistic wellbeing of their mothers. By recognising and addressing these factors, healthcare systems can move toward more compassionate and effective care that acknowledges the challenges and resilience of mothers who face these challenges every day.

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APPENDIX A: CONFIDENTIALITY AGREEMENT FOR RA and INTERPRETER

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Website: www.dhrs.uct.ac.za

Confidentiality Agreement for Interpreter

Ethical guidelines set out by the Declaration of Helsinki (2013) will be adhered to, to ensure that confidentiality, justice, equality, beneficence and non-maleficence, autonomy and dignity of the participants and the research is upheld at all times.

I have been contracted to translate or interpret interviews as part of a research study being conducted by Cecilia Meyer, Department of Health and Rehabilitation Sciences at the University of Cape Town.

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 interpreting.

Confidentiality

I agree to respect the confidentiality of any conversation I interpret. 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 translation/interpretation, 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 Cecilia Meyer.

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.

I …… declare that I agree with the confidentiality agreement and its conditions as stated above on this day …… (date).

_____

Signature of interpreter

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Website: www.dhrs.uct.ac.za

Confidentiality Agreement for Research Assistant

Ethical guidelines set out by the Declaration of Helsinki (2013) will be adhered to. to ensure that confidentiality, justice, equality, beneficence and non-maleficence, autonomy and dignity of the participants and the research is upheld at all times.

I have been contracted to conduct interviews as part of a research study being conducted by Cecilia Meyer, Department of Health and Rehabilitation Sciences at the University of Cape Town.

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

Confidentiality

I agree to respect the confidentiality of any conversation that is held during the interview. 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 interview following the interview guide while using interview skills required to conduct a semi-structured conversation, to elicit information from the participant, to achieve the study's aims and objectives.

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 or to aid the interview process.

I …… declare that I agree with the confidentiality agreement and its conditions as stated above on this day …… (date).

_____

Signature of Research Assistant

APPENDIX B: HUMAN RESEARCH ETHICS COMMITTEE APPROVAL LETTER

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room 45 E-52-E-Floor- Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6492
Email: hrec-submissions@uct.ac.za
Website: www.health.uct.ac.za/home/human-research-ethics

28 March 2023

HREC REF: 094/2023

Ms V Norman
Division of CSD
Health & Rehab Sciences- OMB
Email: vivienne.norman@uct.ac.za
Student: MYRCEC002@myuct.ac.za

Dear Ms Norman

PROJECT TITLE: MOTHERING A NEONATE/YOUNG INFANT WITH FEEDING AND SWALLOWING DIFFICULTIES: BARRIERS, FACILITATORS, AND SUPPORT- MSC CANDIDATE-MS CECILIA MEYER

Thank you for your response letter, addressing the issues raised by the Faculty of Health Sciences Human Research Ethics Committee (HREC).

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until the 30 March 2024.

Please submit a progress form, using the standardised Annual Report Form (FHS016) if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

The HREC acknowledge that the student: Ms Cecelia Meyer will also be involved in this study.

Please quote the HREC REF 094/2023 in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FACULTY OF HEALTH SCIENCES HUMAN RESEARCH ETHICS COMMITTEE

Federal Wide Assurance Number: FWA00001637. Institutional Review Board (IRB) number: IRB00001938 NHREC-registration number: REC-210208-007

HREC/ref 094.2023

APPENDIX C: Western Cape Department of Health Research Approval Letter

DIRECTORATE: HEALTH INTELLIGENCE
Health.Research@westerncape.gov.za
tel: +27 21 483 0866; fax: +27 21 483 6058
24th Floor, 4 Dorp Street, Cape Town, 8001

REFERENCE: WC_202304_018
ENQUIRIES: Dr Sabela Petros

University of Cape Town
Anzio Road
Observatory
Cape Town
7925

For attention: Mrs Vivienne Norman, Prof Brenda Morrow, Ms Cecelia Meyer

Re: Mothering a neonate/young infant with feeding and swallowing difficulties: barriers, facilitators, and support.

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research. Please contact the following people to assist you with any further enquiries in accessing the following sites:

Mowbray Maternity Hospital	**Chantel J Stewart**	**021 659 5579**

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, provided that normal activities at requested facilities are not interrupted and staff are not put under pressure to comply with the research activities.
2. Researchers must provide the department with an electronic copy of a Final Report using the Annexure 9 template within six months of completion of research. This can be submitted to Health.Research@westerncape.gov.za. Future research will not be allowed on the health platform if a Final Report is not submitted.
3. In the event where the research project goes beyond the *estimated completion* date which was submitted, or the final date of the ethics clearance letter, researchers are expected to complete and submit a progress report (**Annexure 8**) and an updated ethics clearance letter to Health.Research@westerncape.gov.za. Failure to do so will render this approval letter void.
4. Please note that if you are conducting a folder audit, and you do not have consent from individual study participants/subjects, you may not capture **identifiable patient information** in your database, as per the Protection of Personal Information Act 4 of 2013 (POPIA).
5. If you do have consent from individual participants in this study, and you are collecting identifiable patient data through your chosen research methodology, you should not keep the data for any longer than is required to complete this research, as per POPIA.
6. The reference number above should be quoted in all future correspondence

Yours sincerely

DR M MOODLEY
PROVINCIAL HEALTH RESEARCH AND EVALUATION
DATE: 19-02-2024

APPENDIX D: Red Cross War Memorial Children's Hospital Approval Letter

Western Cape Government
FOR YOU

DR M SALIE
Acting Manager: Medical Services
Red Cross War Memorial Children's Hospital

Queries: Ellen.Thomas@westerncape.gov.za
Tel: +27 21 658 5383

Date: 05 May 2023

Ms V Norman
Speech-Language Pathology

Dear Ms Norman

RESEARCH: RXH: RCC 370 / WC_202304_018

PROJECT TITLE: Mothering a neonate/young infant with feeding and swallowing difficulties: barriers, facilitators, and support.

