MOTHERS' EXPERIENCE OF FEEDING THEIR PRETERM INFANT DURING THE FIRST MONTHS OF LIFE WITHIN A VULNERABLE POPULATION IN SOUTH AFRICA

By

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Thesis presented in partial fulfilment of the requirements for the degree of 'Master of Speech, Language and Hearing Therapy' in the Faculty of Medicine and Health Sciences at Stellenbosch University

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March 2021

DECLARATION

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ABSTRACT

Background: Preterm birth is a rising and significant threat to maternal and child health globally. Being the mother of a preterm infant is universally described as a challenging and stressful experience. Mothers of preterm infants with low socio-economic status and from linguistic minority groups, such as poor Afrikaans speaking mothers, face additional challenges that may influence their experience of caring for their preterm infant, namely poverty and limited linguistic and cultural representation within the health constitution. The universal challenges of being a mother of a preterm infant, combined with the more specific challenges of living in poverty and experiencing poor linguistic and cultural representation, bring about risks for both mother and infant. This includes poor maternal mental health; poor mother-infant bonding and attachment; and potential suboptimal developmental outcomes for the child.

Research aims: The main aim was to describe and explain how Afrikaans-speaking mothers, living in low socio-economic circumstances in the Western Cape, experienced caring for their preterm infant in the first months of life. The outcomes may facilitate better understanding of the early communication and feeding intervention needs of mothers of at-risk neonates from culturally and linguistically diverse contexts living in poverty.

Method: The study entailed a cross-sectional, qualitative design which was exploratory and descriptive in nature. Eleven participants, selected through a purposive sampling method, participated in individual in-depth interviews where a semi-structured discussion schedule was implemented. Nine interviews were then thematically analysed. Participants were Afrikaans-speaking mothers with low socio-economic status who brought their preterm infant (chronological age range of three to six months) for a follow-up appointment at a High-risk Clinic at a public tertiary hospital in Cape Town. The participants were a vulnerable group about whom little information was available in the research literature.

Findings: The task of feeding their preterm infant during the hospitalisation period was a significant experience for the participants. Feeding was perceived as a progressive task that is goal-driven and continuously demands a new method of feeding, higher volumes of milk, and increased weight gain in the infant to reach the eventual goal of discharge from hospital. This task was perceived as stressful due to various factors of which insufficient breastmilk supply was a significant contributor. Furthermore, the hospital setting was perceived as something that added to their anxiety surrounding feeding, but simultaneously had the potential to decrease their anxiety. The mothers felt that over time and with experience both they and their infants gradually became more comfortable and skilled in the task of feeding. When the mother-infant dyad was able to breastfeed successfully it was described as an '*amazing experience'* and one that made the participants feel like mothers at last.

Conclusion: The participants experienced feeding as one of the most significant stressors related to caring for their infant, especially in the first months of life while the infant was hospitalised. Various factors were identified that had positive and/or negative influences on this experience. The study findings have implications

with regard to future research, as well as education and clinical practice for all healthcare professionals working with preterm mother-infant dyads from culturally and linguistically diverse contexts living in poverty.

SAMEVATTING

Agtergrond: Premature geboorte is ‘n stygende en beduidende bedreiging vir moeder- en kindergesondheid wêreldwyd. Om die moeder van ‘n premature baba te wees, word universeel as ‘n uitdagende en stresvolle ervaring beskryf. Moeders van premature babas met lae sosio-ekonomiese status en wat behoort aan linguistiese minderheidsgroepe, soos arm Afrikaanssprekende moeders, ervaar bykomstige uitdagings wat hul ervaring van sorggewing vir hul premature baba kan beïnvloed, naamlik armoede en beperkte kulturele en linguistiese verteenwoordiging in die gesondheidstelsel. Die universele uitdagings verbonde daaraan om die moeder van ‘n premature baba te wees, tesame met die meer spesifieke uitdagings van in armoede te lewe en beperkte linguistiese en kulturele verteenwoordiging te ervaar, lei tot risiko’s vir beide moeder en kind. Dit sluit in swak moederlike geestesgesondheid; swak moeder-baba binding en gehegtheid; en potensiële suboptimale ontwikkelingsuitkomstes vir die kind.

Navorsingsdoelstellings: Die oorkoepelende doelstelling was om te verken en beskryf hoe Afrikaanssprekende moeders wat in lae sosio-ekonomiese omstandighede in die Wes-Kaap lewe, dit ervaar het om vir hulle premature baba in die eerste maande van lewe te sorg. Die bevindings kan bydra tot ‘n beter begrip van die behoeftes van arm moeders van babas met moontlike risiko faktore vanuit kultureel en linguisties diverse populasies, aangaande die vroeë kommunikasie- en voeding intervensie.

Metode: Die studie het gebruik gemaak van ‘n dwarssnit, kwalitatiewe ontwerp wat verkennend en beskrywend van aard is. Elf deelnemers is deur ‘n doelgerigte steekproefnemingmetode geselekteer, en het aan individuele en in-diepte onderhoude deelgeneem deur middel van ‘n semi-gestruktureerde besprekingsskedule. Nege van die onderhoude is tematies ontleed. Die deelnemers is Afrikaanssprekende moeders met lae sosio-ekonomiese status, wat hulle premature baba na ‘n opvolgafspraak by ‘n Hoë-risiko Kliniek by ‘n openbare tersiêre hospitaal in Kaapstad gebring het. Die deelnemers is ‘n kwesbare groep oor wie beperkte navorsingsliteratuur beskikbaar is.

Bevindinge: Om ‘n premature baba tydens die hospitaliseringstydperk te voed, is ‘n prominente evaring vir die deelnemers. Voeding is ervaar as ‘n progessiewe taak wat doelgedrewe is en voortdurend ‘n nuwe voedingsmetode, hoër volumes melk en verhoogde gewigstoename by die baba vereis om die uiteindelike doel van ontslag uit die hospitaal te bereik. Die taak is as stresvol ervaar weens verskeie faktore waarvan onvoldoende borsmelkvoorsiening ‘n beduidende bydraer is. Verder is die hospitaalopset ervaar as iets wat bydra tot hul angs aangaande voeding, maar terselfdetyd die potensiaal gehad het om hul angs te verminder. Die moeders het gevoel dat hulle self en die baba met verloop van tyd en toenemende ervaring geleidelik meer gemaklik en geskool geraak het in die taak van voeding. Wanneer die moeder-baba tweetal in staat was tot suksesvolle borsvoeding, is dit beskryf as ‘n wonderlike ervaring en een wat die deelnemers uiteindelik soos moeders laat voel het.

Slotsom: Die deelnemers het voeding ervaar as een van die mees beduidende stressors wat met die sorggewing van hul baba verband hou, veral in die eerste lewensmaande terwyl die baba gehospitaliseer is. Verskeie faktore

is geïdentifiseer wat ‘n positiewe en/of negatiewe invloed op die ervaring gehad het. Die navorsingsresultate het implikasies vir toekomstige navorsing, asook die opleiding en kliniese praktykvoering van alle persone in gesondheidsberoepe wat diens lewer aan moeders met premature babas uit kultureel en linguisties diverse populasies wat in armoede lewe.

ACKNOWLEDGEMENTS

I'd like to slightly change the well-known African proverb '*it takes a village to raise a child*' to '*it takes a village to complete a masters*' in order to thank everyone who supported me during this journey. My village consisted of the following stakeholders:

The Harry Crossley Trust – your financial support made this journey possible.

My research supervisor – I view your insight and tactful guidance as the ultimate standard and will continue to strive towards this ideal throughout my professional career.

My parents – you afforded me the ability as well as necessary opportunities to pursue a postgraduate degree.

My husband – by now, you have the exceptional ability to reason with me regarding speech therapy-specific topics, even though you are an accountant.

My God – nothing would be possible or meaningful without You.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF ABBREVIATIONS

ASHA – American Speech-Language-Hearing Association

CAQDAS – Computer-assisted qualitative data analysis software

ECI – Early communication intervention

ELBW – Extremely low birth weight

GGLN – Good Governance Learning Network

HCP – Health care professional

HIV/AIDS – Human immunodeficiency virus / Acquired immunodeficiency syndrome

HPCSA – Health Professions Council of South Africa

HRC – High-risk clinic

HREC – Health Research Ethics Committee

KMC – Kangaroo mother care

LBW – Low birth weight

LMIC – Low- and middle-income countries

NG – Nasogastric

NHRC - National Health Research Committee

NHRD - National Health Research Department

NICU – Neonatal intensive care unit

OG – Orogastic

SASLHA – South African Speech-Language-Hearing Association

SES – Socio-economic status

SLT – Speech-language therapist

UNICEF – United Nation's Children Fund

VLBW – Very low birth weight

WHO – World Health Organisation

CHAPTER ONE: INTRODUCTION

Background & Rationale

Preterm birth is a rising and significant threat to maternal and child health globally, and in South Africa in particular. Worldwide, approximately 5 – 18 % of births are preterm (World Health Organisation [WHO], 2017). The prevalence of preterm delivery is substantially higher in low- and middle-income countries (LMICs) with an estimated 60% of preterm births occurring in Africa and Asia (Blencowe et al., 2012). Low socio-economic status (SES) is associated with a higher incidence of preterm birth (Potjik, Kerstjens, Bos, Reijneveld, & de Winter, 2013). South Africa presents various risk factors for preterm birth that also complicate caring for a preterm infant. These factors include the high burden of disease, resource constraints in various respects and on many levels, and inequalities relating to social determinants of health (Dawes, Biersteker & Irvine, 2008). Poverty is viewed as fundamental to these risk factors and currently, more than 54, 4 % of South Africans are living in low socio-economic settings (Statistics South Africa, 2017). As modern technology and advances in neonatal care are ensuring the survival of preterm infants at younger gestational ages and with lower birthweights (WHO, 2017), LMICs are experiencing increased neonatal morbidity rates and challenges to already overburdened and poorly resourced health services.

Being the mother of a preterm infant is universally described as a challenging and stressful experience. Preterm infants are at risk for various medical, neurological, and developmental complications (Huddy, Johnson & Hope, 2001) that may influence current and future communication and feeding skills. These potential comorbidities accompanying preterm birth may have physical, psychological, social, and financial implications for mothers in the short and/or long term (Petrou, 2005). The mother of a preterm infant has a unique early parenting experience in caring for her infant (Pascoe, Bissessur & Mayers, 2016) and various factors may influence this experience. Firstly, mothers commonly experience feelings of unpreparedness (Minde, 2002), insecurity, anxiety, and self-doubt (Swift & Scholten, 2009; Leonard & Mayers, 2008) that may limit positive interaction with their infant. Secondly, infant-specific challenges such as a small physique (Crisp, 2006), sleepiness (Pascoe et al., 2016) and poor feeding skills (Crapnell et al., 2013) may alter maternal experiences of caring for their infant. Thirdly, being hospitalised in a Neonatal Intensive Care Unit (NICU) is a novel experience (Swift & Scholten, 2009) governed by strict rules and the presence of a variety of medical equipment (Leonard & Mayers, 2008). The mothers of preterm infants are a vulnerable group facing unique hardships which may potentially alter the nature of mother-infant interactions in the first months of life.

Mothers of preterm infants with low socio-economic status and from linguistic minority groups, such as poor Afrikaans-speaking mothers, face additional challenges that make them especially vulnerable and may influence their experience of caring for their preterm infant. In addition to poverty this includes limited linguistic and cultural representation within the health constitution (mothers with a low SES from the other indigenous South African languages are in a similar situation). Firstly, mothers living in poverty experience high levels of psychosocial stress in combination with limited access to social and economic resources (Crapnell et al., 2013). Challenges such as teenage pregnancies, substance abuse, low levels of education,

limited emotional support networks, and limited knowledge regarding typical childhood development (Minde, 2002) may further complicate the task of caring for a preterm infant. Secondly, Afrikaans mothers constitute a group that is poorly represented in a health constitution where English is the language of choice of the healthcare professional [HCP] (Penn & Watermeyer, 2018). The three official languages in the Western Cape arranged from most to least spoken are Afrikaans, isiXhosa, and English (Plüddemann, Braam, Broeder, Extra, & October, 2004). Since this would presumably hold true for health workers as well, Afrikaans mothers in the Western Cape may be more likely to receive health care in their mother tongue than speakers of other indigenous languages. The influence of cultural differences and the absence of indigenous and local healthcare knowledge should, however, not be underestimated. The encounters between HCPs and mothers in health care settings typically rely on some form of lingua franca or a common language to enable communication since their languages and cultures are likely to differ (Penn, 2007). English fulfils the role of the bridging language between speakers from different linguacultural settings within the South African health care system (Mgoqi, 2017). Afrikaans-speaking mothers are therefore often obliged to receive health care in their second or third language (Hussey, 2013), which creates linguistic and especially cultural barriers, thereby limiting their access to quality interventions. The universal challenges of being a mother of a preterm infant, combined with the context-specific challenges of living in poverty and experiencing poor linguistic and cultural representation, bring about risks for both mother and infant. This includes poor maternal mental health; poor mother-infant bonding and attachment; and potential sub-optimal feeding and communication development.

The obligation for speech-language therapists (SLTs) to support vulnerable and at-risk mother-infant dyads during the neonatal period is becoming more evident. An increasing number of infants in South Africa are at risk for neurodevelopmental delays, such as feeding or communication delays, due to the high frequency of preterm birth (South African Speech-Language-Hearing Association [SASLHA], 2017). Existing early communication intervention (ECI) guidelines emphasize the involvement of the mother (primary caregiver) in the intervention process (Craig et al., 2015), since their perceptions and experiences of caring for their infant are strong influences on future communication and feeding development. Maternal perceptions and experiences of caring for a preterm infant in South Africa will differ from one setting to another due to varying living conditions, including cultural and linguistic backgrounds. ECI provided to vulnerable populations, such as Afrikaans mothers of preterm infants with low SES, should be sensitive and accommodate their unique perceptions and experiences. This will allow SLTs to utilise the neonatal period optimally, to support mothers in stimulating communication and feeding development, and to prevent and timeously identify communication and feeding delays or disorders (SASLHA, 2017). Limited local and international research is available about the perceptions and experiences of caring for a preterm infant amongst mothers from linguistic minority groups who live in poverty. The poor representation of these vulnerable groups in research literature makes them susceptible to healthcare that is not contextually appropriate and sensitive toward their unique realities and experiences.

The main aim of the study was to describe and explain how Afrikaans mothers living in low socio-economic circumstances in the Western Cape experience caring for their preterm infant in the first months of life. The

goal was achieved by articulating the following research question: *How do Afrikaans mothers, living in low socio-economic circumstances in the Western Cape, experience caring for their preterm infant in the first months of life?* The answer to this question will assist in fulfilling South African speech-language therapists' current need to know 'what works best for whom, when and how' (SASLHA, 2017, p.3) with regard to ECI for at-risk neonates and mothers in our culturally and linguistically diverse context.

Outline of Chapters

Chapter one (Introduction): This chapter introduces the research topic by briefly describing the context and rationale for the study, as well as the main research aim.

Chapter two (Literature Review): A comprehensive and critical review of literature related to the research topic, including the issue of prematurity on the whole; prematurity in the South African context; factors influencing the communication development of a preterm infant; and an overview of ECI in preterm infants in South Africa. Bronfenbrenner's ecological systems theory (Rosa & Tudge, 2013) is used to provide an ecological perspective on the factors influencing a preterm infant's communication development.

Chapter three (Methodology): This chapter presents a detailed description of the research aims, design, and collection and analysis procedures. The scientific rigour of the study is also discussed throughout this chapter.

Chapter four (Findings): The findings of the study are set forth in an in-depth description of the six main themes, as well as an overview of maternal perceptions regarding feeding methods alternative to breastfeeding.

Chapter five (Article): This chapter presents a concise version of the study in an article format intended for future publication. The manuscript adheres to the guidelines set out by the South African Journal of Communication Disorders.

Chapter six (Discussion): The discussion of the research findings firstly highlights the significance of the outcomes by discussing similarities and/or contradictions between individual themes, as well as between the current findings and those reported in existing literature. Secondly, the study limitations and strengths are covered. Lastly, implications and recommendations for future research, health professional education, and clinical practice are discussed.

CHAPTER TWO: LITERATURE REVIEW

Introduction to prematurity and health care in South Africa

An overview of prematurity

Preterm birth is defined as birth occurring at less than 37 weeks gestational age (Wang, Dorer, Fleming & Catlin, 2004). Preterm birth is firstly classified according to the infant's gestational age, and secondly the infant's birth weight (Rossetti, 2001). In terms of gestational age, the following classifications are commonly used: moderate to late preterm (32 – 37 weeks), very preterm (28 – 32 weeks) and extremely preterm (younger than 28 weeks). In terms of birth weight, the following classifications exist: low birth weight (LBW - weight below 2500 grams), very low birth weight (VLBW - weight below 1500 grams) and extremely low birth weight (ELBW - weight below 1000 grams). The lack of prenatal development is a major determinant of neonatal mortality and morbidity and may have various long-term consequences for both the infant and caregiver(s). These infants are at risk for various medical, neurological, and developmental complications (Huddy, Johnson & Hope, 2001) that will be discussed later in this chapter. Higher rates of cerebral palsy, sensory deficits, learning disabilities and respiratory illnesses have been reported in children born prematurely compared to children born after a full-term pregnancy. The high morbidity rates accompanying prematurity also often has long-term physical, psychological and financial implications for caregivers (Petrou, 2005). According to Kerstjens, de Winter, Bocca-Tjeertjes, Bos and Reijneveld (2012), the morbidity risks present inversely with gestational age: as the gestational age of the infant decreases, the potential risks increase at an exponential rate.