Thank you for submitting your study to the Red Cross War Memorial Children's Hospital Research Committee for review.

It is a pleasure to inform you that the Red Cross Children's Hospital Research Committee has formally approved your application to conduct above-mentioned study.

Approval is granted until 30 March 2024 as per your ethics approval, HREC 094/2023.

Kindly submit a renewal request if your study continues beyond the approval period with a progress report. If the study is completed within the approval period, please inform the committee. A copy of your final document to be submitted after completion of your project.

Kindly quote the reference **RXH: RCC 370 / WC_202304_018** in all your correspondence.

Yours sincerely,

DR M SALIE
ACTING MANAGER: MEDICAL SERVICES

APPENDIX E: Mowbray Maternity Approval Letter

Department of Health
Dr. Chantal Stewart
Head of Clinical Unit:
Obstetrics
Mowbray Maternity Hospital
Chantal.Stewart@westerncape.gov.za | Tel: 021 659 5578

Ms Vivienne Norman
Communication Sciences and disorders
UCT

e-mail: Vivienne.Norman@uct.ac.za

Mothering a neonate/young infant with feeding and swallowing difficulties: barriers, facilitators

Dear Ms Norman

You are granted permission to proceed with your research at Mowbray Maternity Hospital until 15 May 2024.

Please note the following:

a) Your research may not interfere with normal patient care.
b) Hospital staff may not be asked to assist with your research.
c) No additional costs to the hospital should be incurred.
d) **As there is only one records clerk, folder requests should be given two weeks in advance, and no pressure should be applied for a quick service. Only 50 folders per week may be requested at one time**.
e) No patient folders may be removed from the premises or be inaccessible.
f) Please provide the researcher with a copy of this letter as verification of approval.
g) Confidentiality must be maintained at all times.
h) Should you require additional research time beyond the stipulated expiry date, please apply for an extension.
i) On completion of your research, please forward any recommendations/findings that can be beneficial in terms of further action, development or policy review.
j) Please forward a copy of the publication or report on completion of the research.

Good luck with your project.
Yours sincerely

Dr Chantal Stewart
Chair
MMH Research Committee
18/5/2023

APPENDIX F: PARTICIPANT INFORMATION SHEET

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PARTICIPANT INFORMATION SHEET

TITLE: Mothering a neonate/young infant with feeding and swallowing difficulties: barriers, facilitators, and support.

REFERENCE NUMBER: **HREC:**

PRINCIPAL INVESTIGATOR: Vivienne Norman

CO-INVESTIGATOR / SUPERVISOR: Prof Brenda Morrow

STUDENT INVESTIGATOR: Cecilia Meyer

INTRODUCTION:

My name is Cecilia Meyer, and I am currently completing a Masters in Speech-Language Pathology at the university of Cape Town (UCT). I am a qualified Speech-Language Therapist and South African certified Lactation Consultant. I am interested in finding out more about the experiences of mothers of new babies with feeding and swallowing difficulties while they are in the hospital.

You are invited to participate in a research study. This study has been approved by the Human Research Ethics Committee of UCT and will follow the ethical guidelines that set out by the international Declaration of Helsinki (2013), and the National Department of Health's Ethics in Health Research: Principles, Processes and Structures (2015).

What is this research study all about?

This research is looking at what you, as a mother of a baby with feeding and swallowing difficulties, feel has helped you or made it harder for you to care for your baby while in the neonatal unit. We would like to find out directly from mothers, what helped them and what made it more difficult so that we can try to make changes that will be more supportive to mothers when their baby with feeding and swallowing difficulties is in hospital in future.

Why have you been invited to participate?

You are a mother of a baby who is between the ages of 0-3 months, who has some difficulty with feeding and swallowing and you will therefore be able to explain to us what has helped you and what has made it more difficult during your baby's stay in the hospital.

What will your role be?

I will interview you which we will be an audio recorded interview. This will mean I will ask you some questions such as your age, name and how long you have been at the unit. Other questions about your time with your baby in the unit, what things you felt were helpful and what you think might be more helpful, will be asked. I will then sum up your answer and say it back to you to make sure that all the information I have is right and you feel as if I have understood what you said correctly. You can tell me if you want me to add anything or change anything. This will take about 45-60 minutes. We will find a quiet private space where we can have this conversation. The interview will be done in a private room that will be in or nearby the unit your baby is in, in the hospital (RXCMH/MMH).

Will you or your baby benefit from taking part in this research?

No, there is no direct benefit to you or your baby for taking part in the study. There is no money for taking part in the study. The information you, and other mothers, give us may help us as healthcare professionals to provide better support to mothers in the future.

Are there any risks involved in your taking part in this research?

No, there are no risks for getting physically hurt if you are part of the research, because you will only be answering questions. There is a chance that you may be upset while you are talking with me as you may feel emotional when explaining your baby's illness and/or what

you have experienced here. If you are upset while I am asking questions, we will stop and continue later or if you would like to end the session, that will be done immediately. If you would like to talk to someone for support I will refer you to the hospital services.

If you do not agree to take part, what alternatives do you have?

It is completely your choice if you want to take part in the study or not. If you do not want to be part of the study, you can say so, and everything will continue as before, your baby will continue to receive the same care. If you decide to take part in the study and later feel that you do not want to continue you can decide to stop at any time and you do not have to say why.

Who will have access to your/your infant's medical records?

Only myself and my supervisors will be able to look into your baby's medical file. This is just to check to make sure that your baby is between the ages of 0 – 3 months, has some feeding and swallowing difficulty, and has been in the unit for at least one week.

Will my information be shared?

Your personal information will not be shared with anyone and any information that links you to what you have told us will be taken out. The researcher will change your name and use a 'reference code' (e.g., Mother 1) and will be used instead of your name. Any information about you and your baby that does not have to do with the research will be taken out of the information collected and will not be put in the study. Any information that is kept in the study will be put in in a way where others will not know it is you. All the documents that have your information and your interview answers will be kept locked away safely and anything electronic will be protected by a password. When the study has been written, all the information will be given to my research supervisor based at UCT where it will be stored safely for five years after the study has been published.