The aetiology of preterm birth is not yet clear, although there is consensus that it is multifactorial (Goldenberg, Culhane, Iams & Romero, 2008). Factors associated with prematurity include specific types of environmental exposure, genetic influences, certain maternal medical conditions, certain foetal medical conditions, infertility treatments, and iatrogenic prematurity. According to Lawn et al. (2006), preterm birth rates in high-income countries range from five to seven percent. The percentage in LMICs is estimated to be substantially higher but is challenging to determine. Firstly, accurate and complete population data and medical records are often scarce within developing countries (Graafmans et al., 2001). Secondly, estimate rates are influenced by various factors such as national differences in birth registration processes, varying procedures used to determine gestational age, and varying religious practices which may discourage the registering of preterm births (Graafmans et al., 2001). According to the WHO (2017), an estimate of 9.6% of all births across the world in 2005 was preterm. This translates to an estimate of 12.9 million births that may be defined as preterm. Approximately 85% of this burden was concentrated in Africa and Asia, thus supporting the claim that preterm birth rates are substantially higher in LMICs.

Modern technology has resulted in the survival of many preterm infants at younger gestational ages, as well as with lower birth weights (WHO, 2017). Although the availability of such technologies is still unevenly distributed between high-income countries and LMICs, the situation in LMICs is improving. This will lead to

an increase in morbidity rates and poses a potential challenge to overtaxed and under-resourced health, education, and social service sectors.

Prematurity in South Africa

The WHO (2017) reports a definite discrepancy in the number of preterm births, as well as the survival of preterm infants, between high-income countries and LMICs. LMICs, such as South Africa, display higher rates of preterm births together with lower survival rates of preterm infants. The WHO (2018) states that annually an estimated 15 million babies are born prematurely with approximately 84,000 of these births occurring in South Africa. Sadly, 10 % of these children born in South Africa do not survive, despite the births mostly taking place at healthcare facilities (WHO, 2018). SASLHA (2017) also states that an increased number of infants and children in South Africa will continue to be at risk for neurodevelopmental delays due to this high frequency of preterm birth. Caregivers in South Africa are exposed to a myriad of factors that firstly increase preterm birth rates and secondly complicate the task of caring for a preterm infant. The following section aims to outline and discuss some of these risk factors.

In 2017, Statistics South Africa (2017) reported that an estimate of 54, 4% South Africans were living in poverty and that this figure was continuously increasing. The recent COVID-19 pandemic has a significant influence on the livelihoods of South Africans and ensures a steep increase in poverty, as well as lasting effects on citizens' health, education, and employment prospects. Laborde, Martin and Vos (2020) state that urban and rural populations in sub-Saharan Africa will intensely experience the effects of the pandemic and a 23% increase in people living in poverty may be expected, equating to 80 million people. Caregivers from low socio-economic status (SES) settings are faced with multiple challenges that may threaten childhood outcomes (Dawes et al., 2008). Poverty is described as one of the greatest threats to healthy childhood development (Statistics South Africa, 2017). Firstly, the living conditions of caregivers with low SES may be viewed as a potential risk to optimal childhood development. This includes inadequate access to quality healthcare, poor nutrition, poor housing and sanitation, and high rates of infectious diseases such as Human immunodeficiency virus / Acquired immunodeficiency syndrome (HIV/AIDS) and Tuberculosis (Dawes et al., 2008). Secondly, the work environments of poor caregivers (if they are employed) often entail long hours, physical labour, stressful routines and exposure to dangerous situations or substances as described by Goldenberg et al. (2008). Added to this, there is a lack of quality early childhood development facilities that are accessible or affordable to caregivers living in poverty (Von Fintel, 2015). The majority of facilities available to poor caregivers lack basic infrastructure such as ablution facilities as well as electricity and water supply, and provide a variable quality of education (Von Fintel, 2015). This shortage further complicates caregivers' task of finding and sustaining employment while simultaneously ensuring the safe and sufficient education of their young child. Thirdly, the hardships that mothers with low SES are exposed to are further risk factors for premature birth and may affect caregiving following preterm birth. These challenges include motherhood in teenage years, substance abuse or exposure, low education levels, limited social support, and high levels of depression and anxiety caused by challenging living and working environments (Goldenberg et al., 2008). Additionally,

gender-based violence is a widespread and common phenomenon in South Africa and contributes to the challenging living conditions to which mothers are exposed (Machisa & van Dorp, 2012). A study conducted by the Medical Research Council in South Africa showed that 25% of women in the general population have previously experienced physical violence (Abrahams et al., 2009). Fourthly, it is believed that mothers with knowledge about typical childhood development will more likely create opportunities to facilitate and aid their child's development (Huang, O'Brien Caughy, Genevro, & Miller, 2005). Lower education levels and limited knowledge about childhood development, as often encountered amongst mothers from low SES environments, pose a risk to their child's development. The presence of these risk factors contributes to the high frequency of preterm births in South Africa and complicates the task of caring for a preterm infant.

Besides the various challenges brought about by poverty, South Africa has an additional barrier to effective health care: a population with significant cultural and linguistic diversity. South Africa hosts 44 living languages of which 11 are officially recognised (Hussey, 2013). Furthermore, South Africa provides a home to refugees from various African countries (Lewis, Simons & Fennig, 2016). It is therefore not surprising that linguistic and cultural diversity is a crucial challenge to the provision of quality health care in South Africa and can indeed be described as the 'overlooked' barrier (Hussey, 2013). In fact, Levin (2006) described language and culture as a greater barrier to health care than socio-economic challenges. English is the preferred language of most HCPs, although only the fourth most common mother tongue in South Africa (Penn, 2007). It is predictable, therefore, that more than 80% of medical interactions occur across language and cultural barriers (Penn, 2007). Health care in South Africa is mostly received in the user's second or third language (Hussey, 2013) and practitioners provide little accommodation for users unable to communicate in English (Williams & Bekker, 2008). This phenomenon of 'monolingual health services in a multilingual society' (Elkington & Talbon, 2016) poses a significant barrier to accessing health care for the diverse population of South Africa. The importance of special considerations during health interventions with diverse cultural and linguistic groups, for example Afrikaans populations, will be re-iterated throughout this chapter.

Poverty and a culturally and linguistically diverse population were briefly discussed as two of the most significant challenges to health care in South Africa, and specifically, as factors posing risks to preterm infants and their families. This description is not sufficiently representative of the full complexity of these factors. They are issues that should be well understood by HCPs in South Africa to ensure interventions that are accommodating and effective (Penn, 2014).

Vulnerability in health care

'Vulnerable' is a term often used to describe populations within health care, although the application and the definition of the term are not consistent (Clark & Preto, 2018). According to Waisel (2013, p.188), this term may include 'patients who are racial or ethnic minorities, children, elderly, socio-economically disadvantaged, underinsured or those with certain medical conditions'. These groups run the risk of having poor health care access and/or outcomes due to their specific cultural, economic, ethnic or health attributes. Clark and Preto (2018) warn that the term should be used with caution and due consideration of the possible implications it

may have for the population involved, such as stigmatisation. The study population for the current study may be viewed as a vulnerable group with regard to three attributes, namely, being the mother of a preterm infant (health attribute); having low SES (economic attribute); and belonging to a linguistic minority group (cultural attribute). These attributes, and the potential negative impact they have on maternal experiences of caring for a preterm infant, are discussed at length throughout the literature review. Waisel (2013) states that increased understanding of the impact that belonging to a vulnerable group has on health care may help relevant individuals to make appropriate policy recommendations. Furthermore, it is necessary to raise awareness, to provide education and to publish guidelines with regard to health care for vulnerable groups.

Risk factors affecting the communication development of preterm infants: an ecological perspective

An overview of early communication development

The first year of an infant's life is characterized by rapid development in a variety of domains, including early communication. Rossetti (2001) defines communication as an active process that involves a dynamic exchange of messages. Infants are remarkably sensitive to social stimuli during the first year of life and this period is critical for the development of fundamental communication skills (Beuker, Rommelse, Donders & Buitelaar, 2013). The ability to establish joint attention, take turns, and participate in reciprocal interactions with communicative partners are among the skills referred to as pre-linguistic communication skills (Rossetti, 2001). The pre-linguistic stage of communication thus refers to the period during which children make use of nonverbal means of communication before they transition to words (Watt, Wetherby, & Shumway, 2006). Communication during this stage is often related to expressing physiological needs such as being hungry or tired, or seeking comfort (Rossetti, 2001). Examples of communicative methods used by infants are actions such as moving their limbs and showing facial expressions, and vocalisations such as crying and cooing (Rossetti, 2001).

This critical stage of communication development is often overlooked or misunderstood. Pre-linguistic communication milestones are abstract and less 'visible' than physical milestones such as sitting or walking (Rossetti, 2001), and the early signs of a communication delay or disorder are therefore often overlooked. A communication delay occurs when communication development follows the typical sequence of milestones but at a slower pace than in normally developing peers, whilst a communication disorder entails the presence of atypical communication behaviours (Rossetti, 2001). Timeous and relevant intervention during the early stages of communication development is of the utmost importance as research indicates that the period from birth to six years is critical to the development of basic listening and communication skills (SASLHA, 2017). Neural plasticity is higher during infancy and intervention should thus ideally start when congenital or perinatal risks are identified (SASLHA, 2017). Further evidence suggests that early ECI may benefit future speech-language interventions (Rossetti, 2001) and may influence future language learning and development (Brockmeyer Cates et al., 2012). ECI will be discussed in more depth later in this chapter.

The important role of mothers in early communication development

A process fundamental to all developmental domains, but especially social and communication development, is the process of establishing a secure attachment between the infant and a caregiver (Rossetti, 2001). A secure attachment is defined as a bond where an infant feels secure, safe, calm, and trusting of their caregiver. The feeling of safety allows for optimal development of the infant's nervous system and facilitates their exploration of and engagement with the environment (Rossetti, 2001). The absence of a nurturing and protective relationship may result in impaired social, emotional, and cognitive development in infancy and influence the individual's attachment style throughout adulthood (Alhusen, Hayat & Gross, 2013). The interaction-attachment between a caregiver and infant is a basic aspect of early communication development. Studies comparing maternal and paternal experiences in the NICU and the attachment process with the preterm infant (Fegran, Helseth & Fagermoen, 2008; Hagen, Iversen & Svindseth, 2016) revealed definite differences between the experiences and needs of mothers and fathers. Fathers were more concerned for their partner, while mothers were more concerned for their baby (Hagen et al., 2016). Fathers experienced a limitation on the number of visits allowed in the NICU, spent less time with the infant than the mother did, and often felt alienated from the infant. Mothers also experienced alienation and struggled to bond with the baby but seemed better able to accept support from health personnel (Hagen et al., 2016).

The current study will focus exclusively on maternal experiences, as mothers are mostly responsible for caring for their infant in the first months of life, especially while the infant is hospitalised. This focus will help to keep the study concise. SASLHA (2017) states that the mother-infant dyadic attachment forms the basis of early communication development. Mothers are widely described as the primary caregiver within the literature. Crisp (2006) observed that mothers generally spend more time with their infant than other family members do and are responsible for performing most caregiving tasks. Feeding, especially breastfeeding, is amongst these caregiving tasks and is almost solely a maternal responsibility. Oruche, Gerkensmeyer, Stephan, Wheeler and Hanna (2012) confirm that mothers are usually the primary provider of care to their children. Therefore, they are the primary agent for forming a secure attachment with the infant and facilitating subsequent communication development. Mothers are thus central to optimal early communication development in infants.

Early communication development in preterm infants

Any factor that has a negative impact on an infant's ability to interact and communicate with the environment, and any factor that may limit interaction and communication from the environment creates a threat to typical communication development (Rossetti, 2001). Preterm infants are therefore at risk for communication delays and/or disorders due to a broad range of both biological and environmental factors. Bronfenbrenner's ecological systems theory as explained by Rosa and Tudge (2013) will be used to demonstrate how various proximal (immediate and direct) and distal (distant and indirect) factors reciprocally influence a preterm infant's communication development. This theory identifies five levels of risk factors that range from immediate to distant. Arranged from proximal to distal, the levels are the microsystem, mesosystem, exosystem, macrosystem, and the chronosystem. This model will be applied specifically to the mothers of

preterm infants and the aim is to highlight the significant and direct effect that mothers and their environments may have on a preterm infant's communication development. Bronfenbrenner's theoretical framework aids in organizing the vast number of factors, and their intricate interplay, that may influence early communication development in preterm infants as well as mothers' perceptions of communication development. Level five, the overarching chronosystem, will not be discussed and therefore this discussion does not include temporal changes in a preterm infant's life. Figure 1 illustrates Bronfenbrenner's theoretical framework and the various proximal and distal factors relating to the mother of the infant that may influence the infant's early communication development.

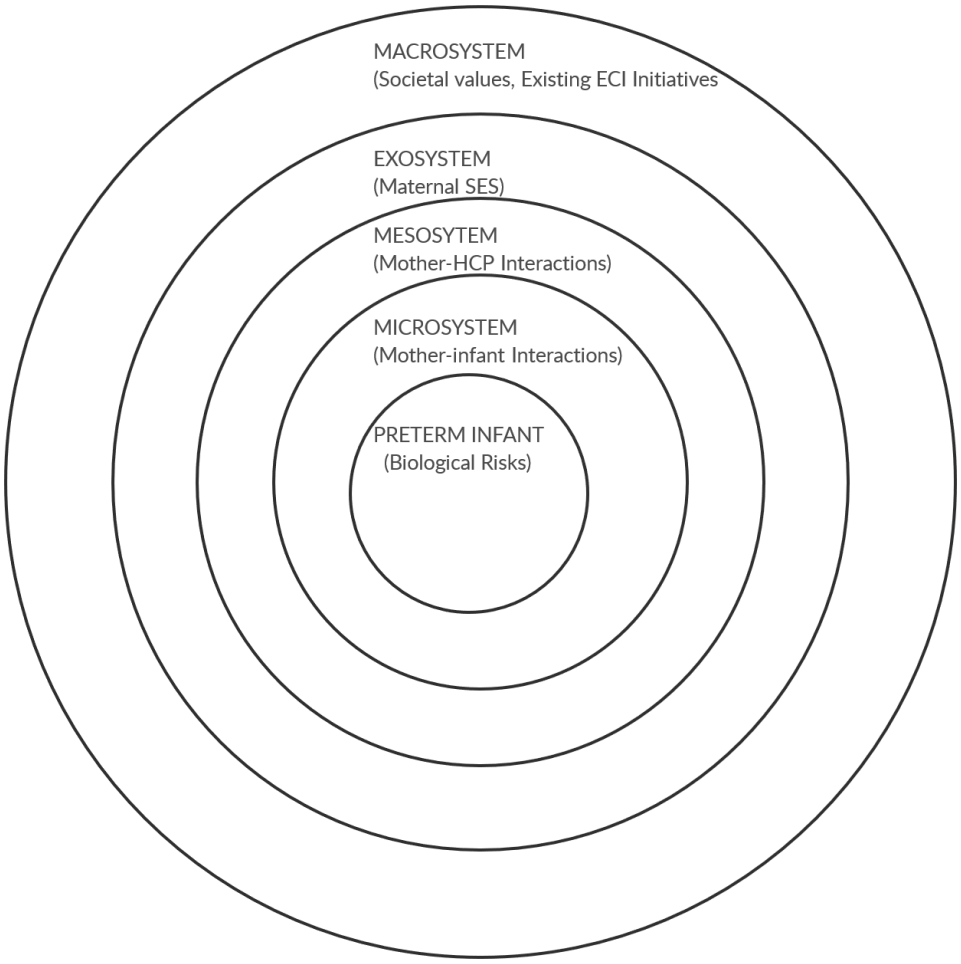

Figure 1: Bronfenbrenner's theoretical framework applied to maternal-related factors potentially influencing the early communication development of the infant.

Biological risk factors for early communication delays and/or disorders in preterm infants

Medical and surgical advances are ensuring that the survival rate of extremely preterm infants is increasing (Ward & Beachy, 2003) and subsequently complications of prematurity are becoming more common. Preterm birth may result in short-term and/or long-term complications and complications vary between infants. Kerstjens et al. (2012) state that morbidity risks present inversely with gestational age: as the gestational age of the infant decreases, the potential risks increase at an exponential rate. Birth weight is a further factor that

functions according to this principle. Most preterm infants born very or extremely preterm will be admitted to a NICU until they have reached sufficient organ maturity to be cared for independent of intensive care (Ward & Beachy, 2003). The immaturity of multiple organ systems places the preterm infant at risk for various acute and/or chronic complications (Darcy, 2009). Neurological complications include central nervous system haemorrhage and/or ischaemia, cerebral palsy, intellectual disabilities, and developmental delays. Sensory complications include poor sensory modulation, hearing impairments, and visual impairments (Minde, 2002). Physiological complications include necrotising enterocolitis, patent ductus arteriosus, chronic lung disease, bronchopulmonary dysplasia, and respiratory distress syndrome (Darcy, 2009). It is clear that preterm infants are born while they are still neurologically, physiologically and anatomically unprepared for life outside of the mother's womb (Crisp, 2006). Therefore, they are not yet able to interact successfully with their environment and often display delayed and/or disordered communication development.

Preterm infants commonly face feeding difficulties. Research suggests that almost one in five of very preterm infants are subject to feeding difficulties, while one in ten healthy full-term infants experience feeding difficulties (Crapnell et al., 2013). Due to neurological, sensory, and physiological immaturity and difficulties as described above, preterm infants often display neurobehavioral dysfunction (Brown, Inder, Bear, Hunt, Anderson & Doyle, 2009). Consequently, the achievement of skills fundamental to successful oral feeding is delayed or disordered. These skills include state regulation, motor organization, rhythmical sucking, and coordinating a suck-swallow-breath pattern (Medoff-Cooper & Ratcliffe, 2005). Additionally, preterm infants often require invasive medical procedures such as intubation which further complicate successful oral feeding. Invasive procedures may potentially delay the initiation of and progress to oral feeding, as well as limiting exposure to or experiences of positive oral feeding (Dodrill, McMahon, Ward, Weir, Donovan & Riddle, 2004). This has the potential to alter feeding experiences for the preterm infant. Difficulty and/or delay in establishing successful oral feeds often lead to psychological distress among mothers. This experience of distress has the potential to alter interaction and attachment between the mother and infant (Crapnell et al., 2013). The task of feeding, and specifically breastfeeding, is an intimate task which contributes to the mother-infant dyadic attachment and provides an opportunity for interaction. The need for alternative and often non-oral feeding methods such as orogastric (OG) or nasogastric (NG) tube feeding creates a barrier to this opportunity (Flacking, Ewald, Nyqvist & Starrin, 2006). The reduced feeding ability of a preterm infant is, therefore, a further risk to communication development.

Environmental risk factors for early communication delays and/or disorders

Microsystem (Mother-infant interactions)

The first set of environmental risk factors that will be discussed pertains to the activities and interpersonal relationships in the infant's face-to-face settings that may inhibit or facilitate communication development (Rosa & Tudge, 2013). These factors are seen as proximal, direct and within the infant's immediate environment. To address the research topic, the focus of this discussion will be on the activities and interpersonal relationship between mother and infant. As explained before, a mother is central to the early

communication development of her preterm infant as she is often the caregiver who has the most interaction with the infant (Crisp, 2006). The nature of mother-infant interactions may be influenced by maternal perceptions and knowledge regarding their preterm infant and early communication development (van Schalkwyk, Gay, Miller, Matthee & Gerber, 2020). Understanding the potential risks or advantages connected to these interactions requires firstly recognising the unique maternal experiences and hardships of having and caring for a preterm infant.

The mother of a preterm infant has a unique early communication and interaction experience with her infant. The reduced interaction abilities of the infant (Pascoe et al., 2016) and the inevitable hospitalisation (Swift & Scholten, 2009) lead to altered experiences and influence maternal perceptions. Negative maternal perceptions regarding early communication can influence maternal behaviour towards the infant and may inhibit the occurrence of natural and positive mother-infant interactions. A study by Nicolaou, Rosewell, Marlow and Glazebrook (2009) found that infants who experience positive interactions with their mothers display improved cognitive and linguistic development. Negative perceptions may therefore adversely affect the communication development of the preterm infant. A scoping review conducted by van Schalkwyk et al. (2020) focused on maternal perceptions of early communication in the preterm population and identified recurring themes from twelve articles within the defined research field. The findings of this scoping review, together with other relevant literature, will be discussed to explain the unique experiences and hardships of mothers of preterm infants.

The mother of a preterm infant experiences various challenging emotions in having and caring for their infant. Firstly, the feeling of maternal unpreparedness is common as giving birth changes from a marked event to a crisis (Minde, 2002). Mercer (2004) explains that a mother's attachment and preparation during pregnancy for taking care of her infant are important processes in attaining a maternal identity. The unexpected birth of a preterm infant, and especially an extremely preterm infant, interrupts these processes of maternal preoccupation and attachment (Minde, 2002). Secondly, anxiety is often experienced due to the infant's compromised medical status, physical appearance, and reduced feeding and communication abilities (Swift & Scholten, 2009; Leonard & Mayers, 2008; Flacking et al., 2006). Thirdly, mothers may feel poorly equipped to take care of and meet the demands of a medically compromised infant. They often experience feelings of self-doubt and insecurity about their own and their infant's capabilities (Kritzinger & Louw, 2003). Flacking et al. (2006) found that this was especially relevant to daily care-taking routines such as bathing, dressing, or interaction with a preterm infant. This may be ascribed to the fact that the medical and physical needs of the infant are prioritised above communication-interaction and therefore the information received from health care professionals tends to focus solely on medical aspects (Kritzinger & Louw, 2003). In summary, feelings of unpreparedness, anxiety, insecurity, self-doubt and guilt are commonly experienced after giving birth to a preterm infant and may create a barrier to natural interaction between the mother and the infant.

As discussed under biological risk factors, preterm infants have an established risk for feeding difficulties. Literature suggests that the presence of these difficulties compromises bonding and attachment by minimising

pleasurable interaction for the mother-infant dyad (Swift & Scholten, 2009; Flacking et al., 2006), thereby affecting communication development. Strict feeding schedules and alternative methods of feeding, together with the infant's reduced feeding abilities, transform the feeding task from mostly pleasurable and natural to stressful and rule bound. An additional feeding-related challenge to mothers of preterm infants is providing their infant with 'mother's milk' (McInnes & Chambers, 2008). Initiating lactation is challenging due to preterm birth, especially in the case of extremely and very preterm infants (McInnes & Chambers, 2008). Obstetric complications such as caesarean delivery and/or maternal complications such as admission to intensive care may further complicate the initiation of lactation (Lee & Gould, 2009). Maintaining lactation is often a further challenge as very preterm infants are not able to breastfeed. Mothers are often required to express breastmilk and maintain lactation until the infant can breastfeed successfully (Lee & Gould, 2009). Initiating and maintaining lactation are challenging to mothers and increase the stress associated with feeding times.

Maternal perceptions regarding prematurity and the preterm infant may also be viewed as a factor influencing mother-infant interactions. Pascoe et al. (2016) state that the mothers of preterm infants perceive their babies as sleepy and unresponsive. Mothers experience interactions as one-sided and this may lead to uncertainty about the infant's motivation to interact with them (Tanner, 2010). The physical attributes and behaviour of the preterm infant are also believed to influence maternal perceptions. A small physique, unnatural skin colour, and the presence of various types of medical equipment increase anxiety (Crisp, 2006). Furthermore, preterm infants struggle with sensory modulation and are often disorganized in their overall behaviour (Miles & Holditch-Daves, 1995) causing them to appear hypo- or hyperactive. This may leave mothers at a loss as to how to appropriately interact with them, which leads to reduced interaction between the mother and infant. The degree of medical complications also seems to have a significant influence on maternal perceptions. Minde (2002) found that there is a clear association between illness and mother-infant interaction. In her comparison study between mother-infant dyads with hospitalised and sick versus healthy infants, she found that the sicker infants had lower levels of motor activity and alertness leading to lower levels of smiling and touching from the mother. This study also concluded that the recovery of maternal behaviour lagged behind their infant's recovery and that this was still noticeable at three months after discharge home. Thus, even after a sick infant had recovered physically and reached healthy levels of activity, maternal behaviours remained at a lower level. This is worrisome as it implies that a mother's diminished interaction with her preterm infant may extend beyond hospitalisation and into the infant's first year(s) of life.

The barrier that hospitalisation poses to natural mother-infant dyadic interaction is discussed in a significant amount of literature (Crisp, 2006; Leonard & Mayers, 2008; McInroy & Kritzinger, 2005; Nicolaou et al., 2009; Swift & Scholten, 2009; Minde, 2002). The hospital, and specifically the NICU, is a novel environment for most mothers (Swift & Scholten, 2009). The presence of medical equipment, such as incubators, monitors, and feeding and respiration tubes further creates an intimidating context. Added to this, policies regarding physical handling, feeding times, and visiting hours lead to a rule-bound environment. These factors create both physical and emotional barriers between the mother and her infant and limit the occurrence of natural

interaction. Mothers often perceive themselves as redundant or passive onlookers during hospitalisation as they can make few decisions about their infants (Minde, 2002). Care-taking routines are determined by the medical establishment and mothers often have limited participation in these tasks. The constant presence of other people such as doctors, nurses, fellow-patients, and family members invades the privacy and intimacy that mothers desire with their infants (Crisp, 2006). This limits the mother's opportunities to interact freely and intuitively with her infant. These factors become significant if one considers the high rate of hospitalisation amongst preterm infants during their early years of life. Minde (2002) states that readmission to hospital is on average 2,5 times higher than in full-term infants. Preterm infants and their mothers may thus be exposed to 'communication depriving' environments on a relatively frequent basis.

Maternal perceptions and behaviour relating to early communication improve with the practice of Kangaroo Mother Care (KMC). Several studies (Feldman, Eidelman, Sirota & Weller, 2002; Flacking et al., 2006; Green & Phipps, 2015; Kritzinger & Louw, 2003; Mcinroy & Kritzinger, 2005; Kritzinger & Van Rooyen, 2014; Pascoe et al., 2016) indicate that mothers who practice KMC have a strong awareness of their role in early communication development. KMC refers to an intervention where infants are placed on the mother's chest with skin-to-skin contact for prolonged periods. The increase in mother-infant interaction leads to an increase in the mother's sensitivity to her infant's behavioural cues (Kritzinger & van Rooyen, 2014) and an increase in maternal confidence (Feldman et al., 2002). A comparison study by Kritzinger and Van Rooyen (2014) concluded that mothers who practiced KMC had a better understanding of their infants, responded more naturally during interactions, and formed more positive perceptions about their preterm infants when compared to mothers who did not practice KMC.

From the preceding discussion, it is clear that difficulties in the relationship between a mother and her infant can serve as a major risk factor to a preterm infant's early communication development. The mothers of preterm infants are a vulnerable population that faces unique challenges which may alter their perceptions of and interactions with their infant. By identifying and understanding these challenges, as well as protective factors such as KMC, we can provide effective early intervention to both the preterm infant and the vulnerable mother.

Mesosystem (Mother-HCP interactions)

The interaction between the factors in the infant's immediate environment (such as the mother and HCPs) makes up the mesosystem and may influence an infant's communication development in a unique manner (Rosa & Tudge, 2013). This section will focus specifically on the interaction between mothers and HCPs to illustrate how the interaction between these two groups of direct role-players may inhibit or facilitate communication development in the preterm infant. Firstly, the relationship between mothers and nursing staff may act as a barrier to or facilitator of natural mother-infant interaction. The important role that nursing staff can play in supporting mothers through an uncertain time is widely described in the literature. This is especially true for nurses who work in the NICU and assist mothers with KMC. Davy, Bergh and van Rooyen (2011) highlight the leadership role of nursing staff by describing KMC as 'primarily a nursing intervention with

medical support'. Furthermore, Aagaard and Hall (2008) state that nursing staff not only have to care for the preterm infant but also have to support the mother through a challenging period and toward the feeling of being a real mother. Nursing staff thus have the potential to stimulate bonding and give mothers a sense of purpose by actively including them in their caring responsibilities. At the same time, nursing staff who exclude mothers from care provided to infants may contribute to maternal feelings of incompetency which may alter mother-infant interactions and typical communication development. The role of SLTs to support mothers with regard to early communication, bonding, and feeding whilst in the NICU will be discussed under the macrosystem.

A second important factor to consider is the linguistic and cultural barriers that may exist between mothers and HCPs. The three official languages in the Western Cape arranged from most to least spoken are Afrikaans, isiXhosa and English (Plüddemann et al., 2004). Afrikaans thus has the highest number of mother tongue speakers in the Western Cape (Plüddemann et al., 2004) although the use of this language in professional environments, such as health care settings, is limited. The encounters between HCPs and mothers in health care settings rely on a common language or lingua franca to enable communication since their languages and cultures are likely to differ (Penn & Watermeyer, 2018). English is the language of choice of HCPs to bridge linguistic differences, even though it is only the fourth most spoken language in South Africa (Penn, 2007). South Africa is thus providing 'monolingual health services in a multilingual society' (Elkington & Talbon, 2016) as discussed earlier in the chapter. Afrikaans mothers from low socio-economic settings with limited educational opportunities may have little prior exposure to English as a language of learning and teaching, and may subsequently battle to optimally participate in health care provided in English. Afrikaans mothers, especially those with low educational attainment and socio-economic status, may thus be viewed as a vulnerable group that is not well represented in our health care constitution. This may complicate the effective transfer of information from (non-Afrikaans speaking) HCPs to Afrikaans mothers, and vice versa. Mothers may also be reluctant to implement behaviours that differ from their cultural beliefs. Although the attainment of developmental milestones is culturally independent, large differences exist between and within cultures regarding maternal knowledge, beliefs, and practices concerning early childhood development (Huang et al., 2005). HCPs who provide care to this vulnerable population therefore require insight into the perceptions and knowledge of mothers to provide culturally competent and appropriate intervention.

Exosystem (Maternal SES)

The potential influence that distal connections between the infant and their environment may have on early communication development should not be underestimated (Rosa & Tudge, 2013). This discussion will concentrate on the SES of Afrikaans mothers of preterm infants and how this status may facilitate or inhibit early communication development. As discussed earlier, the majority of South Africans have a low SES (Statistics South Africa, 2017) which poses a threat to optimal childhood development. Low SES is viewed as a risk factor for preterm birth (Goldenberg et al., 2008) and many preterm infants are born into poor SES. Alant and Lloyd (2005) also pointed out that poverty can be both the cause and the consequence of disability for at-risk infants. Poverty mostly entails challenging living and working conditions, as well as a higher prevalence

of maternal hardships. These hardships include teenage pregnancies, poor education, substance exposure or abuse, limited emotional and social support networks, and limited knowledge regarding typical childhood development (Minde, 2002). Ertem et al. (2007) found that mothers with more knowledge of childhood development are more likely to provide appropriate stimulation, thereby improving their child's developmental outcome. Crapnell et al. (2013) also report that parents from lower SES have fewer economic and social resources but are exposed to higher levels of psychosocial stress. This potentially creates challenges in providing high-quality nutrition, daily structure and routines, and access to early intervention or rehabilitation services. These factors associated with low SES may thus influence a mother's ability to create environments that stimulate communication development. Alternatively, individual and community resilience within disadvantaged groups may facilitate early communication development in preterm infants. Increased levels of social support and positive peer relationships for mothers have been described as facilitators in vulnerable communities (Good Governance Learning Network [GGLN], 2014).

Macrosystem (Societal values and existing ECI initiatives)

The macrosystem contains the most remote set of factors which may influence the communication development of a preterm infant (Rosa & Tudge, 2013). The national health care policies that govern ECI (here referring to Early *Communication* Intervention) provided to preterm infants in South Africa fall under this category. Linguistic and cultural diversity within the health system has already been discussed and, therefore, cultural aspects will not be discussed under this level.

An overview of ECI

ECI refers to a transdisciplinary practice where SLTs and audiologists provide services to the families of young children (from birth to the age of three years) with emerging communication and language impairments, feeding and swallowing difficulties, hearing loss and disorders, or those who are at risk of developing difficulties in these areas (SASLHA, 2017). Early communication intervention (ECI) differs from the concept of early childhood intervention in the sense that ECI has a specific focus on the areas of communication outlined above (American Speech-Language-Hearing Association [ASHA], 2008). Early intervention and investment from parents can make a significant difference in a child's communication and cognitive development, as well as later academic performance. SASLHA (2017) regards ECI as the most effective type of treatment by SLTs or audiologists due to the neuroplasticity of the brain in younger children.

ECI in preterm infants and neonates

Preterm birth and low birth weight are classified as risk conditions that may cause secondary communication disorders, although the developmental difficulties are often not yet fully apparent or expressed at the time of admission (SASLHA, 2017). The neonatal period offers SLTs a unique window period to access the mothers of preterm infants and to engage in preventative and promotive attempts with this vulnerable population. This timely engagement is critical as the mother-infant dyad often returns to underserved and hard to reach communities following discharge. While infants are in NICU or KMC units, SLTs have an important

opportunity to provide mothers with information regarding typical hearing and communication development, the advantages of breastfeeding, and the fundamental role of a mother in an infant's communication development (Kritzinger & Van Rooyen, 2014). Furthermore, information specifically relating to preterm infants can be shared with mothers to enhance their understanding of the infant's unique behaviour and needs. This includes developmental stages, stress signs, communication cues, appropriate sensory stimulation, and feeding support (Pike, Kritzinger & Krüger, 2017). KMC provides a useful vehicle for ECI amongst hospitalised preterm infants. As described earlier in this chapter, KMC is an evidence-based nursing intervention where the infant is positioned upright, skin-to-skin and securely on the mother's chest (Pattinson, Bergh, Malan & Prinsloo, 2006). This intervention primes mothers for communication intervention as they are naturally more attuned to their infant (Kritzinger & Van Rooyen, 2014). KMC thus provides the ideal opportunity for communication intervention and SASLHA (2017) recommends that neonatal communication intervention programmes be implemented in conjunction with an existing KMC programme for optimal results. KMC thus offers benefits to preterm infants, their mothers and the health system (Pattinson et al., 2006).

ECI in South Africa

ECI has received increased attention and advocacy in South Africa (SASLHA, 2011b) and notable progress has been made in the past 20 years with regard to practice and research (SASLHA, 2017).

In terms of practice, Pattinson et al. (2006) concluded that KMC leads to increased survival of preterm and low birth weight infants in South Africa and that KMC is being practised extensively amongst this vulnerable population in South Africa. ECI services are readily available at urban health facilities but unfortunately semi-urban and rural facilities are still underserved (SASLHA, 2017). Primary health care facilities offer ideal opportunities for ECI programmes, although these facilities are still largely underserved in South Africa (Kathard & Pillay, 2013). Various national and provincial initiatives strive to promote Early Childhood Development (Berry, Biersteker, Dawes, Lake, & Smith, 2013). Examples include the Road to Health Booklet, the First 1000 Days programme and Mom.Connect programmes. These initiatives play a critical role in increasing awareness of normal early childhood development and serve as protective factors for childhood development. One must, however, consider the following: is adequate information regarding specifically early communication development and intervention provided? Is the information sensitive to the diverse perceptions of our multicultural and multilingual population? Is the information sensitive to the unique experiences and vulnerabilities of mothers of preterm infants? The question that arises is: what special considerations and accommodations are needed to deliver adequate ECI services to mothers of preterm infants living in low SES circumstances, and who may be referred to as culturally and linguistically diverse?

There has been a commendable research effort in the area of ECI in at-risk populations in South Africa. Some valuable research relevant to this study focussed on ECI training programmes among neonates in various languages (Kritzinger & van Rooyen 2014; Strasheim, Kritzinger & Louw, 2011); developing a feeding assessment scale for neonates (Viviers, Kritzinger & Vinck, 2016); and breastfeeding in late preterm infants in KMC (Pike et al., 2017). SASLHA (2017) states that further research is required, specifically focusing on

how to provide ECI services to at-risk and culturally and linguistically diverse families. The current need is 'to know what works best for whom, when and how' (SASLHA, 2017, p.3). In South Africa there is limited research regarding ECI in the preterm population, and more specifically ECI that advocates for the support of the mothers of preterm infants. This complicates our responsibility of providing appropriate ECI services, and especially the provision of effective prevention and education services to mothers of preterm infants. Information regarding maternal perceptions of early communication and feeding in preterm infants, especially among socially and economically disadvantaged groups, will assist greatly in knowing 'whom, when and how' (SASLHA, 2017, p.3) to support these vulnerable mother-infant dyads. A study conducted by Buys (2020) explored maternal experiences of having, caring for, feeding, and communicating with their preterm infants amongst a group of isiXhosa-speaking mothers with low SES. This study highlighted the need for increased support to the mothers of preterm infants with regard to their mental wellbeing. It further emphasized the need for similar studies to be done with mothers from different cultural backgrounds to generate knowledge that will assist HCPs in delivering culturally appropriate ECI services. The current study responds to Buys's (2020) recommendation by focusing on maternal experiences of caring for a preterm infant amongst a particular cultural and linguistic group, namely Afrikaans-speaking mothers with low SES.