Will you be paid to take part in this study and are there any costs involved?

You will not be paid if you choose to be part of the study. Being part of the study will not cost you anything. The interview will be done when your baby is sleeping and when you are free

and not needed to do anything. The interview will happen at the hospital in a private and quiet room so you will not need to travel anywhere.

If you have any more questions, please do not hesitate to contact the researcher or research supervisors.

Kind Regards,
Cecilia Meyer

Cecilia Meyer
0734899312
MYRCEC002@myuct.ac.za
Student Researcher, Master's Student at the University of Cape Town

Vivienne Norman
vivienne.norman@uct.ac.za
Senior Lecturer at the University of Cape Town

Brenda Morrow
brenda.morrow@uct.ac.za
Professor at the University of Cape Town

⇒ The UCT FHS Human Research Ethics Committee can be contacted on 0214066338 in case participants have any questions regarding their rights and welfare as research subjects on the study.

⇒ You will receive a copy of this information for your own records

Declaration by Investigator

I …… declare that:

- I explained the information in this document to ……..
- I encouraged /her to ask questions and took adequate time to answer them.
- I am satisfied that she adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter.

Signed at (place) ..... on (date) ……. .

_____

Signature of investigator

Declaration by interpreter

I …… declare that:

- I assisted the investigator Cecilia Meyer to explain the information in this document to (name of participant) …….. using the language medium of isiXhosa or Afrikaans.
- We encouraged her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (place) ..... on (date) ……..

_____

Signature of interpreter

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INLIGTINGSBLADSY VIR DEELNEMERS

TITEL: Moedersorg aan 'n neonate baba met voeding-en-sluk probleme: hindernisse, hulpbronne en ondersteuning.

VERWYSINGSNOMMER HREC: 094/2023

HOOF ONDERSOEKBEAMPTE: Vivienne Norman

MEDE-ONDERSOEKBEAMPTE / TOESIGHOUER: Prof Brenda Morrow

STUDENT ONDERSOEKBEAMPTE: Cecilia Meyer

Inleiding:

My naam is Cecilia Meyer en ek voltooi 'n Meestersgraad in Spraak-Taal Patologie aan die Universiteit van Kaapstad (UK). Ek is 'n gekwalifiseerde spraakterapeut en 'n Suid-Afrikaanse gesertifiseerde borsvoedingskonsultant. Ek doen navorsing om meer uit te vind oor die ondervinding van moeders van nuwe babas wat voeding-en-sluk probleme het tydens hul hospitaal verblyf.

U word hiermee genooi om deel te neem aan hierdie navorsingsstudie.
Hierdie studie is goedgekeur deur die Menslike Navorsingsetiekkomitee van die UK (UCT Faculty of Health Sciences' Human Research Ethics Committee – HREC) en sal die etiese riglyne soos uiteengesit deur die Internasionale Verklaring van Helsinki (2013) en die Nasionale Departement van Gesondheidsetiek in gesondheidsnavorsing (2015) volg.

Waaroor handel hierdie navorsing?
Hierdie studie handel oor u, as moeder van 'n baba met voed-en-sluk probleme. Ek ondersoek wat u gehelp of gehinder het om u baba te versorg terwyl julle twee in die neonatale eenheid van die hospitaal is/was. Ons wil graag direk van moeders hoor oor hul ervaring, wat het gehelp and wat het dinge moeliker gemaak. Dit sal ons help om veranderinge te maak, sodate alle moeders met babas wat voed-en-sluk probleme het, in die toekoms beter gehelp kan word.

Hoekom is u genooi om deel te neem?

U is die moeder van ’n baba tussen die ouderdom van 0-3 maande, wat voed-en-sluk probleme het. U kan dus vir ons verduidelik wat u help en wat dit moeiliker maak t vir u en u baba om goed versorg in die hospitaal te wees.

Hoe kan u deelname ons help?

Ek gaan vir u ’n paar vrae vra en die gesprek op band opneem. Die vrae is byvoorbeeld, wat u naam is, hoe oud u is en hoe lank u baba in die neonatale eenheid is. Verdere vrae sal wees oor wat u gehelp het en wat u dink nog gedoen kan word, om moeders beter by te staan in die eenheid.

Ek gaan daarna ’n opsomming van u antwoorde skryf en dit vir u teruglees om seker te maak dat ek al die inligting korrek gehoor het en dat ek u antwoorde reg verstaan het. U is welkom om verdere besonderhede by te voeg of veranderinge aan te bring. Hierdie gesprek gaan om en by 45-60 minute duur en sal in ‘n private kamer plaas vind, naby die eenheid waar u baba is.

Gaan u of u baba finansieel of op ander gebied, deur u deelname aan hierdie studie gehelp word?

Daar is geen direkte voordele aan deelname nie. Geen geld word aan u betaal nie.

Die studie mik daarop om in die vervolg beter hulp te verleen aan moeders soos u wat dalk dieselfde probleme in die eenheid ondervind as wat u het.

Is hierdie navorsing onveilig of skadelik?

Nee, omdat u net vrae gaan beantwoord, kan u nie fisies seerkry nie. U mag wel emosioneel ontsteld word wanneer u oor u baba se siekte en/of u ondervinding hier praat.

Ek sal dan onmiddelik ophou vrae vra en ons kan later die onderhoud voortsit. As u die onderhoud wil staak, sal ek dadelik ophou en mag u die vertrek verlaat.

Indien u emosioneleondersteuning na die onderhoud benodig, sal ek dit namens u met die hospitaal reël.