This explorative and qualitative study therefore aimed to increase insight into maternal perceptions and experiences of caring for preterm infants, especially amongst socially marginalised and disadvantaged groups, by asking the following question: *How do Afrikaans mothers, living in low socio-economic circumstances in the Western Cape, experience caring for their preterm infant in the first months of life?*

CHAPTER THREE: METHODOLOGY

Trustworthiness and Consistency

Please note that the scientific rigour of the research will be introduced and addressed briefly in this section but will be expanded upon throughout the methodology chapter.

Four concepts were used to ensure that the study findings are trustworthy (valid) and consistent (reliable): credibility, dependability, confirmability and transferability (Ali & Yusof, 2012). Credibility was viewed as depending on the researcher's ability to link research findings to reality and to demonstrate that a true picture of the issue under investigation is being presented (Golafshani, 2003). The techniques used to establish credibility will be identified throughout the chapter. Dependability was viewed as the measure to which the study findings are repeatable and consistent (Golofshani, 2003). The methodology chapter aims to provide a thick (Geertz, 1973) and a detailed description of the study to ensure that future investigators will be able to repeat the study. Confirmability was viewed as referring to the researcher's ability to demonstrate that the study findings are based on the data (the participants' responses) and not on the researcher's biases (Golofshani, 2003). An audit trail was kept throughout all phases of the study to document the researcher's thought process and to serve as justification for the research decisions that were made. Additionally, a reflexive journal was kept alongside the audit trail. This journal documented the researcher's preconceived ideas regarding the research topic. Creswell (2007) describes this step as necessary to limit researcher bias and its potential influence on the collection, analysis, and reporting of the data. Furthermore, the research supervisor acted as an external auditor to improve the accuracy of the findings and to ensure that the findings are supported by the data. The last concept considered was transferability. This refers to the degree to which the findings of the study can be generalised to similar contexts, situations, and populations (Golofshani, 2003). This was achieved by providing robust descriptions of the study settings, in particular research participants and interview contexts. Further techniques employed to ensure the trustworthiness and consistency of the study will be identified and discussed in the ensuing sections.

Research Aims

The main aim of the study was to describe and explain how Afrikaans mothers living in low socio-economic circumstances in the Western Cape experienced caring for their preterm infant in the first months of life.

Sub-aims

1. To describe and explain maternal perceptions regarding prematurity;
2. To describe and explain maternal experiences of caring for their preterm infant;
3. To describe and explain maternal experiences of interacting and communicating with their preterm infant;
4. To describe and explain maternal experiences of feeding their preterm infant;
5. To describe and explain maternal perceptions of their role and responsibilities as a mother;

6. To describe and explain maternal perceptions of other important role-players in their infant's caregiving; and
7. To describe and explain maternal needs at the time of hospital discharge.

During data collection it became clear that certain aspects of caring for a preterm infant (feeding) were more prominent (of greater significance) to the mothers than others (communication, general caregiving tasks). Additionally, certain settings (hospitalisation) were more prominent than others (home). Feeding their infant, specifically while hospitalised, was a significant stressor to the research participants and became a central focus during the interviews with the participants and therefore of the study as a whole. Sub-aim number four was thus explored in depth and the outcome of this study pertains mostly to this aim. This data-led decision is discussed comprehensively under the data analysis section later in this chapter.

Research Design

This study entailed a cross-sectional, qualitative design which was exploratory and descriptive in nature. Although the design included elements of phenomenology, a pure phenomenological approach was not followed. The researcher made use of the technique of reflexivity as a means of setting aside personal biases and ensuring the confirmability of the study (Ali & Yusof, 2012). A small group of participants were selected through a purposive sampling method, specifically criterion sampling. They participated in individual in-depth interviews that were guided by a semi-structured discussion schedule. This study design was appropriate as it assisted in exploring and describing the 'meaning for several individuals of their lived experiences of a concept or phenomenon' (Creswell, 2007, p. 57). The phenomenon in question was the experience of caring for a preterm infant in the first few months of life.

Researcher

The researcher is a qualified Speech-Language Therapist pursuing a master's degree in Speech-Language Therapy at Stellenbosch University. The researcher is employed at a tertiary paediatric training hospital and actively involved in providing ECI services to medically compromised infants and their mothers. She is fully bilingual (Afrikaans and English), although Afrikaans is her mother tongue. Her special interests include ECI in high-risk populations and paediatric dysphagia.

Participants

The target population for this study was low SES Afrikaans mothers of preterm infants ranging from ages three to six months (chronological age). As discussed in the literature review, this population may be viewed as a vulnerable group in health care due to their specified health, economic, and cultural/linguistic attributes. The sample frame entailed all the Afrikaans mothers with preterm infants ranging from ages three to six months (chronological age) who attended follow-up appointments at the High-Risk Clinic (HRC) at the Paediatrics out-patients department of a public hospital in Cape Town. Purposive sampling, specifically criterion

sampling, was used to select participants from this sample frame. Patton (2002) describes criterion sampling as a technique used to identify and select information-rich cases in qualitative research. It entails identifying and selecting individuals who are knowledgeable about or experienced with the phenomenon of interest (Creswell, Klassen, Smith & Plano Clark, 2011). The inclusion criteria used to select the sample is described in Table 1. Additional to the inclusion criteria, certain characteristics were considered to ensure variation within the study sample. This variation aimed to increase the transferability of the study. These characteristics included the participant's age, number of children, highest education level attained, employment status, and relationship status. The infant's degree of prematurity and birthweight were further considered. Ensuring variation in the sample is important as it allows for a group of participants that are heterogeneous and provides diverse experiences of the phenomenon being explored (Malterud, Siersma & Guassora, 2016). A total of eleven participants were interviewed before data saturation was reached. Upon review, two participants were excluded from the sample. The first participant was excluded due to the poor quality of the interview, while the second participant was excluded because it transpired that she did not meet all the inclusion criteria. Table 2 lists the characteristics of the nine study participants included in the study. Explicit description of the participants is provided to ensure the trustworthiness of the study, as well as to increase its transferability. A sample size of nine participants (n = 9) complies with the recommended range of two to 25 participants for studies relying on in-depth interviews to investigate a certain phenomenon (Polkinghorne, 1989). Data saturation is reached once no new information arises from the interviews, and it is therefore unlikely that the data gathered from further interviews will change the results or outcome of the study (Malterud et al., 2016). The researcher relied on the following measures to assist in identifying data saturation: sample specificity, dialogue quality, and analysis strategy (Malterud et al., 2016). The heterogeneous nature of the selected sample; the detail-rich narratives collected during the interviews; and the decision to use in-depth analysis strategies to provide a detailed account of this phenomenon, assisted in establishing when data saturation occurred.

Sampling Process

1. The paediatrician managing the HRC was provided with the inclusion criteria as indicated in Table 1.
2. A few weeks in advance, the paediatrician informed the researcher of dates on which potential participants who met the inclusion criteria were scheduled for follow-up medical appointments.
3. On the day of the follow-up appointments, the paediatrician and researcher identified potential participants who met the selection criteria.
4. Following the medical appointment, the researcher invited the identified mothers to participate in an interview. The researcher led the potential participant to the designated interview space and explained the nature and purpose of the study. Upon agreeing to participate, mothers were presented with sufficient information to ensure that informed consent was obtained before the interview commenced. The interviews took place in a private consulting room, near the waiting area of the HRC in the Paediatrics out-patients department of the hospital.

5. This process continued until data saturation was reached after eleven interviews conducted over 5 days.
6. The selected sample was reviewed by the researcher to confirm adherence to the inclusion criteria (Table 1) and to ensure adequate variation in the characteristics specified (Table 2). The final sample consisted of nine participants who met all the inclusion criteria and varied with regard to the specified characteristics. These nine participants provide some of the diversity present in the study population.

Table 1: Inclusion criteria

Criterion	**Notes**
1. Afrikaans first-language speaker	As discussed in the literature review, English is the preferred language of health intervention in South Africa (Levin, 2007). This criterion assisted in exploring the experiences of a minority group that is not well represented in our health care constitution. Furthermore, there were advantages attached to collecting data in both the researcher's and the participant's home language. These include eliminating the need for an interpreter, reducing the study costs, and minimising the risk of communication breakdowns.
2. Older than 18 years	Adolescent mothers face many additional challenges that may influence their perceptions of giving birth to and caring for a preterm infant. This criterion thus aimed to ensure the study's credibility.
3. Low socio-economic status	*Low SES was determined by:* 3.1. Education: No post-matriculation degree or diploma. 3.2. Financial income: Bracket H0 – H1 on the hospital patient income classification scale which represents households with an annual income of R0 – R100 000.
4. Infant of the mother meeting specific criteria	*Infant criteria:* 4.1. Born preterm, thus before 37 weeks gestational age (Rossetti, 2001) 4.2. Born with LBW, VLBW or ELBW (800g – 2500g) (Rossetti, 2001) 4.3. Aged 3 – 6 months chronological age at the time of the data collection 4.4. Medically stable at the time of data collection 4.5. No diagnosed biological, physical, sensory, congenital, or neurological disorders at the time of data collection

The inclusion of criteria 4.4 and 4.5 assisted in ensuring the study's credibility. Medical instability and/or disorders bring about additional challenges that may influence maternal perceptions of giving birth to and caring for a preterm infant.

The study sample thus included nine Afrikaans mothers with ages varying from 18 to 38 years. Five of these mothers were first-time mothers, while the remaining four had other children. Four mothers were unemployed, while the remaining five were employed in positions such as a farm worker, a carer or a cleaner. All the mothers except one stayed in the hospital or on the hospital premises (hostel) for the period of their infant's hospitalisation. The specified mother travelled between the hospital and her home during the start of the infant's hospital stay. After a while, she started staying in the hostel as her travelling expenses were too high and she struggled to express and supply sufficient breastmilk to meet her infant's nutritional requirements for an entire day. Within the study sample, there were two extremely preterm infants, five very preterm infants and two moderately preterm infants. Two infants were born with ELBW and five infants were born with VLBW. The birthweight of the first two participants' infants was unfortunately only indicated as 'less than 2500 g' and the exact birthweight was not documented. Table 2 contains the characteristics pertaining to the nine study participants.

Table 2: Characteristics of the nine study participants

Participant number	**Maternal characteristics**	**Infant characteristics**
PS_P2	Age: 32 years Children: 3 in total Education: Grade 11 Employment: cleaner Relationship status: married to infant's biological father	Degree of prematurity: extremely preterm (26 weeks) Birthweight: less than 2500 g
PS_P3	Age: 32 years Children: firstborn Education: Grade 10 Employment: quality controller Relationship status: in a relationship with the infant's biological father	Degree of prematurity: very premature (30 weeks) Birthweight: less than 2500 g
MS_P2	Age: 18 years Children: firstborn Education: Grade 10 Employment: unemployed Relationship status: in a relationship with the infant's biological father	Degree of prematurity: very preterm (28 weeks) Birthweight: VLBW (1,3 kg)
MS_P3	Age: 24 years Children: firstborn Education: Grade 12, psychology diploma incomplete due to pregnancy Employment: unemployed Relationship status: in a relationship with the infant's biological father	Degree of prematurity: extremely preterm (27 weeks) Birthweight: ELBW (940 g)
MS_P4	Age: 22 years Children: firstborn Education: Grade 12 Employment: unemployed Relationship status: married to infant's biological father	Degree of prematurity: moderately preterm (32 weeks) Birthweight: VLBW (1,36 kg)
MS_P5	Age: 36 years Children: 2 in total	Degree of prematurity: very preterm (29 weeks)

	Education: Grade 10 Employment: clerk Relationship status: single	Birthweight: VLBW (1000 g)
MS_P6	Age: 31 years Children: 4 in total Education: Grade 10 Employment: unemployed Relationship status: married to infant's biological father	Degree of prematurity: very preterm (29 weeks) Birthweight: VLBW (1,25 kg)
MS_P7	Age: 22 years Children: firstborn Education: Grade 12 Employment: carer at a retirement home Relationship status: in a relationship	Degree of prematurity: very preterm (29 weeks) Birthweight: ELBW (955 g)
MS_P8	Age: 38 years Children: 5 in total Education: Grade 7 Employment: farmworker Relationship status: married to infant's biological father	Degree of prematurity: moderate to late preterm (33 weeks) Birthweight: VLBW (1,29 kg)

Materials and Instruments

Discussion schedule

A revised version of a semi-structured questionnaire compiled by Buys (2020), who completed a similar study amongst isiXhosa speaking mothers, was used during the interviews. Buys's (2020) questionnaire was compiled after a thorough review of relevant literature and existing questionnaires (refer to appendix A for Buys's (2020) questionnaire). The Rossetti Infant-Language Scale (Rossetti, 2001) and a study by Ertem et al. (2007) provided the most of the information used to compile this questionnaire. Thereafter the questionnaire was sent to SLTs working in the field of ECI for further contributions and additional insights. The questionnaire contained an initial section to collect biographical information and a further 21 questions which were divided into six sections, namely, perceptions of prematurity; experiences of giving birth prematurely and caring for a preterm infant; communication and interaction; roles; feeding; and other. Besides the 21 core questions, the questionnaire provided potential prompts to elicit additional information as needed. The majority of the questions were open-ended questions to suit the qualitative research methodology and only a few close-ended questions were included. The researcher and the research supervisor translated Buys's (2020) questionnaire into Afrikaans and reviewed the content. Changes were implemented to change the original questionnaire into an open-ended discussion schedule consisting of seven key areas (refer to Appendix B to view the discussion schedule). The discussion schedule started with a broad open-ended question namely: 'Tell me more about your experience of being the mother of a preterm infant'. This allowed participants to guide the direction of the discussion and aimed to increase the confirmability of the study. It further provided the researcher with good information about the aspects of the mothers' experience that they deemed most challenging and significant. For example, the task of feeding their preterm infant whilst in hospital was spontaneously mentioned by the majority of participants as being a particular stressor. The final discussion

schedule thus contained fewer questions than Buys's (2020) semi-structured questionnaire, thereby allowing the participants to steer the conversational topic according to their personal experiences. This contributed towards the confirmability of the study as it prevented the interviewer from focussing on topics that were anticipated to be relevant for the participants. The seven key areas explored in the schedule included maternal perceptions regarding prematurity; caregiving; feeding; communication; maternal responsibilities; additional role-players; and information needs.

Cell phone

A cell phone was used to obtain voice recordings of the interviews. The quality of the recordings was tested before every interview to ensure access to the data collected at a later stage. The ethical considerations of voice recording the interviews will be discussed at the end of this chapter.

Data Collection

Data collection was done in two phases, namely the pilot study and the main study. The interviews took place in a private consulting room, near the waiting area of the HRC in the Paediatrics out-patients department of the hospital. The researcher conducted eleven semi-structured interviews using a discussion schedule (described above). The interviews were voice recorded per cell phone. The researcher made brief notes during and after the interviews to document non-verbal information, such as body language and other information that was not included in the voice recording. The interviews were approximately 30 minutes each. During the interviews, the researcher aimed to ensure credibility and confirmability of the data in several ways. Firstly, the topic of conversation was predominantly guided by the participant with the researcher exploring the areas the participant highlighted. Secondly, the researcher verified the participant's responses frequently to ensure that her understanding was as the participant intended. This was viewed as a type of 'member checking' (Ali & Yusof, 2012, p.37) used to verify the information and also gain further information. Thirdly, the researcher completed a brief reflection on the interview directly after its completion. This reflection served as a descriptive summary of how the interview process progressed, from the perspective of the researcher. These reflections were included in the transcripts of the voice recordings to enable accurate recall of the collected data. Lastly, the reflections also contained preliminary remarks and interpretations that documented the researcher's initial and instinctive analysis of the data. The voice recordings were then transcribed verbatim by the researcher. The transcriptions included a descriptive section containing the participant's biographical information and the researcher's initial reflections as described above (refer to Appendix C for an example of a transcript). To ensure dependability and confirmability of the transcripts, 22% of the data was externally audited by a speech-language therapy doctoral student. This process entailed the random selection of audio recordings of two interviews and the accompanying transcripts, to be reviewed. The auditor concluded that the transcripts provided an accurate and true representation of the voice recordings.

Pilot Study

To ensure the credibility of the discussion schedule and interview process, a pilot study was conducted before the main study. The researcher attended a short course on qualitative research methodologies in health sciences which included the completion of two assignments with supervision from an expert in the field. These assignments entailed designing and executing the pilot study, and assisted in refining the main study. The sampling and data collection procedures, as described above, were completed with three participants and written up by the researcher. Following this the researcher received feedback from her research supervisor and the expert short course presenter on the discussion schedule, the quality of the data collected, and the appropriateness of the data to meet the objectives of the study. The researcher also completed a research report containing a preliminary analysis and the findings of the pilot study which was reviewed by the research supervisor and the expert. The reflection and feedback following the pilot study indicated that no changes to the discussion schedule and minimal changes to the interview process were required. These changes included that the researcher should explore the participant's responses more thoroughly and should verify the participant's responses more frequently. The initial pilot interview was deemed of poor quality and excluded for use in the study. The following two pilot interviews were deemed sufficient and included for use in the study. Two of the pilot interviews were thus included for analysis, together with the data collected in the main study.