U hoef nie bekommerd te wees indien u nie aan die studie wil deelneem nie. Niks sal aan die versorging van u baba verander nie. Alles sal voortgaan soos tevore. U deelname aan die studie is heeltemal vrywillig. U kan ook op enige stadium in die proses besluit om nie meer deel te neem nie. Ons sal dadelik die onderhoud staak en u hoef geen redes vir u besluit om te stop, aan my te gee nie.

Wie sal toegang hê tot my baba se hospitaallêer?

Slegs ek en my toesighouer (studieleier) sal in die lêer mag kyk om seker te maak dat u baba wel 0 tot 3 maande oud is, dat jou baba voed en/of sluk probleme het en ten minste een week in die neonatale eenheid opgeneem is.

Sal die inligting wat ek oor jou en jou baba versamel met ander gedeel word?

U persoonlike inligting is privaat en sal nie uitgegee word nie. Alle inligting wat u kan identifiseer, sal verwyder word.

U naam word vir studiedoeleindes verander en ons sal net ’n kode gebruik omu te identifiseer, byvoorbeeld: Moeder 1. Alle inligting wat nie van toepassing is op die studie nie, sal verwyder word en nie gebruik word nie. As die navorsingsinligting deur ander gelees word sal u nie geïdentifiseer kan word nie.
Tydens die studie word die oorspronklike inligting veilig toegesluit. Wanneer die studie voltooi is, sal my studieleier die inligting by die universiteit veilig bewaar vir 5 jaar nadat die verhandeling gepubliseer is.

Is daar enige onkostes verbonde aan my deelname aan die studie?

Deelname aan die studie gaan u niks kos nie. Ek gaan die onderhoud in die privaatheid van ‘n hospitaalkamer met u voer sodat dit gerieflik is vir u en terwyl u baba slaap en u tyd het. Ons voer die onderhoud by die hospitaal sodat u nie reiskostes moet betaal of reëlings hoef te tref nie.

Indien u enige vrae het, kontak gerus onmiddelik die navorser of die studieleiers.

- ⇒ *Die Menslike Navorsings Komitee van UK kan gekontak word by 0214066338 indien daar enige navrae is ten opsigte van die regte en welsyn van die deelnemers aan hierdie navorsing.*
- ⇒ *Jy sal ń afskrif van hierdie dokument ontvang vir persoonlike rekord.*

Groete,

Cecilia Meyer
0734899312
MYRCEC002@myuct.ac.za
Student Researcher, Master’s Student at the University of Cape Town

Vivienne Norman
vivienne.norman@uct.ac.za
Senior Lecturer at the University of Cape Town

Brenda Morrow
brenda.morrow@uct.ac.za
Professor at the University of Cape Town

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Website: www.dhrs.uct.ac.za

IPHEPHA LOLWAZI LOMTHATHI-NXAXHEBA

ISIHLOKO: Ukukhulisa umntwana osanda kuzalwa / usana oluncinci olunengxaki yokondla kunye nokuginya: imiqobo, abaququzeleli kunye nenkxaso.

INOMBOLO YESALATHISO: **HREC:**

UMPHANDI OYINTLOKO: Vivienne Norman

OMNYE UMPHANDI: Prof Brenda Morrow

UMPHANDI ONGUMFUNDI: Cecilia Meyer

INTSHAYELELO:

Igama lam ndinguCecilia Meyer, ndigqibezela iMasters kwiSpeech-Language Pathology kwiDyunivesithi yaseKapa (UCT). Ndiyingcaphephe eqeqeshelwe ukuNyanga ngoLwimi kunye noMcebisi oqinisekisiweyo wokuncancisa waseMzantsi Afrika. Ndinomdla wokwazi banzi malunga namava oomama babantwana abatsha abanobunzima bokutya kunye nokuginya ngelixa besesibhedlele.

Uyamenywa ukuba uthathe inxaxheba kuphando. Olu phando luvunyiwe yiKomiti yemigaqo yokuziphatha zoPhando lwe-UCT (UCT FHS Human Research Ethics Committee) kwaye iya kulandela izikhokelo zokuziphatha ezibekwe sisibhengezo samazwe ngamazwe sase-Helsinki (2013), kunye neSebe lezeMpilo leSizwe leeNdlela zokuziphatha kuPhando lwezeMpilo: iMigaqo, iiNkqubo kunye nolwakhiwo (2015).

Lumalunga nantoni olu phando?

Olu phando lujonge ukuba yintoni wena, njengomama wosana olunengxaki yokutya nokuginya, uvakalelwa kukuba ikuncedile okanye yenze kwanzima ukuba ukhathalele usana lwakho

ngelixa ukwiyunithi yeentsana. Singathanda ukufumanisa ngokuthe vetshe koomama, ukuba bancedwa yintoni kwaye yintoni eyenza kube nzima ngakumbi ukuze sizame ukwenza utshintsho oluya kubaxhasa ngakumbi oomama xa usana lwabo olunengxaki yokutya kunye nokuginya lusesibhedlele kwixesha elizayo.

Kutheni umenyiwe ukuba ube nenxaxheba?

Ungumama womntwana ophakathi kwenyanga 0-3, onengxaki yokuncancisa nokuginya kwaye uya kukwazi ukusicacisela ukuba yintoni le ikuncedileyo nokuba yintoni eyenze kubenzima kakhulu ngexesha losana lwakho lokuhlala esibhedlele.

Iyakuba yintoni indima yakho?

Ndizakuba nodliwano-ndlebe nawe, olu ludliwanondlebe sizakulirikhoda. Oku kuya kuthetha ukuba ndiza kukubuza imibuzo efana neminyaka yakho, igama kunye nokuba unexesha elingakanani kule yunithi yeentsana. Eminye imibuzo malunga nexesha lakho nosana lwakho kwiyunithi, zeziphi izinto oziva zabaluncedo kwaye ocinga ukuba zinokuba luncedo ngakumbi. Ndizakushwankathela impendulo yakho kwaye ndiyibuyisele kuwe ukuze ndiqinisekise ukuba lonke ulwazi endinalo luchanekile kwaye uziva ngathi ndiyiqondile into oyithethileyo. Ungandixelela ukuba ufuna ndongeze nantoni na okanye nditshintshe nantoni na. Oku kuya kuthatha malunga nemizuzu eyi-45-60. Siza kufumana indawo ethe cwaka yabucala apho singanale ncoko. Udliwano-ndlebe luya kwenziwa kwigumbi labucala eliya kuba ngaphakathi okanye kufutshane neyunithi akuyo umntwana wakho, esibhedlele (RXCMH/MMH).

Ngaba wena okanye usana lwakho niya kuzuza ngokuthatha inxaxheba kolu phando?

Hayi, akukho nzuzo ingqalileyo kuwe okanye kusana lwakho ngokuthatha inxaxheba kuphando. Akukho mali yokuthatha inxaxheba kuphando. Ulwazi osinika lona kunye nabanye oomama, lusenokunceda thina njengabasebenzi bokhathalelo lwempilo ukubonelela ngenkxaso engcono koomama kwixesha elizayo.

Ngaba kukho nayiphi na ingozi ebandakanyekayo ekuthatheni kwakho inxaxheba kolu phando?

Hayi, akukho mngcipheko wokwenzakala emzimbeni ukuba uyinxalenye yophando, kuba uya kube uphendula imibuzo kuphela. Kukho ithuba lokuba ukhathazeke ngelixa uthetha nam

njengoko unokuziva uvakalelwe yintliziyo xa uchaza isigulo somntwana wakho kunye / okanye into oye wadibana nayo apha. Ukuba ukhathazekile ngelixa ndibuza imibuzo, siya kumisa kwaye siqhubeke kamva okanye ukuba ungathanda ukuphelisa iseshini, oko kuya kwenziwa ngoko nangoko. Ukuba ungathanda ukuthetha nomntu ukuba akuxhase ndizakuthumela kwiinkonzo zasesibhedlele.

Ukuba akuvumi ukuba nenxaxheba, ziziphi ezinye iindlela onazo?

Lukhetho lwakho ngokupheleleyo ukuba uyafuna ukuthatha inxaxheba kuphando okanye hayi. Ukuba akufuni ukuba yinxalenye yoluphando, ungatsho, yaye yonke into iya kuqhubeka njengangaphambili, usana lwakho luya kuqhubeka lufumana inyameko efanayo. Ukuba ugqiba ekubeni ube nenxaxheba kwesi sifundo yaye kamva uvakalelwa kukuba akufuni ukuqhubeka unokuyeka nanini na yaye akuyomfuneko ukuba uchaze isizathu.

Ngubani oza kufikelela kwiirekhodi zonyango zakho/zosana lwakho?

Ndim kunye nabaphathi bam kuphela abaya kukwazi ukujonga ifayile yonyango yomntwana wakho. Oku kukujonga nje ukuqinisekisa ukuba umntwana wakho uphakathi kweenyanga ezi-0 ukuya kwezi-3 ubudala, unobunzima bokutya nokuginya, kwaye ubekwiyunithi yeentsana ubuncinane iveki enye.

Ngaba inkcukacha zam kuya kwabelwana ngazo?

Iinkcukacha zakho zobuqu aziyi kwabelwana ngazo nabani na kwaye naluphi na ulwazi olunxulumanisa noko usixelele kona luya kukhutshwa. Umphandi uya kutshintsha igama lakho kwaye asebenzise 'ikhowudi yokwalathisa/referensi' (umzekelo, uMama 1) kwaye iya kusetyenziswa endaweni yegama lakho. Naluphi na ulwazi olumalunga nawe nosana lwakho olungenanto yakwenza nophando luya kukhutshwa kulwazi oluqokelelweyo kwaye aluyi kufakwa kuphando. Naluphi na ulwazi olugcinwe kuphando luya kufakwa ngendlela apho abanye bangazi ukuba nguwe. Onke amaxwebhu aneenkcukacha zakho kunye neempendulo zodliwano-ndlebe ziya kugcinwa zitshixelwe ngokukhuselekileyo kwaye nantoni na ekwi-elektroniki iya kukhuselwa nge-password. Xa uphando lubhaliwe, yonke ingcaciso iya kunikwa umphathi wam wophando ose-UCT apho iya kugcinwa ngokukhuselekileyo iminyaka emihlanu emva kokuba uphando lupapashiwe.

Ngaba uya kuhlawulwa ngokuthatha inxaxheba koluphando kwaye ngaba kukho naziphi na iindleko ezibandakanyekayo?

Awuyi kuhlawulwa ukuba ukhetha ukuba yinxalenye yoluphando. Ukuba yinxalenye yoluphando akuyi kukubiza nto. Udliwano-ndlebe luya kwenziwa xa umntwana wakho elele kwaye xa ukhululekile, kwaye kungekho mfuneko yokuba wenze nantoni na. Udliwano-ndlebe luya kwenzeka esibhedlele kwigumbi labucala nelizolileyo ngoko ke akuyi kufuneka uhambe naphi na.

Ukuba unayo nayiphi na imibuzo, nceda ungathandabuzi ukuqhagamshelana nomphandi okanye abaphathi bophando.