Main Study

Following the pilot study and the required adjustments of the interview process, the main study commenced following the same sampling and data collection procedures. Interviewing of participants continued until data saturation was reached after eight participants were interviewed following the pilot study and no new information surfaced during interviews. The researcher familiarised herself with the data throughout the data collection phase and performed preliminary analyses after each interview to identify recurring themes and new information. Following the main study, the eight interviews were reviewed to ensure sufficient quality for inclusion in the study. The first interview of the main study was excluded due to the participant not being 18 years of age. The remaining seven interviews were deemed sufficient for inclusion in the study.

A total of nine interviews were thus included in the study. Two of the interviews were conducted during the pilot study and the remaining seven interviews conducted during the main study.

Data Analysis

The computer-assisted qualitative data analysis software (CAQDAS) program *ATLAS.ti 8 Windows* was used to assist with the data management and analysis. The researcher attended a five-day course on using this software to analyse qualitative data presented by the African Doctoral Academy of Stellenbosch University. Thematic analysis, as described by Braun and Clarke (2006), was used to analyse the collected data. This method is defined as a way of identifying, analysing and reporting patterns within qualitative data. Furthermore, it minimally organizes data and enables description of the data in rich detail. To ensure the

transferability of the study, a thick description will be provided on the process of analysis. As advised by Braun and Clarke (2006), several decisions regarding the exact analysis procedure are to be made explicit and described comprehensively. After thorough consideration of the collected data and discussion with the research supervisor, the following analytical questions were answered:

What constitutes a theme? A theme was viewed as patterned responses in the collected data (Braun & Clarke, 2006). The significance of themes was not measured by their frequency in the data set or other quantifiable measures but rather by their relevance to the research question.

A rich description of the data set versus a detailed account of one particular aspect? A detailed account of one particular aspect, namely maternal perceptions regarding the feeding of their preterm infant whilst hospitalised, was decided upon. This decision was based on three factors. Firstly, mothers spontaneously gravitated towards this topic during the interviews. Secondly, mothers identified this task (feeding) and setting (hospital) as being the major stressors during the first few months of the infant's life. Lastly, the format of this master's degree thesis is a 'Master's by publication'. This format is better suited for a detailed account of one particular aspect due to the word limitations and format restrictions of journal manuscripts.

Inductive versus theoretical thematic analysis? An inductive approach to thematic analysis was followed. The themes are thus strongly linked to the data and not imposed by pre-existing theoretical frameworks. This decision also contributed to the decision to provide a detailed account of one aspect as the data clearly illustrated that feeding whilst the infant was hospitalised was a significant factor from the perspective of the mothers of preterm infants.

Semantic versus latent themes? Semantic themes were used in this study. The explicit and surface meanings of data were thus used to organise, describe, and eventually interpret the data as opposed to underlying ideas or assumptions as in the case of latent themes.

Epistemology: essentialist/realist versus constructionist thematic analysis? An essentialist/realist approach was used to theorize the maternal experiences of prematurity straightforwardly. This is based on the assumption that *meaning* and *experience* and *language* share a unidirectional relationship. This approach is supported by the decision to use semantic themes as opposed to latent themes.

The following six steps, as proposed by Braun and Clarke (2006), were followed during the analysis process:

1. *Familiarization with the data*. The researcher familiarized herself with the data by ensuring multiple exposures to the data in its various forms. This included conducting the interviews, transcribing the voice recordings, reading the transcripts repeatedly and documenting early analytical remarks.
2. *Generating initial codes*. The completed transcripts (Microsoft Word documents) were uploaded to ATLAS.ti 8 Windows. These documents were then coded systematically. Codes were assigned to individual ideas or thoughts nestled in the words and/or sentences in the transcripts. Code names were kept as succinct as possible in an attempt to capture exactly what the participant said (semantic codes).

After three transcripts had been coded, the coding list became relatively stable. The code list was then applied to the remaining transcripts. New codes that were derived were added to the code list and the already-coded transcripts were reviewed in an iterative fashion. Using the ATLAS.ti 8 Windows software assisted greatly in managing and organising the initial codes. After the entire data set was coded, the researcher collated the code list and reviewed the transcripts against the complete code list. This step of data analysis was time-consuming as it required moving back and forth between transcripts as new codes were derived.

3. *Searching for themes*. ATLAS.ti 8 Windows was used to group related codes together to form potential themes. The relations between individual codes (thoughts or ideas) were used to determine which codes should be grouped together to constitute a theme. An initial thematic map was generated for review by the research supervisor and the researcher. This map contained the name of the theme, a description of the theme, the code names and definitions included in the theme, as well as authentic quotations (refer to Appendix D for the thematic map).
4. *Reviewing themes*. The initial thematic map as described above was used to review the themes. During this step, the goal was to ensure that the themes are consistent with the coded extracts and the data set (Braun & Clarke, 2006). The research supervisor assisted the researcher in reviewing the themes. This was done as a form of analyst triangulation and an attempt to eliminate any blind spots the researcher may have had and thus to increase credibility (Ali & Yusof, 2012).
5. *Defining and naming themes*. The researcher engaged in ongoing analysis to refine each theme. This included forming a clear name, comprehensive definition, and detailed narrative for each theme. Again, the research supervisor assisted in reviewing the final themes to ensure the credibility of the findings (Ali & Yusof, 2012).
6. *Producing the report*. Compiling and presenting the findings of the study was the final step in the analysis process. This included the completion of a thesis document and a journal article. The researcher aimed to portray the lived experiences of Afrikaans mothers of preterm infants by providing a clear and compelling narrative. The researcher re-read the scoping review she published with colleagues (van Schalkwyk et al., 2020), as well as new publications that appeared after the completion of this scoping review, to assess whether the findings correlate with what is described within the literature. This was done as a form theoretical triangulation that aimed to improve the credibility of this study (Ali & Yusof, 2012).

Ethical Considerations

Please note that all ethical considerations are addressed in this section, and are not discussed throughout the chapter.

Ethical clearance and permission

Approval to conduct this study (HREC project ID: 6707) was provided by the Health Research Ethics Committee (HREC) of Stellenbosch University (refer to Appendix E). Following ethics approval from the HREC, the approval letter and protocol were submitted to the National Health Research Committee (NHRC) through the National Health Research Department (NHRD) where permissions for the study were obtained at both provincial and hospital level (refer to Appendix F). Permission to conduct the study within the follow-up clinic where participants were recruited was gained from the paediatrician in charge of the clinic.

Obtaining informed consent from participants

All potential participants were provided with a comprehensive overview of the study before being asked to indicate their acceptance or rejection of the invitation to participate. Information was provided both in a written and spoken format in Afrikaans (refer to Appendix G). Information was discussed with the potential participants to ensure that they fully comprehended the information provided. The participants were informed that participation is voluntary and that they may withdraw their participation at any time (before or after consenting to participate) without suffering negative consequences. If participants agreed to participate in the study, an informed consent form (refer to Appendix G) containing all the relevant study information was signed before the interview.

Potential harm/benefit to participants

The study presented minimal risk of harm to participants as data was collected via interviews only and no direct treatment was provided to patients. The study also presented limited direct benefit to participants. An Afrikaans pamphlet outlining communication and feeding milestones within in the first year of life was provided to all potential participants to increase their awareness of typical development.

Participant remuneration

The participant recruitment process ensured that no financial costs were involved on the participants' behalf. Potential participants were attending their preterm infant's medical appointment on the day of the interview and thus no additional travelling was required to participate in the study. Participants were, however, expected to spend additional time at the hospital on the day of their appointment and refreshments were made available to compensate for this favour and inconvenience. Participants were not reimbursed or offered financial rewards for their participation in the study.

Data handling

The participants' names were not collected during the data collection process. They were assigned an identifying code based on their participation in the pilot study or main study, as well as their order of participation. 'PS' represented the pilot study, 'MS' represented the main study and 'P' represented participant. For example, 'PS_P3' represented the third participant of the pilot study. Transcribed interviews were stored

as password-protected Microsoft Word documents on a secure flash drive. Participants are and will be strictly referred to by their assigned codes in all texts or presentations resulting from the research. The participants' true identities will thus be protected at all times.

Acknowledgements and dissemination

Acknowledgement will be provided to all who contributed to this study (please also see the Acknowledgements within this thesis document). The findings of this study will be shared with colleagues and students at the Division of Speech-Language and Hearing Therapy's (Stellenbosch University) annual research day. Furthermore, the findings will be distributed amongst the broader professional community on different platforms such as at national conferences and through publication in a peer-reviewed journal.

CHAPTER FOUR: FINDINGS

This chapter provides a detailed account of the participants' perceptions regarding the feeding of their preterm infants, especially while hospitalised. During data collection, participants were naturally inclined to speak about the task of feeding their infant and in particular while the infant was hospitalised. Feeding their preterm infant during hospitalisation was thus an intense and prominent experience for the participants. Iterative coding (Braun & Clarke, 2006) of the nine transcripts resulted in six main themes. Additionally, an overview of maternal perceptions regarding feeding methods alternative to breastfeeding is provided at the end of the chapter.

The following conventions are used in this chapter:

1. The names of themes are indicated in underlined, bold text (**example**).
2. The names of divisions within themes are indicated in bold text (**example**).
3. Quotations are indicated in italic text (*example*).
4. Quotations are presented in English after translation from Afrikaans by the researcher.
5. Quotations are numbered in square brackets at the start of the quotation. Appendix H contains a list with each quotation number and its corresponding Afrikaans quotation, English quotation and the participant involved.
6. Afrikaans quotations appear in brackets after the English translation in the case of quotations that are of special relevance due to the terminology used by the participant.
7. Additional information appears in square brackets in the quotations if clarification is required to understand specific terminology used by the participant.

A summary of the experiences of the participants regarding the feeding of their preterm infant during the hospitalisation period can serve to provide an overview of the themes to follow. The mothers experienced the feeding of their preterm infant as a progressive task that is goal-driven and continuously demands a new method of feeding, higher volumes of milk, and increased weight gain in the infant, in order to reach the eventual goal of discharge from hospital. This task was perceived as stressful due to various issues such as insufficient breastmilk supply. Furthermore, the hospital setting was perceived as something that added to their anxiety, but simultaneously had the potential to decrease their anxiety. The mothers felt that over time and with experience both they and the infants gradually became more comfortable and skilled in the task of feeding. When the mother-infant dyad was able to breastfeed successfully it was described as an '*amazing experience'* and one that made the participants feel like mothers at last.

Theme 1: Feeding was a progressive task aimed at '*going home*'

The participants perceived the task of feeding their preterm infants in the hospital setting as something that changed frequently and progressively worked towards the ultimate goal of discharge. The task itself was perceived to change with regard to two aspects, namely the method of feeding and the feeding volume. Firstly, the method of feeding their infant entailed '*something new*' on a frequent basis. The preterm infant's feeding journey was described as starting with tube feeding (OG or NG). This was associated with the infant being in the NICU and an incubator. From there they progressed to cup feeding and occasionally syringe feeding. A participant described this progression as, [1] '*first she had a tube in her mouth so she fed through the tube. After the tube, she went to the cup*'. Following these methods, the mother and infant were then challenged to progress to breastfeeding. Mothers associated breastfeeding with KMC and being in a general ward where they were able to share a bed with their infant. [2] '*…then it is kangaroo and breastfeeding. And she must now drink straight from my breasts*'. Breastfeeding was viewed as the eventual target and a big step towards discharge, [3] '*because I knew the breast is the thing that is going to let her go home*'. This progression was described as follows:

[4] *'In the beginning, the infant is not with you. He is in the incubator. For now, it must be like this because he is still too small. And then you start to feed, they teach you how to feed the baby. Cup feeding and after cup feeding, you go to another ward where your baby is with you. And from there you go home'*

The length of an infant's hospital stay differed according to infant-specific factors, for example gestational age and birthweight. The time infants spent in hospital ranged from three to eleven weeks. All the mothers except one stayed in the hospital or on the hospital premises (in a hostel) during this period. The specified mother initially travelled between the hospital and her home but decided to stay in the hostel after a while. Participants were thus away from home for a prolonged period, which places their strong desire for the infant to be discharged from hospital in context.

These frequent changes in feeding methods contributed to maternal stress related to the feeding task. Mothers grew comfortable with feeding their infant in a certain manner, for example via a NG tube. When a new feeding method was introduced, the mother was expected to rebuild her skill and confidence using a new method such as cup feeding.

Secondly, the feeding volumes always entailed '*more*'. The millilitres of milk the infant consumed during a feed were perceived to go '*higher and higher every day*'. Thus, mothers were expected to express more breastmilk to meet the new feeding volume required. This expected increase also added to maternal stress and will be discussed under theme 3. Contradictory to this stress, mothers were relieved when the feeding volumes increased as this meant steady weight gain and growth for the infant. One mother recounted:

[5] *'And as it goes on, then her ml's [*millilitres of milk required*] goes higher and higher every day. Then you must make more and more pots of milk every time. But I always had more pots of milk in the fridge. Because the more she started to drink, the quicker her percentage [*weight*] went up*'

In combination with the '*something new*' and '*more*' required of the mother and infant, the infant was also expected to gain weight steadily. The infant's weight was monitored and documented daily. Mothers strongly linked infant weight gain with subsequent discharge from hospital. The infant's weight was thus perceived as a method of determining whether the infant was progressing towards the eventual goal of discharge.

[6] *'And then you always work towards the goal where they are 1, 8 [*kilograms*]… the weight. Because then you can go home'*

This daily monitoring and 'chasing' of weight often resulted in feelings of hopelessness. One mother said that [7] *'… to me it just felt like I was never going to get there [*referring to 1, 8 kilograms*] and it's still far because they said he must be this certain weight before we can move [*go home*]'.*

From the above, it is clear that discharge from the hospital was seen as the ultimate reward and the goal that mothers worked towards tirelessly. They described the following as criteria for attaining this goal: successful breastfeeding and steady weight gain with a target weight of 1, 8 kilograms or more. The feeding journey was thus seen as progressively working towards these goals.

Theme 2: Feeding was a significant contributor to stress '*in the beginning*'

The task of feeding their infant was a significant cause of stress for the participants. The stress related to feeding tasks were especially prominent '*in the beginning*' of the infant's life. It can be speculated that participants' description of '*in the beginning*' also refers to the hospitalisation period. Various factors related to feeding were described as contributors to the mothers' anxiety. This included worries regarding poor weight gain and growth of the infant, messing during feeding times, insufficient breastmilk supply and difficulty with the task of breastfeeding itself. It was also clear that the progressive nature of the feeding task, as discussed under theme 1, strongly contributed to maternal anxiety. Mothers were striving towards the goal of discharge from hospital and therefore any factor that interfered with the attainment of this goal potentially added to maternal stress. It is therefore not surprising that the criteria for discharge from hospital, as explored under theme 1, were also the causes of maternal stress. Plausible explanations of why mothers so strongly longed to go home are discussed under theme 5.

The first contributing factor to maternal stress relates to the growth of the preterm infant. Mothers felt that [8] '*it's actually very stressful… to watch how your infant must grow*.' Mothers used the terms weight (gewig) and growth (groei) interchangeably and made a clear connection that increased weight meant that their infant was growing. A growing infant subsequently meant that discharge from hospital was coming closer and closer. This made mothers excited whilst poor weight gain had the opposite effect – [9] '*so it was very hard because he didn't pick up weight everyday… so the one day I'm excited because he picked up weight but the next day I'm off [*sad*] because yes [*referring to no or poor weight gain*]…'.* Mothers grew anxious as they were monitoring their infant's weight daily. They also felt confused and hopeless when the infant's weight did not go up, even though they were doing all the things they were told would contribute to weight gain.

[10] *'Every day we look in the files to see how much they weigh. Or you can also ask the sister or so. But then you are confused because you ask – what must I do for the child to pick up weight, what exactly must I do? Then they say you must KMC the child, you must express your milk and give your own milk but for me, it was like I'm doing all of those and I was sitting with him for almost the whole day. In the afternoon I would decide, OK, I'm not going to sleep anymore. I'm only going to be with him so he can pick up quicker [*referring to weight gain*] and then I didn't understand because I'm doing everything right, but still [*referring to the infant not gaining weight*].'*

Besides being stressed about poor weight gain, mothers also anxiously anticipated potential weight loss or regression in their infant's weight gain pattern. One mother explained that [11] '*if she drops [*referring to weight*] then they have to put the tube back in and then I will stay here even longer and I just want to go home'*. The possibility of the infant's nutrition being the cause of delayed discharge was anxiety-provoking to these mothers who longed to go home.

The second factor that acted as a stressor to mothers was breastmilk. It is important to note that breastmilk does not always equal breastfeeding. Whilst in hospital, mothers were encouraged to express their breastmilk for the infant to still receive the mother's milk whilst using methods such as tube feeding or cup feeding. They were concerned regarding not having breastmilk and thus not being able to provide their infant with '*my milk*'.

[12] *'I started praying to the Lord, I prayed for my milk because at that stage I was like the children need milk because they must grow*.'

Breastmilk held great significance in the mothers' experience of having a preterm infant in hospital. A lack of breastmilk left mothers anxious and hopeless. The reasons for this will be comprehensively explored under a separate theme. One mother answered the following when asked about her experience of having a preterm infant:

[13] *'To me the experience was… it was fine when I found out I was pregnant but afterwards, it was horrible! It was horrible! Because I had no milk and I didn't know what to do… because she cries the whole time and they are forcing me for milk and I was just like I don't have milk! So the doctor gave me a pill or something to make milk but it also didn't help so… I was like… I was at a point where I was crying because she was crying. I didn't know what to do!'*

Mothers were also concerned about the task of breastfeeding itself. They were stressed and sad when their infant wasn't able to breastfeed successfully. They explained that once an infant was able to breastfeed, they were ready for discharge from the hospital. A delay in successful breastfeeding thus meant a delay in going home.

[14] *'It was very stressful. Very, very, very. Because I knew the breast is what's going to let her go home. And her weight was already 1, 8 [*kilograms*] and then she still couldn't go because she couldn't breast [*breastfeed*].'*

[15] *'So to me it was okay in the beginning, it was just sad that I couldn't breastfeed him. I cried a lot because I couldn't breastfeed him because I thought my child is never going to take the breast.'*

A further factor that mothers perceived as stressful was when the infant was messing during feeds. This issue, however, seemed to resolve over time. Perhaps mothers associated messing with feeds with a newly introduced feeding method and the infant and/or the mother herself struggling to manage this new method. As described, [16] *'She messed for the first few days – spit it [*milk*] out, didn't really know how to swallow it. And then afterwards it got easier for me'.* Furthermore, it is also possible that mothers' stress about messing with feeds were related to their stress regarding their infant's growth. Messing during feeds results in a lesser intake of milk and potentially lower growth.