Ozithobileyo,

Cecilia Meyer

0734899312

MYRCEC002@myuct.ac.za

Umfundi onguMphandi, uMfundi weMasters kwiDyunivesithi yaseKapa

Vivienne Norman

vivienne.norman@uct.ac.za

Umfundisi wemfundo ephakamileyo oMkhulu kwiDyunivesithi yaseKapa

Brenda Morrow

brenda.morrow@uct.ac.za

UNjingalwazi kwiDyunivesithi yaseKapa

- ⇒ IKomiti yemigaqo yokuziphatha zoPhando lwe-UCT (UCT FHS Human Research Ethics committee) kungaqhagamshelwana nayo kule nombolo 0214066338 xa abathathi-nxaxheba banayo nayiphi na imibuzo malunga namalungelo abo nentlalontle njengabathathi nxaxheba kuphando.
- ⇒ Uya kufumana ikopi yolu lwazi uzigcinele kwiirekhodi zakho

APPENDIX G: PARTICIPANT CONSENT FORM

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Participant Consent Form

By signing below, I …….. agree to take part in a research study entitled Mothering a neonate/young infant with feeding and swallowing difficulties: barriers, facilitators, and support. **I declare that:**

- I have read or had read to me this information and consent form and it is written in a language in which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be punished/ have any bad effect on the healthcare and treatment of me or my infant in any way.
- I consent to having the interview's audio recorded.

Signed at (place) …….. on (date) …….. .

_____

Signature of participant

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Deelnemer Vrywarings Vorm

Hiermee stem ek, _____ in om deel te neem aan ‘n navorsingstudie, naamlik: *Moedersorg aan ‘n neonate baba met voeding-en-sluk probleme: hindernisse, hulpbronne en ondersteuning.*

Ek verklaar die volgende:

- Ek het, of iemand het vir my hierdie informasie gelees, tesame met die vrywarings vorm. Dit is geskryf in ‘n taal wat ek verstaan en waarin ek gemaklik is.
- Ek het kans gehad om vrae te vra en al my vrae is voldoende beantwoord.
- Ek verstaan dat my deelname in hierdie studie vrywillig is en dat ek nie onder druk geplaas word om deel te neem nie.
- Ek mag hierdie studie enigetyd verlaat sonder dat ek gestraf word. Dit sal geen negatiewe gevolge hê op my, of my baba se gesondheidsorg of behandeling nie.
- Ek gee toestemming dat die onderhoud se oudio opgeneem word.

Geteken by (plek)_____op (datum)_____

_____
Handtekening van deelnemer

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Ifomu yeMvume yoMthathi-nxaxheba

Ngokutyikitya ngezantsi, mna ..... ndiyavuma ukuthatha inxaxheba kuphando olunesihloko esithi Ukukhulisa umntwana osandul 'ukuzalwa/usana oluncinane olunengxaki yokutya nokuginya: imiqobo, abaququzeleli kunye nenkxaso.

Ndivakalisa ukuba:

- Ndiyifundile okanye ndilufundele olu lwazi kunye nefomu yemvume, kwaye ibhalwe ngolwimi endithetha ngalo kwaye ndikhululekile.
- Ndibe nethuba lokubuza imibuzo kwaye yonke imibuzo yam iphendulwe ngokwanelisekileyo.
- Ndiyaqonda ukuba ukuthatha inxaxheba koluphando **kungokuzithandela** kwaye khange ndinyanzeleke ukuba ndithathe inxaxheba.
- Ndingakhetha ukuluyeka uphando nangaliphi na ixesha kwaye andisayi kohlwaywa/ndibe nesiphumo esibi kukhathalelo lwempilo kunye nonyango lwam okanye losana lwam nangayiphi na indlela..
- Ndiyavuma ukuba kurekhodwe iaudio yodliwano-ndlebe.

Ityikitywe e (indawo) ..... ngo (umhla) ....

_____

Umtyikityo womthathi-nxaxheba

APPENDIX H: INTERVIEW GUIDE

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Procedural Checklist:

Standard Operating Procedure		
1.	Introduce yourself	
2.	Briefly explain the study	
3.	Explain consent and remind them that it will be **audio recorded**	
4.	Explain that the study can be stopped at any time	
5.	**Begin tape recording**	
6.	Biographical information	
7.	Interview questions	

Interview Guide:

Remember to make use of ACTIVE listening!

- Being fully present in the conversation
- Showing interest - good eye contact
- Noticing (and using) non-verbal cues
- Asking open-ended questions to encourage further responses
- Paraphrasing and reflecting back what has been said
- Listening to understand rather than to respond
- Withholding judgment and advice
- OBSERVE WAIT AND LISTEN

Non-scripted prompt ideas:

- *Can you give me an example of that?*

- *How did you feel about that?*
- *Can you explain that?*

Interview Questions:

1. **Tell me about your baby's feeding/how they feed?**

Prompt 1: Do they feed orally or are they tube fed?
Prompt 2: What difficulties have you experienced feeding them/during feeding times?

2. **What does the word "mothering" mean to you?**

Prompt 1: When I talk about mothering, what do you understand by that?
Prompt 2: What does a mother do/How does a mother take care of their baby? (If the mother does not offer any ideas)

3. **Describe your experience of mothering your baby here/in this unit?**

Prompt 1: What have you been able to do and not do, as a mother, in this unit?
Prompt 2: How is this different to what you think a mother does?

4. **Can you tell me about what has helped you care/mother your baby while in this unit?**

Prompt 1a: Who here has helped you through this time (i.e., healthcare worker here)?
Prompt 1b: What are some structures that you've seen here that have helped you during this time (i.e., mother support group)?

5. **What do you feel has made it more challenging to mother for your baby here?**

Prompt: Tell me about what makes it difficult?

Interviewer: "This will now be our last question and then we will finish the interview"

6. **What do you think would have helped you more through this experience?**

Prompt 1: What suggestions or changes would you make to make your mothering experience in the unit better?

Prompt 2: Would you have liked more information? More face to face with a professional? Support group?

Concluding statement:

Thank you so much for participating in the study. It really means a lot to me and the research. The information from the study will be made available once it has been written up and sent in for examination. The information will be sent to the hospital, and you can access it all here.

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Riglyne vir studie onderhoud.

1. **Vertel my hoe u baba drink en hoe word hy/sy gevoed./ Hoe word u baba gevoed**

    a) Drink u baba aan die bors, bottel of word hy/sy met 'n buis gevoed?
    b) Watter probleme ondervind u tydens voeding? Waarmee sukkel u en/of die baba tydens voeding?