Theme 3: Breastmilk was '*the biggest thing*' in hospital

The mothers experienced their breastmilk supply as one of the biggest problems during the hospital stay, especially at the start of their infant's life. This theme contains the reasons for breastmilk being particularly stressful for mothers.

The participants expressed a firm belief that breastmilk is the best for their infant. They preferred the infants to receive '*my milk*' regardless of the feeding method. Furthermore, they perceived breastmilk as the thing what will help their infant the '*quickest*'. HCPs in South Africa promote breastfeeding and the use of breastmilk for various health benefits for both mother and infant. The greatest benefit, as perceived by the participants, was steady weight gain and subsequently, an expedited discharge. It is therefore not surprising that difficulties with breastmilk were a major cause of concern to the participants. This becomes significant if one considers that the mothers of preterm infants are prone to struggle with lactation at the start of their infant's life as discussed in the literature review.

[17] *'In the beginning when he was born, I struggled with the milk and that stressed me out a bit because they told me that he must get my milk because it will help him quicker.'*

Firstly, mothers were anxious about having sufficient breastmilk supply for their infant. They were concerned that they would not be able to meet the prescribed millilitres as the infant's feeding volumes increased on a frequent basis.

[18] *'But actually the only thing about them [*nursing staff*] is – you must give your milk. That was such a big stress to me, the milk. And then they move it up, they move it up up up – at the end, it is so much milk that can't even almost give that total… because in the beginning, I slept at home and then maybe I leave a day's milk but then they move it upper and upper and upper. Then I can't give that total anymore'*

Secondly, the process of expressing milk was hard for mothers. For some mothers, it was their first time having to express milk and they did not know how to do this. They also found the process fruitless as often they would try to express but no milk would be produced. Expressing breastmilk was also explained as being painful and

this further complicated the task. These factors were especially relevant to the mothers of extremely or very preterm infants, and during the beginning of their hospital stay.

[19] *'Because you must express and many of us don't know how to express and it's sore and your milk doesn't come'*

Mothers felt bombarded with the message from HCPs that they must express and provide the infant with the mother's own milk. They perceived especially nursing staff to '*push*' and '*force*' them to express their milk even though it was clear that they were struggling with lactation. They felt that breastmilk was the only thing HCPs were interested in while caring for them and their infant. It seems that the mothers experienced little recognition from HCPs of the difficulties they faced with lactation.

[20] *'Yes because here it's like they push you for milk and the whole thing is just milk, milk, milk!'*

[21] *'And they were just like you must breastfeed, you must express milk and I was like I can't. Even that where you must wake up every two hours to express, I had to do that even though I didn't have milk and nothing comes!'*

Furthermore, mothers felt judged by nursing staff if they were unable to provide their infant with their own milk. One mother explained that [22]*'it was like hell there cause the nurses gossip, the whole milk thing, I don't have milk so they will gossip and force me for milk and all that. So it was really horrible!'*

It seems that breastmilk was seen as an elixir in hospital. Having a good supply made you rich, or you have limited supply and are left poor and hopeless. The mothers of extremely or very preterm infants were in the latter condition for most of their hospital stay.

Ironically, mothers were stressed about the fact that they shouldn't be stressed in order to produce breastmilk. The participants explained that being anxious inhibited milk production, and if they were anxious, they wouldn't be able to provide their infant with their own milk. Mothers anticipated their anxieties to be a cause of poor milk production and in return became anxious about being anxious. This also made them feel confused about their emotions and how they should express the various thoughts and feelings they experienced.

[23] *'There were days that I didn't know must I cry, must I laugh… because on the one side, I can't stress because my children are drinking my milk so I must be calm otherwise I won't have milk for them. And wow, this was hard'*

An alternative concern to participants was that if they were unable to provide expressed breastmilk, their infant will have to receive formula milk which may be harmful to their intestines. Participants were told by HCPs that very preterm infants' intestines are potentially too premature to digest formula milk. Thus HCPs' concern that giving formula to a very preterm infant may harm their intestines was absorbed by the mothers of the infants – [24] *'And they didn't want to give her formula because she was too young and they are scared for her intestines and all that.'*

Theme 4: Breastfeeding was '*amazing*'

Mothers experienced breastfeeding their infant as a remarkably positive experience which they thoroughly enjoyed. A mother described her experience as follows:

[25] *'The Saturday when the sister told me I must breastfeed him it was such an amazing feeling that he was on my breasts… I can't explain it to anyone that amazing feeling, it's like butterflies that I felt inside of me when he drank from me the first time.'*

The participants perceived this '*amazing experience*' to be very advantageous to both mother and child. The perceived advantages can be divided into two categories, namely physiological advantages and interaction-attachment advantages. Physiological advantages included increased breastmilk production, weight gain for the infant, a healthy infant and lastly discharge from hospital. Interaction-attachment advantages included increased bonding, proximity and communication between the mother and the infant.

Physiological advantages of breastfeeding

The mothers noticed that their breastmilk supply increased as they started to breastfeed their infant. This brought about great relief to their previous concern of not having sufficient breastmilk to meet the required feeding volumes as discussed under theme 3.

[26] *'When the milk came a bit better, then it started coming. Because the one was sent home before the other [*mother of twins*] and then he could start drinking and it stimulated the breast and then the milk came better.'*

Mothers also felt that '*fresh breastmilk*' resulted in the greatest weight increase and growth for their infant. '*Fresh breastmilk*' referred to breastmilk that was not expressed and stored in the fridge but rather drank directly from the mother's breast. Mothers strongly associated breastfeeding with growth and explained that breastfeeding made them excited, [27] '*because why, she is going to grow now*.'

[28] *'Because they said he picks up quicker and the milk that I had to express had to go in the fridge so it's not fresh milk that they give him. So, then I felt excited about the milk that he is getting from me because now it is fresh milk'*

There is a statistically significant difference in the energy and macronutrients (carbohydrate, fat, protein) between fresh and stored breastmilk (Pramitasari, Sidiartha & Pratiwi, 2019). This difference is more significant in the comparison between fresh and frozen (seven days) breastmilk and less significant when fresh and refrigerated (24 hours) breastmilk are compared. Participants' preference to provide their infant with fresh breastmilk is thus scientifically supported, although the difference in nutrients between fresh and stored breastmilk has no clinical importance and breastmilk in any form is strongly recommended (Pramitasari et al., 2019).

Mothers believed that breastfeeding was '*amazingly healthy*' for their infant. The breastmilk contained all the nutrients the infant needed and thus the mothers preferred breastfeeding and breastmilk as opposed to using formula milk.

[29] *'Because breastfeeding is amazingly healthy. It has everything in. That's why I'm not much about box milk. I'll give him much more of this [*points to breast*] than that. But obviously, I have to give him that if I'm not at home.'*

Lastly, mothers associated breastfeeding with discharge from the hospital. This was linked to their perceptions that breastfeeding led to an increase in weight gain and growth and is '*amazingly healthy*'. This message was emphasised by HCP in the hospital and breastfeeding was one of the important criteria for discharge, as discussed in the previous themes. Mothers were thus excited about breastfeeding, [30] *'because I knew the breast is what's going to let her go home.'*

Interaction-attachment advantages of breastfeeding

Mothers experienced breastfeeding as an opportunity to bond with their infant. This intimate task helped them to create a bond with their infant albeit under challenging circumstances.

[31] *'Where I got the mother-and-child feeling the first time was when I had him here [*points to chest*] by me. Then I felt it between us two.'*

Mothers felt that this task provided them with an opportunity to be close to their infant and enjoyed this proximity. The extremely and very preterm infants were in incubators after birth and the mothers thus had limited opportunities to be physically close to their infants during this period. Breastfeeding and the accompanying KMC brought about a new opportunity where mothers were encouraged to do exactly this – [32] *'It was just amazing because he has to sit here [*shows to breasts*] with me the whole day.'*

Breastfeeding was also viewed as an opportunity to interact and communicate with the infant. The mothers reported that most of the communication with their infant happened during the reciprocal task of breastfeeding.

[33] *'The main one of how I communicate with him is by breastfeeding him. That is a very special time with my child. Because then it is to me like he's drinking a part of me. All and all (Van alles en alles) … that is very special to me.'*

Breastfeeding was the thing that made these women feel like mothers at last. The task of breastfeeding their infant was associated with actively fulfilling the role of being a mother. This made the mothers proud because now they were able to provide and care for their infant.

[34] *'It made me feel good because now it feels to me like okay, now I am a mother at last (laughs). I am now a mother because he drinks from me.'*

Before being able to breastfeed the mothers often felt like passive onlookers while others fulfilled the role of caring for the infant. Especially while the infants were still in the incubator, mothers felt as if they were '*just sitting*' and not being a mother.

[35] *'Yes, so to me it actually was like before he started drinking from my breasts, I felt like I'm not really like I'm not actually a mother because I mean he was still in the small incubator and I must just sit there and yes*.'

Breastfeeding thus provided mothers with an '*amazing*' opportunity to be close to their infant, to interact and communicate with their infant and at last to develop a mother-infant bond. Most importantly, breastfeeding and KMC were the tasks that made mothers feel like mothers, after a period of anticipation.

Theme 5: The hospital setting was both stressful and helpful

This theme conveys how mothers perceived the hospital environment as both positive and negative simultaneously. Within individual participants' experiences of the hospital setting there were thus contradicting impressions. For example, a participant perceived some HCPs as helpful while others were perceived as impatient and strict. Experiences can be divided into two groups, namely experiences of the general environment and experiences of HCPs specifically. These two factors cannot be separated from one another, however, and should be considered in conjunction.

General experiences related to the hospital setting

The hospital environment was perceived as a stressful and novel context by the mothers of preterm infants. They explained that [36] '*the hospital is no one's home'* and therefore this setting was something outside of their comfort zone. Mothers were separated from their children and support networks at home. Additionally, this setting was also new and not part of their frame of reference. This foreign environment, isolated from their families at home, complicated the feeding task between mother and infant as mothers were generally stressed and uncomfortable. These experiences may begin to explain why mothers were intensely longing for the infant to be discharged from the hospital as discussed under themes 1 and 2.

[37] *'But when we got home then everything changed. I was really stressed in the hospital because I'm not a hospital person and I don't know hospitals.'*

Mothers perceived the hospital setting as controlled. The caretaking and feeding of their infants were governed by a strict schedule. This schedule left them with little room to spontaneously interact with and care for their infant. Feeding was thus more complicated in the hospital as mothers had to feed their infant at fixed times and couldn't feed according to their infant's demand and *'signals'.*

[38] *'It was actually harder in hospital than it was at home… I think it's because the hospital is very controlled like you must feed at this time, you must change the nappy when you feed her, you must do it… but at home, it's more like they give signals when the nappy is wet or… like she will cry when she's hungry or if her nappy is wet.'*

Despite these negative perceptions, some mothers expressed that they accepted the fact that they had to remain in hospital with their infant because this is what was required to ensure their infant's health.

[39] *'If you must stay, you must stay – it is your child's health. You can't be against it.'*

They explained that although the hospital setting was stressful and novel, the thing that made them happy was knowing their infant was healthy. Therefore, they were able to endure this challenging environment to make sure their infant could access the necessary care and '*tests*' until the doctor said it was safe for them to go home. Until they felt they knew everything was '*normal*' with their infant.

[40] 'It's just that what makes you happy is knowing your baby is healthy. Because lots of tests and stuff are done and you tell yourself I want a healthy baby, a baby whose brains is right. You want them to do all the tests with your baby… so you stay, and you check that all the tests that the doctor does are okay. Actually, you must go home with a good heart, you must know that everything is now normal with your baby. Not go home and then oh no, I don't know if my child is normal. But it is nice when the doctor tells you, now everything is normal with the baby. You walk away with a normal baby, even if he came before the time.'

Specific experiences regarding HCPs

Mothers felt that HCPs supported them by demonstrating how to perform certain caregiving tasks. They valued physical demonstrations and discussions about how to handle and feed their infant. Mothers greatly appreciated HCPs who supported them in this way.

[41] *'So then she will come and sit and talk to us and explain the baby must be held like this and you must do this with the baby and if the baby chokes then you must put your hand here and close the nose and hold the head up. So, there it was much better, they helped us a lot.'*

Contrary to this positive experience of HCPs assisting the mothers, some HCPs were perceived as impatient and strict. This was attributed to the nursing staff more than to other HCPs, although not all nursing staff was perceived in this light. Some were perceived as helpful, while others were perceived as impatient. Firstly, mothers felt that some nursing staff was strict during feeding times.

[42] *'It's just sometimes the nurses were a little… when we feed. They were actually strict.'*

The mothers also perceived nursing staff as unwilling to demonstrate tasks more than once. They felt like they were expected to master tasks after a single demonstration even though it was their first time performing the task.

[43] *'They were almost like you must just know how… almost like they are doing this work for years so now they show you only once and you must already know the next time.'*

A mother explained that it was hard for mothers when nursing staff were impatient with them as they were vulnerable and didn't understand why the nurse was rude to them. The mothers were vulnerable and sensitive, and negative interactions such as scolding were often taken personally and were difficult to handle.

[44] *'Make an example – like I will maybe ask now how must I make with this or how must I make with that? Then they [*nursing staff*] maybe feel like, no man, I have explained this how many times already to this one and to that one. Then they will maybe scold you and then you don't know why they are saying so or why they are so rude.'*

Mothers also felt that HCPs could provide them with more support regarding the task of breastfeeding specifically. When the infants started to breastfeed, they often struggled, and the mothers felt that HCPs could have supported them by teaching them how to breastfeed.

[45] *'It's just with the breastfeeding. I always thought that someone can come and teach us and tell us how the breastfeeding works 'cause why the baby just takes the breast in the beginning and struggles a bit.'*

Mothers thus had contrasting experiences regarding the hospital setting and HCPs. The hospital setting was perceived as novel and anxiety-provoking, although mothers were willing to endure this context to ensure their infant received the intervention they required. The support offered by HCPs on how to complete caregiving tasks were valuable and appreciated, although the some of the nursing staff were perceived as impatient and strict.

Theme 6: Feeding became *'easier'* as mother and infant *'got used to it'*

As discussed under previous themes, mothers felt that feeding difficulties were especially prevalent '*in the beginning*' of their infant's life. This theme indicates how mothers gradually became more comfortable with feeding their infants and how they acquired certain skills. Furthermore, it describes how mothers perceived their infants' journey of learning to suck and drink. The theme will be described under three questions exploring what and how mothers and their infants learned regarding feeding tasks. This theme includes maternal experiences during the hospitalisation period, as well as experiences once the mother-infant dyad had gone home.

What did mothers learn?

The mothers felt that they became more comfortable with feeding their infant as they acquired the following skills: how to recognize the infant's hunger cues; learning the infant's specific preferences; how to handle the infant; and how to use feeding equipment.

Firstly, mothers became more familiar with their infant's hunger cues and this assisted them in recognizing what their infant wanted. Mothers thus learned how to 'read' their infant and be more sensitive towards their early behaviours and signals.

[46] *'Like now I will know… she will suck on her hand if she's hungry.'*

Secondly, the mothers started to understand their infant's specific preferences with regard to feeding. They often experimented with different feeding methods or equipment and in this trial-and-error process they found the option that was best accepted by their infant.

[47] *'It's just bottle. I just give bottle now too, uhh, she knows how to suck now… but she only sucks on rounds teats like the one that is like a nipple. Cause I tried to buy one that looks like a nipple the most so she can learn how to suck.'*

Thirdly, mothers became more comfortable in handling and positioning their infant. In the beginning, they felt unsure about how to approach these tasks but gradually they acquired the skill. This was especially relevant to first-time mothers.

[48] *'In the beginning, it was very awkward to me because it's my first baby, I don't know to handle him, how to take him and just now I hurt him…'*

Lastly, mothers learned how to use different feeding equipment such as bottles and tubes. For example, they learned how to prepare a bottle for their infant and how to clean the bottles. These skills may appear insignificant but were new to some mothers and were something that they had to learn to do.

[49] *'So it was like very difficult for me because I didn't know how to do the stuff and now I must learn and then I become irritated… like I had to learn about like bottles and all that – making bottles, cleaning bottles.'*

How did the mothers become more comfortable with caring for their infant?

The mothers described three methods whereby they learned how to care for their infant, namely observation, direct instructions from HCPs, and self-guidance.

Firstly, the mothers observed others in the hospital environment to see how certain tasks were done. This includes HCPs, other mothers and even their infant. They would watch nursing staff perform caregiving tasks and listen to doctors' conversations to learn about caring for their infant. They also observed their infant to learn their individual preferences as described above.

[50] *'I learned everything here [*referring to the hospital*]. I didn't know anything about premature. I learned everything day after day… observed the nurses, listened to what the doctors are talking, and then I also started watching her and this is how I learned.'*

Secondly, mothers learned how to care for their infant by following direct instructions from HCPs. This was especially useful in learning about developmental milestones and thus when to start with certain feeding tasks such as introducing solid foods.

[51] *'We started with the porridge yesterday and he eats the porridge very nicely. We are going to start with the vegetables and fruits now because the doctor said we must now also start with that.'*

Lastly, mothers became comfortable in caring for their infant by attempting to perform tasks in '*my own way*'. Mothers felt unsure about how to perform caregiving tasks in the beginning but tried to perform them in a way that they felt comfortable with. During the trial processes, mothers became familiar with their infant and learned how to perform caregiving tasks with confidence

[52] *'I showed myself and helped myself. Okay, I did look around a little bit to see how it must be done…to me, it was that I'm not sure if I must do it so or so but okay I'm going to try doing it in my own way and then it works!'*

What did the infants learn?