2. Wat verstaan u onder *moedersorg* (mothering)?

a) Wanneer ek die woord *moedersorg* gebruik, wat dink u bedoel ek daarmee?
b) Hoe dink u moet 'n moeder haar baba versorg? Wat moet sy doen?

3. Beskryf u ondervinding met moedersorg hier in hierdie neonatale eenheid.

a) Wat moedersorg betref, wat kan u maklik in die eenheid, as moeder, doen of nie doen nie?
b) Hoe verskil dit van wat u dink 'n' moeder behoort te doen?

4. Vertel my wat u gehelp het in die eenheid om u baba te versorg soos wat u dink 'n moeder 'n baba moet versorg?

a) Watter personeel het u deur hierdie tyd gehelp?
b) Watter ander hulpmiddels is hier wat u gehelp het? ('n ondersteuningsgroep?)

5. Hoekom is dit moeiliker om u baba in hierdie eenheid moedersorg te gee?

a) Vertel vir my wat dit moeilik maak? Waarmee sukkel u veral?

6. Wat dink u sou gehelp het om jou ondervinding hier makliker te maak?

a) Wat kan in die eenheid verander om dit hier makliker vir 'n ma soos u te maak? Het u aan enige oplossings vir probleme wat u hier ondervind het gedink? Vertel my meer daarvan.
b) Sou u meer inligting oor die behandeling van jou baba wou hê? Dalk wil u meer gesprekke met die professionele personeel in die eenheid wou hê?
c) Sou u baat vind daarby om deel van 'n ondersteuningsgroep te wees saam met ander moeders in die eenheid wat dieselfde probleme as u ondervind het?

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Isikhokelo sodliwano-ndlebe:

1. **. Ndixelele malunga ngokutyisa umntwana wakho / ukuba umtyisa njani?**

Umqondiso 1: Ngaba utyiswa ngomlomo okanye ngombhobhomwokutya umntwana?
Umqondiso 2: Bobuphi ubunzima othe wadibana nabo xa umtyisa/ngexesha lokutya?

2. **. Igama elithi "ukubangumama" lithetha ntoni kuwe?**

Umqondiso 1: Xa ndithetha ngokuba ngumama uqonda ntoni apho?
Umqondiso 2: Wenza ntoni umama/Umama ulunakekela njani usana lwakhe? (Ukuba umama akanikezeli naziphi na izimvo)

3. **. Chaza amava akho okuba ngumama wosana lwakho apha/kule yunithi?**

Umqondiso 1: Yintoni okwazileyo ukuyenza nongakwazanga ukuyenziyo njengomama kuleyunithi?
Umqondiso 2: Yohluke njani lento kwinto ocinga ukuba yenziwa ngumama?

4. **.Ndicela undixelele ngento ekuncedileyo ukuhoya usana lwakho ngelixesha ukule yunithi?**

Umqondiso 1a: Ngubani olapha okuncedileyo ngelixesha (oko kukuthi, umsebenzi wezempilo apha)?
Umqondiso 1b: Zeziphi ezinye izinto ozibonileyo apha eziye zakunceda ngelixesha (oko kukuthi, Izinto ezifana namaqela enkxaso yomama)?

5. **. Yintoni obona ngathi yenza ukuba kubenzima ukuba ngumama kumntwana wakho apha?**

Umqondiso: Khawutsho yintoni le yenza kubenzima?

6. .Yintoni ocinga ukuba ibinokukunceda ngakumbi ekuhoyeni umntwana wakho?

Umqondiso 1: Zeziphi iingcebiso okanye utshintsho onokuthi ulwenze ukwenza ukuhoya umntwana wakho njengomama kwiyunithi kubengcono?
Umqondiso 2: Ngaba ngowuthande ukufumana ulwazi olungakumbi? Ukudibana ubuso ngobuso obungakumbi nengcali? Iqela lenkxaso?

APPENDIX I: BIOGRAPHICAL INFORMATION OF PARTICIPANTS

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Case History Questions:

1. What is your home language?
2. How old are you?
3. How many children do you have?
4. What do you do for a living?
5. Please explain to me why your baby is in hospital.
6. How long has your baby been admitted in the hospital for?
7. Are you staying in the same room as your infant here at the hospital?
8. What feeding difficulties does your baby have?

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Gevallestudievrae:

1. Wat is u huistaal?
2. Hoe oud is u?
3. Hoeveel kinders het u?
4. Werk u? Wat se werk doen u?
5. Verduidlik asb vir my waarom is u baba in die hospitaal.
6. Hoe lank is u baba al in die hospitaal?
7. Is u saam met u baba in die selfde kamer in die hospitaal?

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Imibuzo ye-Case history:

1. Loluphi ulwimi lwakho lwasekhaya?
2. Mingaphi iminyaka yakho?
3. Bangaphi abantwana onabo?
4. Ingaba uziphilisa njani?
5. Ndicela undicacisele ukuba kutheni umntwana wakho esesibhedlele.
6. Usana lwakho lunexesha elingakanani lulaliswe esibhedlele?
7. Ngaba uhlala kwigumbi elinye nosana lwakho apha esibhedlele?
8. Bobuphi ubunzima bokutyiswa umntwana wakho anabo?

APPENDIX J: INSTITUTION INFORMATION AND PERMISSION LETTER

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Dear Sir/Madam

RE: Permission to conduct research study at [INSTITUTION NAME] in Cape Town

TITLE: Mothering a neonate/young infant with feeding and swallowing difficulties: barriers, facilitators, and support.