The mothers explained that their infants didn't immediately know how to '*drink*'. This referred to the infant's sucking abilities and the inability to breastfeed shortly after birth. Mothers further explained that this was due to their infants not being as fully developed as a full-term infant. Their infants didn't '*click*' that they must suck and didn't know how to suck yet.

[53] *'Their insides are almost like not fully developed… like where a full nine-month baby when you give birth, they give your baby to you and you put baby on the breast and the baby clicks immediately I must drink now and so on. The difference is with them that they can't just drink when they come out, they are like they don't know that they must drink.'*

Gradually the infant acquired the ability to suck and thus started to drink from the mother's breast. This required exposure to and practice of having to breastfeed.

[54] *'And then I started putting him on [*referring to breastfeeding*] and so and he learned nicely and luckily started drinking nicely and so.'*

Besides breastfeeding, the mothers felt that exposure to and practice of feeding methods helped their infant to learn how to feed. Again, '*in the beginning*' feeding was challenging to the infant, for example via a cup, but over time the infant acquired this skill and '*got used to it*'.

[16] *'She messed for the first few days – spit it out, didn't really know how to swallow it and then afterwards it became easier for me because the more I gave the cup to her, the more she got used to the cup.'*

<u>An overview of maternal perceptions regarding tube feeds, cup feeds and bottle feeds.</u>

This section does not constitute a theme but rather an overview of the mothers' experiences of feeding methods alternative to breastfeeding. This includes tube feeding, cup feeding, and bottle feeding. Breastfeeding was explored in more depth in the previous themes. It is important to note that it is only the method of feeding which is being discussed here, and not the use of breastmilk versus formula milk. For example, all the

mentioned feeding methods can be completed using expressed breastmilk and use of any specific method does not necessarily indicate the use of formula milk. Exploration of this topic was not an aim of the study, and the topic was not explicitly explored in the interviews. However, during the interviews the mothers spontaneously discussed the various feeding methods. The discussion that follows is therefore not comprehensive but is included in the thesis since it may be clinically useful and may guide future research efforts.

Tube feeding (OG or NG tubes)

A common position amongst the mothers of preterm infants was that tube feeding was a relatively positive experience. Firstly, mothers felt that it was an easy method of feeding with limited participation required from the mother or the infant.

[55] *'The feeding I gave through the tube and that was to me… actually it was easy.'*

Secondly, mothers recognized that the infant gained weight whilst being tube fed. As discussed under previous themes, weight gain was an important goal to the mothers. Mothers were positive about tube feeding as it assisted with weight gain for the infant and thus eventual discharge from hospital.

[56] *'Uhm then it is the little tube that they… with all the feeding things my child's weight picked up nicely. So to me, that wasn't a problem.'*

An alternative position was taken by a mother who felt the tube through the nose or mouth was unnatural. This position was not explicitly explained but rather implied by the mother's gestures and facial expressions.

Cup feeding

The mothers had contrasting perceptions regarding cup feeding. While some mothers experienced it as positive, others experienced it as negative. Mothers who expressed positive experiences with cup feeding explained that the infant managed this method well. Feeding times were thus pleasant and less stressful.

[57] *'I had to feed her with a cup and she drank from the cup very strongly.'*

Mothers who expressed negative experiences with cup feeding explained that the infant struggled to manage this method. This resulted in choking and messing during feeding times, which understandably made mothers anxious.

[58] *'It's just the cup feed was irritating – ugh, I hate the cup feed. I hated it. Because most of the time with the cup feed then he chokes and that I can't take. So when I got home, I stopped the cup feed.'*

Bottle feeding

Some mothers reported positive perceptions regarding bottle-feeding their infant, whilst some were neutral in their reporting. The mothers did not report any negative perceptions regarding bottle-feeding their infant. It was clear that all mothers were actively using this method of feeding at home. Firstly, bottle feeding was

described as a plan B to breastfeeding and one that the infant often preferred over breastfeeding. Mothers explained that they tried breastfeeding but when the infant rejected the breast, they tried bottle feeding. They also linked this to the infant's preference for formula milk rather than breastmilk.

[59] *'And then I bought her a bottle and since then she drinks bottle and she also doesn't want breastmilk. Only formula. Because I tried to give her breast and she didn't want it. She doesn't want to suck. She only sucks once and then she doesn't worry anymore and then I saw that she probably doesn't want the breastmilk so I'm going to try the formula.'*

Secondly, mothers felt that bottle-feeding provided them with more freedom than breastfeeding. They mentioned that with bottle-feeding they can leave the infant in the care of a family member and they become more mobile to have '*free time*'. This perception was especially prominent in younger mothers.

[60] *'When I started giving him breast and then he didn't want to take the breast and then we bought him the bottle and the milk and then it went a little better. Now if I want to walk then I take him to my auntie and then I take the milk and the bottle. So, if he drank breast then I couldn't have free time…'*

Some mothers preferred breastfeeding to bottle feeding but had to turn to bottle feeding upon returning to work. From the statements above, it is clear that mothers are actively relying on bottles to feed their infants, especially after they have returned home. This was, however, described as an alternative or plan B to breastfeeding.

CHAPTER FIVE: ARTICLE

The thesis follows the format of 'Masters by publication' which requires an article to be prepared for submission and future publication. The article was prepared for submission to the South African Journal of Communication Disorders and adheres to the guidelines set out by this journal. The main guidelines include a word limit of 3000 words (excluding the abstract, tables, figures and references), the inclusion of specified sections (structured abstract, introduction, methodology, results, discussion and conclusion), and limitations of the number of references (60) and tables and figures (10) included in the manuscript.

Vulnerable mothers' experience of feeding their preterm infant during the first months of life

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ABSTRACT

Background: Preterm birth is a rising and significant threat to maternal and child health globally. The universal challenges of being the mother of a preterm infant, combined with context-specific challenges such as poverty and poor linguistic and cultural representation, bring about risks for both mother and infant. This includes poor maternal mental health; poor mother-infant bonding and attachment; and potential suboptimal developmental outcomes for the child.

Objectives: This article describes and explains how Afrikaans-speaking mothers, living in poverty, experienced feeding their preterm infant in the first months of life.

Method: A cross-sectional, qualitative design that was exploratory and descriptive in nature was followed. Participants were selected through a purposive sampling method and participated in individual semi-structured interviews. Nine interviews were thematically analysed. The participants were a vulnerable group about whom little research literature was available.

Findings: Feeding was perceived as a progressive task that continuously demands a new method of feeding, higher volumes of milk and weight gain in the infant to reach the goal of discharge from hospital. It was stressful due to various factors of which insufficient breastmilk supply was a significant contributor. The hospital setting was perceived as something that added to the participants' anxiety surrounding feeding, but simultaneously had the potential to decrease their anxiety. The mothers felt that over time both they and their infants became skilled in the task of feeding. When the mother-infant dyad was able to breastfeed successfully, it made the participants feel like mothers for the first time.

Conclusion: Feeding was experienced as one of the most significant stressors related to caring for the infant, especially while hospitalised. Various factors were identified as positive and/or negative influences on this experience. The findings have implications for healthcare professionals working with preterm mother-infant dyads, especially from underserved and socially marginalised communities.

Keywords: Mothers; Experiences; Feeding; Caring; Preterm; Infant; Hospital; Vulnerable

INTRODUCTION

An increasing number of infants in South Africa are at risk for neurodevelopmental delays due to the high frequency of preterm birth (South African Speech-Language-Hearing Association [SASLHA], 2017). South Africa presents various risk factors for preterm birth that also complicate caring for a preterm infant. These factors include the high burden of disease, resource constraints in various respects and on many levels, and inequalities relating to social determinants of health (Dawes, Biersteker & Irvine, 2008). As modern technology and advances in neonatal care are ensuring the survival of preterm infants at younger gestational ages and with lower birthweights (World Health Organisation [WHO], 2017), low- and middle-income countries are experiencing increased neonatal morbidity rates and challenges to already overburdened and poorly resourced health services.

Being the mother of a preterm infant is universally described as a challenging and stressful experience. Preterm infants are at risk for various medical, neurological and developmental complications (Huddy, Johnson & Hope, 2001) that may influence current and future feeding skills. The potential comorbidities of babies that are born preterm may have physical, psychological, social, and financial implications for their mothers in the short- and/or long-term (Petrou, 2005). The mother of a preterm infant has a unique early parenting experience in caring for her infant (Pascoe, Bissessur & Mayers, 2016) which may potentially alter the nature of mother-infant interactions in the first months of life.

Mothers of preterm infants with low socio-economic status (SES) and from linguistic minority groups, such as poor Afrikaans-speaking mothers, face additional challenges that make them especially vulnerable and may negatively influence their experience of caring for their preterm infant. In addition to poverty this includes limited linguistic and cultural representation within the health constitution (mothers with a low SES from all of the indigenous South African languages are in such a situation). Firstly, mothers living in poverty experience high levels of psychosocial stress in combination with limited access to social and economic resources (Crapnell et al., 2013). Secondly, Afrikaans mothers constitute a group that is poorly represented in a health constitution where English is the language of choice of many healthcare professionals (HCPs) (Penn & Watermeyer, 2018). The universal challenges of being a mother of a preterm infant, combined with the context-specific challenges of belonging to an underserved and socially marginalised group, bring about risks for both mother and infant. This includes poor maternal mental health; poor mother-infant bonding and attachment; and potential sub-optimal feeding and communication development.

Existing early communication intervention (ECI) guidelines emphasize the involvement of the mother (primary caregiver) in the intervention process (Craig et al., 2015), since their perceptions and experiences of caring for their infant are strong influences on future communication and feeding development of the child. ECI provided to vulnerable populations, such as Afrikaans mothers of preterm infants with low SES, should be sensitive and accommodate their unique perceptions and experiences. This will allow speech-language

therapists to utilise the neonatal period optimally, to support mothers in stimulating communication and feeding development, and to prevent and timeously identify communication and feeding delays or disorders (SASLHA, 2017). Limited local and international research is available about the experiences of caring for a preterm infant amongst mothers from linguistic minority groups who live in poverty. The poor representation of these vulnerable groups in research literature and thus professional knowledge makes them susceptible to healthcare that is not contextually appropriate and sensitive toward their unique realities.

The main aim of the study was to describe and explain how Afrikaans mothers living in low socio-economic circumstances in the Western Cape experience caring for their preterm infant in the first months of life. The goal was achieved by articulating the following research question: *How do Afrikaans mothers, living in low socio-economic circumstances in the Western Cape, experience caring for their preterm infant in the first months of life?* The answer to this question will assist in fulfilling South African speech-language therapists' current need to know 'what works best for whom, when and how' (SASLHA, 2017, p.3) with regard to ECI for at-risk neonates and mothers in our culturally and linguistically diverse context.

METHOD

Study Design

This study entailed a cross-sectional, qualitative design which was exploratory and descriptive in nature. A small group of mothers participated in individual in-depth interviews that were led by a semi-structured discussion schedule.

Study population and setting

The sample frame entailed all the Afrikaans mothers with preterm infants ranging from ages three to six months (chronological age) who attended follow-up appointments at the High-Risk Clinic at the Paediatrics out-patient department of a public hospital in Cape Town. Purposive sampling, specifically criterion sampling, was used to select participants. The inclusion criteria are described below (Table 1). Additional to the inclusion criteria, specified characteristics pertaining to the participant and her infant were considered to ensure variation within the sample as listed (Table 2). Mothers that met the inclusion criteria were identified by the researcher and the paediatrician responsible for the clinic and invited to participate in the study following their paediatric appointment. This process continued until data saturation was reached (after 11 interviews conducted over five days). The selected sample was reviewed by the researcher for a second time to confirm that all the inclusion criteria were met and to ensure that the interviews were of sufficient quality for inclusion in the study. The final sample consisted of nine participants (n=9). The heterogeneous nature of the selected sample; the detail-rich narratives collected during the interviews; and the decision to use in-depth analysis strategies to provide a detailed account of this phenomenon, assisted in establishing when data saturation occurred (Malterud, Siersma & Guassora, 2016).

Table 1: Inclusion criteria

Criterion	**Notes**
Afrikaans first-language speaker	English is the preferred language of health intervention in South Africa (Levin, 2007). This criterion assisted in exploring the experiences of a minority group that is not well represented in our health care constitution. Furthermore, there were advantages attached to collecting data in both the researchers' and the participant's home language. These include eliminating the need for an interpreter, reducing the study costs, and minimising the risk of communication breakdowns.
Older than 18 years	Adolescent mothers face many additional challenges that may influence their perceptions of giving birth to and caring for a preterm infant. This criterion thus aimed to ensure the study's credibility.
Low SES	*Low SES was determined by:* 3.1. Education: No post-matriculation degree or diploma. 3.2. Financial income: Bracket H0 – H1 on the patient income classification scale of the study site (a hospital) which represents households with an annual income of R0 – R100 000.
The participant's infant meeting certain criteria	*Infant criteria:* 4.1. Born preterm, thus before 37 weeks gestational age (Rossetti, 2001) 4.2. Born with low birthweight (LBW), very low birthweight (VLBW) or extremely low birthweight (ELBW) (800g – 2500g) (Rossetti, 2001) 4.3. Aged 3 – 6 months chronological age at the time of the data collection 4.4. Medically stable at the time of data collection 4.5. No diagnosed biological, physical, sensory, congenital, or neurological disorders at the time of data collection

Table 2: Characteristics of the nine study participants

Participant number	**Maternal characteristics**	**Infant characteristics**
PS_P2	Age: 32 years Children: 3 in total Education: Grade 11 Employment: cleaner Relationship status: married to infant's biological father	Degree of prematurity: extremely preterm (26 weeks) Birthweight: less than 2500 g
PS_P3	Age: 32 years Children: firstborn Education: Grade 10 Employment: quality controller	Degree of prematurity: very premature (30 weeks) Birthweight: less than 2500 g

	Relationship status: in a relationship with the infant's biological father	
MS_P2	Age: 18 years Children: firstborn Education: Grade 10 Employment: unemployed Relationship status: in a relationship with the infant's biological father	Degree of prematurity: very preterm (28 weeks) Birthweight: VLBW (1,3 kg)
MS_P3	Age: 24 years Children: firstborn Education: Grade 12, psychology diploma incomplete due to pregnancy Employment: unemployed Relationship status: in a relationship with the infant's biological father	Degree of prematurity: extremely preterm (27 weeks) Birthweight: ELBW (940 g)
MS_P4	Age: 22 years Children: firstborn Education: Grade 12 Employment: unemployed Relationship status: married to infant's biological father	Degree of prematurity: moderately preterm (32 weeks) Birthweight: VLBW (1,36 kg)
MS_P5	Age: 36 years Children: 2 in total Education: Grade 10 Employment: clerk Relationship status: single	Degree of prematurity: very preterm (29 weeks) Birthweight: VLBW (1000 g)
MS_P6	Age: 31 years Children: 4 in total Education: Grade 10 Employment: unemployed Relationship status: married to infant's biological father	Degree of prematurity: very preterm (29 weeks) Birthweight: VLBW (1,25 kg)
MS_P7	Age: 22 years Children: firstborn Education: Grade 12 Employment: carer at a retirement home Relationship status: in a relationship	Degree of prematurity: very preterm (29 weeks) Birthweight: ELBW (955 g)
MS_P8	Age: 38 years Children: 5 in total Education: Grade 7 Employment: farmworker Relationship status: married to infant's biological father	Degree of prematurity: moderate to late preterm (33 weeks) Birthweight: VLBW (1,29 kg)

Data Collection

Eleven interviews were conducted in a private consulting room near the clinic using a discussion schedule. An initial pilot study was completed with three participants to ensure the credibility of the discussion schedule and the interview process. Following review and discussion of the pilot study between the authors and an external expert in the field, no changes were made to the discussion schedule and minimal changes were recommended for the interview process. Two of the interviews from the pilot study were deemed suitable and were included in the study data. The main study was completed with eight participants of which seven interviews were included in the study data. A total of nine interviews were thus included in the study (two interviews from the

pilot study and seven interviews from the main study). The discussion schedule entailed a revised version of a semi-structured questionnaire compiled by Buys (2020) who completed a similar study amongst isiXhosa speaking mothers. Buys's (2020) questionnaire was translated into Afrikaans and the content was reviewed by the authors to facilitate an open-ended discussion exploring seven key areas namely maternal perceptions regarding prematurity; caregiving; feeding; mother-infant interaction; maternal responsibilities; additional role-players in their infant's care and development; and information needs. This allowed participants to guide the direction of the discussion and aimed to increase the confirmability of the tool (Ali & Yusof, 2012). The interviews were voice recorded. The voice recordings were transcribed verbatim by author one. To ensure dependability and confirmability of the transcripts, 22% of the data was externally audited by a speech-language therapy doctoral student. During the interviews, the participants spontaneously gravitated towards the topic of feeding their preterm infant and it was clear that feeding was the most prominent experience of caring for their infant.

Data Analysis

Thematic analysis, as described by Braun and Clarke (2006), was used to analyse the data. An inductive approach to thematic analysis was used by creating semantic codes and themes that focused on the explicit meaning of the collected data. Author one familiarised herself with the data by conducting the interviews; transcribing the audio recordings; reading the transcripts repeatedly; and documenting early analytical remarks. The transcripts were coded in an iterative fashion and grouped into six main themes. The computer-assisted qualitative data analysis software (CAQDAS) program *ATLAS.ti 8 Windows* was used to assist with managing and organising codes and themes. Refined codes and themes were assigned following various reviews and discussions between the authors to increase the credibility of the study (Ali & Yusof, 2012). Analysis provided a detailed account of one particular aspect of the participants'experiences, namely feeding their preterm infant in the first months of life.

Ethical considerations

Ethical approval was obtained from the Health Research Ethics Committee of Stellenbosch University (N15/10/13), the National Health Research Committee and the National Health Research Department. Informed consent was obtained from all participants in their language of choice. The participants' true identities were protected at all times. Transcribed interviews were stored as password-protected Microsoft Word documents on a secure flash drive.

RESULTS

Six themes (outlined in Table 3) arose during data analysis and provide an overview of the participants' experiences of feeding their preterm infant during the lengthy period of hospitalisation after the infant's birth. Participants were naturally inclined to speak about the task of feeding their infant, especially concerning the period that the infant was hospitalised.