HREC REFERENCE NUMBER:

PRINCIPAL INVESTIGATOR: Vivienne Norman

CO-INVESTIGATOR / SUPERVISOR: Prof Brenda Morrow

STUDENT INVESTIGATOR: Cecilia Meyer

I am writing to request permission to conduct a research study entitled "Mothering a neonate/young infant with feeding and swallowing difficulties: barriers, facilitators, and support" at your institution. My name is Cecilia Meyer, and I am currently a postgraduate student in Speech-Language Pathology at the University of Cape Town (UCT). Vivienne Norman and Brenda Morrow are my research supervisors, and both hold senior lecturer positions at UCT. I graduated from the UCT in 2020 completing a BSc in Speech-Language Pathology. In 2022 I completed a postgraduate qualification in lactation consultation and am working as a qualified Speech-Language Therapist and South African Certified Lactation Consultant.

This study has been approved by the Human Research Ethics Committee of UCT and will adhere to the ethical guidelines set out by the international Declaration of Helsinki (2013),

and the National Department of Health's Ethics in Health Research: Principles, Processes and Structures (2015).

Overview of the study:

This research study will explore the facilitators, barriers, and support to mothering a neonate/young infant, with feeding and swallowing difficulties, in the South African context. The structures and experiences that affect the caregiver need to be investigated to understand how it impacts them, their care for their infant and ultimately the development of the infant. Studies have shown that parents felt traumatised by the experience of having an infant in the NICU and experienced feelings of guilt, anxiety, and anger. Additionally, the frequent medical procedures and uncomfortable environment hinder the newborns' development and unsettle the mother's feelings and confidence. in addition to the stressful NICU environment, feeding and swallowing difficulties (FSD)[1] are associated with increased caregiver stress. The support needs of the parents need to be identified and included in the recovery plan so as to provide family-centred care. Families of these infants require informational, emotional and practical support to navigate caring for their infant especially ones with complex medical issues, including FSD. It is important for the staff working with these parents meet their support needs to improve the healthcare provided to the infant and their family and so that the infant can be cared for confidently in-hospital and ultimately upon discharge. Therefore, to provide contextually relevant, evidence-based intervention services, we need to understand the barriers, facilitators and support identified by mothers of neonates/young infants with FSD in a local context. This information can be used to develop more appropriate intervention, including support, to infants with FSD, and their mothers, during hospitalization in early infancy.

Participants:

[1] FSD is defined as the inability to orally consume food in an age-appropriate manner that cooccurs with medical, nutritional, feeding skill or psychosocial dysfunction as per the definition of pediatric feeding disorder (Goday et al., 2019).

I will be recruiting between 6-9 participants in total. Mowbray Maternity Hospital and Red Cross War Memorial Children's Hospital are both research sites for this study, therefore about 3-5 participants will be recruited from each site. The participants will be recruited from the neonatal high care, special care or kangaroo-mother-care unit (MMH) or neonatal high care (RCWMCH) of the respective institution. The selection criteria of the participants include:

- Mother of neonate/young infant with a diagnosis of feeding and swallowing difficulties currently admitted to a neonatal facility
- Admitted and present at the healthcare facility for a minimum of seven days
- Medically stable neonate

The research supervisor has discussed the study with the onsite SLT and will collaborate with her to identify potential participants, but the researcher will be responsible for recruitment so as not to blur lines between clinical services and research. The researcher will approach the potential participants and inform them about the study and provide them with written information (in their preferred language of Afrikaans, English or isiXhosa) which they can review or have read to them. Once the potential participants have had time to consider the information they can decide whether or not they would like to participate, those who agree to participate will complete an informed consent form.

After a participant has signed consent, the researcher will arrange an interview time that is convenient for the participant and will be held onsite for approximately 45-60 minutes. Where necessary, a translator will be used during the interviews to translate the sessions in either Afrikaans or isiXhosa as the researcher is not fluent in those languages. A confidentiality agreement will be implemented with the translator before data collection commences. Participants will be assigned a reference code to maintain anonymity and confidentiality. All identifying information will be removed from the data and stored separately to the interviews. All information will be stored securely in adherence to data management protocols.

There are no costs to the institution or participants for participating in the study but there is also no payment to participants. The researcher will arrange for the interview to take place in a private, quiet space in the hospital when the infant is sleeping, and the mother is not

required. The study will not result in any additional workload for hospital staff and will not interfere with any medical care.

There are no physical risks to participants, however there is a risk of the participants (mothers) becoming emotional during the interview. The interviewer will ask the mothers if they would like to pause and continue or terminate the session. Mothers will be offered the opportunity to be referred to onsite support if they indicate the need. The mothers and their infants will not directly benefit from this research. The potential benefits of this research are long-term; the results of the study may be used to inform and improve clinical practice in terms of the support that healthcare professional provide to mothers of neonates / young infants with feeding and swallowing difficulties, which may result in benefit to future mothers and their infants.

The final research will be shared with the institution after examination.

- ⇒ For any complaints or enquiries regarding the ethical conduct of this study please contact: Professor Marc Blockman: Chair of Human Research Ethics Committee: 021 406 6492
- ⇒ For any concerns or enquires regarding the study itself, please do not hesitate to contact the researcher or supervisors.

Kind Regards,

_____

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Professor at the University of Cape Town

Institution to sign here:

I, _____, hereby give permission for the study "Mothering a neonate/young infant with feeding and swallowing difficulties: barriers, facilitators, and support" with HREC to be conducted at _____.

_____ _____
Signature Date

APPENDIX K: COVID-19 CONSIDERATIONS

UNIVERSITY OF CAPE TOWN
IYUNIVESITHI YASEKAPA • UNIVERSITEIT VAN KAAPSTAD
HEALTH SCIENCES

DHRS
Department of Health and Rehabilitation Sciences
FACULTY OF HEALTH SCIENCES

Divisions of Communication Sciences & Disorders • Disability Studies • Nursing & Midwifery • Occupational Therapy • Physiotherapy

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Observatory, Cape Town, South Africa, 7925
Telephone: +27 (0) 21 406 6401
Website: www.dhrs.uct.ac.za

COVID-19:

All COVID-19 protocols of the healthcare facility will be adhered to. The interviews will be done with compliance to the national lockdown regulations according to the alert level the nation is on at the time of data collection.