Table 3: Themes describing maternal experiences of feeding their preterm infant while hospitalised

Feeding was a progressive task aimed at *'going home'*
Feeding was a significant contributor to stress *'in the beginning'*
Breastmilk was '*the biggest thing*' in hospital
Breastfeeding was '*amazing*'
The hospital setting was both stressful and helpful
Feeding became *'easier'* as mother and infant '*got used to it'*

Feeding was a progressive task aimed at *'going home'*

> 'It was very stressful. Very, very, very. Because I knew the breast is what's going to let her go home. And her weight was already 1,8 [kilograms] and then she still couldn't go [home] because she couldn't breast [breastfeed].' (PS_P2)

Feeding the infant was experienced as something that changed frequently and was closely tied towards the goal of discharge. Mothers described the following as criteria for attaining this goal: successful breastfeeding and steady weight gain with a target weight of 1, 8 kilograms or more. The task itself was perceived to change with regard to two aspects, namely the method of feeding and the feeding volume. Firstly, the method of feeding their infant entailed '*something new*' on a frequent basis. These changes contributed to maternal stress as the mother was expected to rebuild her feeding skill and confidence using a new method. Secondly, the feeding volumes always entailed '*more*'. The millilitres of milk the infant consumed during a feed were perceived to go '*higher and higher every day*'. Thirdly, the infant was expected to gain weight steadily and this was monitored and documented daily. This monitoring often resulted in feelings of hopelessness and the infant's weight was perceived as a numerical indicator of the infant's progress towards the eventual goal of discharge.

Feeding was a significant contributor to stress *'in the beginning'*

> 'In the beginning when he was born, I struggled with the milk and that stressed me out a bit because they told me that he must get my milk because it will help him quicker.' (MS_P7)

The task of feeding their infant was a significant cause of stress for the participants and was especially prominent '*in the beginning*' of the infant's life. Various factors related to feeding were described as contributors to the mothers' anxiety, including worries regarding poor weight gain and growth of the infant; messing during feeding times; insufficient breastmilk supply; and difficulty with the task of breastfeeding itself. The progressive nature of the feeding task further strongly contributed to maternal anxiety. Mothers were striving towards the goal of discharge from hospital and therefore any factor that interfered with the attainment of this goal added to maternal stress.

Breastmilk was '*the biggest thing*' in hospital

> 'That was such a big stress to me, the milk. And then they move it up, they move it up up up – at the end, it is so much milk that I can't even almost give that total.' (MS_P6)

> 'And they were just like you must express milk and I was like I can't. Even that where you must wake up every two hours to express, I had to do that even though I didn't have milk and nothing comes!' (MS_P3)

The mothers experienced their breastmilk supply as one of the biggest problems during the hospital stay. They preferred their infants to receive '*my milk*' as they believed this would help their infant the '*quickest*' by facilitating steady weight gain and subsequently, an expedited discharge. Firstly, mothers were concerned that they would not be able to meet the prescribed millilitres as the infant's feeding volumes increased on a frequent basis. Secondly, the process of expressing milk was hard for mothers as it was often novel, painful or fruitless. Thirdly, mothers felt bombarded with the message of expressing breastmilk and perceived nursing staff to '*push*' and '*force*' them to express their milk even though it was clear that they were struggling with lactation. It appears that breastmilk was perceived as an elixir in hospital. Having a good supply made you rich, while a limited supply left you poor and hopeless. The mothers of extremely or very preterm infants were the latter for most of their hospital stay.

Breastfeeding was '*amazing*'

> 'The Saturday when the sister told me I must breastfeed him it was such an amazing feeling that he was on my breasts… I can't explain it to anyone that amazing feeling, it's like butterflies that I felt inside of me when he drank from me the first time.' (PS_P3)

> 'It made me feel good because now it feels to me like okay, now I am a mother at last (laughs). I am now a mother because he drinks from me.' (MS_P7)

Mothers experienced breastfeeding their infant as a remarkably positive experience which they thoroughly enjoyed. Breastfeeding was described as advantageous to both mother and child. Physiological advantages reported include increased breastmilk production; weight gain for the infant; a healthy infant; and lastly discharge from hospital. Interaction-attachment advantages described include increased bonding; proximity; and communication between the mother and the infant. After having to rely on alternative methods to feed their infant, such as oro- and nasogastric tube feeding, syringe feeding, and cup feeding, breastfeeding was the task that made mothers feel like mothers for the first time.

The hospital setting was both stressful and helpful

> 'It was actually harder in hospital than it was at home… I think it's because the hospital is very controlled like you must feed at this time, you must change the nappy when you feed her, you must do it… but at home, it's more like they give signals when the nappy is wet or… like she will cry when she's hungry.' (MS_P3)

> 'If you must stay, you must stay – it is your child's health. You can't be against it.' (MS_P8)

> 'It's just sometimes the nurses were a little… when we feed. They were actually strict.' (PS_P2)

The hospital setting was perceived as novel, controlled and anxiety-provoking, although mothers were willing to endure this context to ensure their infant received the intervention they required. The support offered by HCPs on how to complete caregiving tasks were valuable and appreciated, although some of the nursing staff was perceived as impatient and strict.

Feeding became *'easier'* as mother and infant '*got used to it'*

> 'I learned everything here. I didn't know anything about premature. I learned everything day after day… observed the nurses, listened to what the doctors are talking, and then I also started watching her and this is how I learned.' (PS_P2)

> 'She messed for the first few days – spit it [milk] out, didn't really know how to swallow it. And then afterwards it got easier for me.' (MS_P4)

The mothers felt that they became more comfortable with feeding their infant as they acquired the following skills: how to recognize the infant's hunger cues; learning the infant's specific preferences; how to handle the infant; and how to use feeding equipment. They described three methods whereby they learned these skills, namely observation; direct instructions from HCPs; and self-guidance. With regards to their infant's learning, they experienced that '*in the beginning*' their infants didn't immediately '*click*' that they must suck and didn't know how to suck because they were not as fully developed as a full-term infant. According to the mothers , their infants '*got used to it*' with exposure and practice and learned how to feed.

DISCUSSION

The participants experienced the feeding of their infant as one of the most significant stressors related to caring for their infants, especially in the first months of life while the infant was hospitalised. This finding frequently appears in research literature (Buys, 2020; Flacking, Ewald, Nyqvist & Starrin, 2006; Swift & Scholten, 2009; Leonard & Mayers, 2008; Ericson & Palmér, 2019) and various factors are thought to contribute to feeding being a challenging task. The most prominent contributor in this study was the strong association between successful oral feeding and discharge from the hospital. Participants described feeding as a progressive task that worked towards one goal, namely '*going home'*. The mothers formulated a clear recipe for discharge from hospital: present a breastfeeding infant with a weight of at least 1,8 kilograms. This strong association between successful oral feeding and discharge from hospital is perhaps a major cause of the anxiety surrounding feeding. Successful feeding results in discharge from hospital, while difficulty with feeding results in an extended hospital stay.

An important question to ask is why the mothers associated successful oral feeding so closely with discharge from hospital. According to Thoyre (2001) it is due to the intense monitoring associated with oral feeding within the neonatal hospital context. The participants in the current study felt bombarded with the message that they must express breastmilk and supply specified amounts of breastmilk for their infant as breastmilk is

'*the thing that is going to send us home the quickest'*. The big focus and daily monitoring of the infant's weight gain gave the participants a perception of the infant's weight as a numerical measure of their progress towards discharge and had a strong influence on maternal mental health.

The way that HCPs package and convey messages regarding feeding to the mothers of preterm infants should be carefully considered. Firstly, HCPs must adjust the packaging of their message to accommodate the unique hardships that the members of this vulnerable population encounter. The following hardships were highlighted in the current study and are also supported by literature: high stress levels (van Schalkwyk, Gay, Miller, Matthee & Gerber, 2020); difficulty with initiating and maintaining lactation (Lee & Gould, 2009; Ericson & Palmér, 2019); reduced feeding abilities of the infant (Crapnell et al., 2013); limited reciprocal interaction with their infant (Pascoe et al., 2016); and being in an unfamiliar hospital environment for prolonged periods with limited support (Swift & Scholten, 2009). An important recommendation for health professions education is thus to focus on developing awareness and sensitivity toward, and skills in addressing the unique hardships (Penn, 2014) of vulnerable mother-infant dyads from diverse backgrounds.

Secondly, HCPs must find creative ways to motivate mothers to use expressed breastmilk and to breastfeed their infant as prescribed by the WHO (2020). Perhaps it is necessary to ask whether HCPs are promoting breastmilk and its advantages, or whether they are promoting discharge from hospital and '*the thing that is going to send us home the quickest'*. Promoting the use of breastmilk and breastfeeding by focusing on the inherent advantages versus focusing on an expedited discharge may produce different long-term outcomes in adhering to these practices. The first option may increase internal motivation to follow the prescribed health behaviours. The second option runs the risk of producing an intense, and likely unsustainable short-term motivation to use breastmilk and breastfeed as a means to an end (discharge from hospital). It is recommended that future research efforts explore ways in which HCPs can encourage mothers of preterm infants to use breastmilk or to breastfeed, in a way that is sensitive towards their unique realities and preferences, and ensures their long-term commitment to these practices.

The findings of this study have clinical implications for the way HCPs (especially speech-language therapists) are currently approaching ECI, and specifically feeding support to mothers. Firstly, increased awareness and acknowledgement is required of the unique challenges the mothers of preterm infants from low socio-economic settings face. Secondly, HCPs should increase their focus on mothers as equally important receivers of intervention while the mother-infant dyad is hospitalised. Thirdly, creative ways should be considered to provide emotional support and protect the mental health of these mothers while their infants are hospitalised. Potential ideas include in-hospital support groups; a system to flag and monitor mothers at risk of mental illness; and access to mental health services if indicated. Lastly, bonding and the attainment of a maternal identity should be encouraged during all stages of the preterm infant's hospital stay. This can be achieved by actively including mothers in all caregiving tasks, especially feeding, from the start of the infant's journey.

CONCLUSION

Mothers of preterm infants with low SES and from linguistic minority groups, such as poor Afrikaans-speaking mothers, are a vulnerable group with a unique early parenting experience in caring for their infant. The task of feeding their infants was experienced as one of the most significant stressors related to caring for their infants, especially in the first months of life while the infant was hospitalised. HCPs working with preterm mother-infant dyads should be aware, sensitive and accommodate mothers' unique realities. Furthermore, HCPs should seek effective methods to promote the prescribed feeding practices. These methods should aim to internally motivate this vulnerable group to follow the prescribed feeding practices while still accommodating the unique hardships they encounter. This will allow HCPs to utilise the neonatal period optimally and to improve maternal mental health; mother-infant bonding and attachment; and the developmental outcomes of the infant.

Acknowledgements: The researchers are grateful to all stakeholders who made this study possible with their participation.

Competing interests: The authors declare that they have no financial or personal relationships that may have inappropriately influenced them in writing this article.

Author contributions: The authors conceptualised the study together. Author one collected and analysed the data, and wrote the manuscript. Author two supervised the process, reviewed the manuscript and provided feedback.

Data availability: The data supporting the findings of the study are available from the corresponding author upon reasonable request.

REFERENCES

Ali, A. M., & Yusof, H. (2012). Quality in qualitative studies: The case of validity, reliability and generalisation. *Issues in Social and Environmental Accounting*, *5*(1/2), 25–64. Retrieved 22 June, 2020, from http://www.iiste.org/Journals/index.php/ISEA/article/view/952

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, *3*(2), 77-101.

Buys, K. H. S. (2020). *Maternal experiences of prematurity, feeding and infant communication within a vulnerable population in South Africa*. Unpublished Master's Thesis. Stellenbosch: Stellenbosch University.

Crapnell, T. L., Rogers, C. E., Neil, J. J., Inder, T. E., Woodward, L. J., & Pineda, R. G. (2013). Factors associated with feeding difficulties in the very preterm infant. *Acta Paediatrica*, *102*(12), 539-545.

Creswell, J.W. (2007). *Qualitative Inquiry and Research Design: Choosing amongst five approaches.* Lincoln, Nebraska.

Craig, J.W., Glick, C., Phillips, R., Hall, S.L., Smith, J. & Browne, J. (2015). Recommendations for involving the family in developmental care of the NICU baby. *Journal of Perinatology, 35*, 5-8. doi:10.1038/jp.2015.142.

Dawes, A, Biersteker, L. and Irvine, M. (2008). What makes a difference to child outcomes in the period 0–4? *Inputs for quality ECD interventions: Scaling up ECD 0–4 years in South Africa*. Cape Town: HSRC

Ericson, J., & Palmér, L. (2019). Mothers of preterm infants' experiences of breastfeeding support in the first 12 months after birth: A qualitative study. *Birth, 46*(1), 129–136. https://doi.org/10.1111/birt.12383

Flacking, R., Ewald, U., Nyqvist, K. H., & Starrin, B. (2006). Trustful bonds: a key to "becoming a mother" and to reciprocal breastfeeding. Stories of mothers of very preterm infants at a neonatal unit. *Social Science and Medicine*, *62*(1), 70-80. Doi: 10.1016/j.socscimed.2005.05.026

Huddy, C. L. J., Johnson, A., & Hope, P. L. (2001). Educational and behavioural problems in babies of 32–35 weeks gestation. *Archives of Disease in Childhood - Fetal and Neonatal Edition*, *85*(1), F23-F28.

Lee, H. C., & Gould, J. B. (2009). Factors influencing breast milk versus formula feeding at discharge for very low birth weight infants in California. *The Journal of pediatrics*, *155*(5), 657-662.

Leonard, A., & Mayers, P. (2008). Parents' lived experience of providing Kangaroo Mother Care to their preterm infants. *Health SA Gesondheid,* 13 (4), 16-28.

Levin, M. E. (2006). Language as a barrier to care for Xhosa-speaking patients at a South African paediatric teaching hospital. *South African Medical Journal*, *96*(10), 1076-1079.

Malterud, K., Siersma, V.D. and Guassora, A.D. (2016). Sample Size in Qualitative Interview Studies: Guided by Information Power. *Qualitative Health Research, 26*, 1753-1760. https://doi.org/10.1177/1049732315617444

Pascoe, M., Bissessur, D., & Mayers, P. (2016). Mothers' perceptions of their premature infant's communication: A description of two cases. *Health SA Gesondheid (Online)*, *21*(1), 143-154. Doi: 10.4102/hsag.v21i0.945

Penn, C. (2014). Asking new questions and seeking new answers: The reality of aphasia practice in South Africa. *Topics in language disorders*, *34*(2), 168-181.

Penn, C., & Watermeyer, J. (2018). *Communication across cultures and languages in the health care setting: Voices of care*. London: Palgrave Macmillan.

Petrou, S. (2005). The economic consequences of preterm birth during the first 10 years of life. *BJOG: An International Journal of Obstetrics & Gynaecology*, *112*, 10-15.

Rossetti, L. M. (2001). *Communication Intervention: Birth to Three, 2nd ed.* Clifton Park, NY: Delmar.

South African Speech-Language-Hearing Association (SASLHA) Ethics and Standards Committee. (2017). *Practice Guidelines for Audiologists and Speech-Language Therapists in Early Communication Intervention*. Retrieved 4 August 2020, from www.saslha.co.za

Swift, M. C., & Scholten, I. (2009). Not feeding, not coming home: parental experiences of infant feeding difficulties and family relationships in a neonatal unit. *Journal of Clinical Nursing, 19*(1-2), 249-258. Doi: https://doi.org/10.1111/j.1365-2702.2009.02822.x

Thoyre, S.M. (2001). Challenges mothers identify in bottle feeding their preterm infants. *Neonatal Network, 20*(1), 41‑50.

van Schalkwyk, E., Gay, S., Miller, J., Matthee, E., & Gerber, B. (2020). Perceptions of mothers with preterm infants about early communication development: A scoping review. *South African Journal of Communication Disorders*, *67*(1), 1-8.

World Health Organisation (WHO). (2017). *Preterm birth: Fact Sheet No.363*. Retrieved September 18, 2019, from http://www.who.int/mediacentre/factsheets/fs363/en/

World Health Organisation (WHO). (2020). *Infant and young child feeding.* Retrieved October 3, 2020, from https://www.who.int/news-room/fact-sheets/detail/infant-and-young-child-feeding

CHAPTER SIX: DISCUSSION

The participants, mothers of preterm infants, experienced the feeding of their infant as one of the most significant stressors related to caring for their infants, especially in the first months of life while the infant was hospitalised. This finding is reported frequently in the literature (Buys, 2020; Flacking et al., 2006; Swift & Scholten, 2009; Leonard & Mayers, 2008; Ericson & Palmér, 2019) and various factors are thought to contribute to feeding being such a challenging task. The most prominent contributor in this study was the strong association between successful oral feeding and discharge from the hospital. Participants described feeding as a progressive task that worked towards one goal, namely '*going home'*. HCPs expected infants to gain weight, to consume ever-increasing amounts of expressed breastmilk and eventually to breastfeed. The mothers thus formulated a clear recipe for discharge from hospital: present a breastfeeding infant with a weight of at least 1,8 kilograms. This strong association between successful oral feeding and discharge from hospital is perhaps a major cause of the anxiety surrounding feeding. Successful feeding results in discharge from hospital, while difficulty with feeding results in an extended hospital stay.

An important question to ask is why the mothers associated successful oral feeding so closely with discharge from hospital. According to Thoyre (2001), the intense monitoring associated with oral feeding within the hospital context explains why parents associate this task with discharge. Daily weight monitoring, the use of specified millilitres of expressed breastmilk, and breastfeeding were strongly encouraged by HCPs throughout the mothers' hospital stay. These practices are in line with the latest WHO and United Nation's Children Fund (UNICEF) guidelines that recommend that infants should be breastfed exclusively for the first six months of life. They can then continue breastfeeding for up to two years of age and beyond while consuming complementary foods (WHO, 2020). It is to be expected that HCPs will eagerly promote these practices to ensure infant health, survival, and eventual discharge from hospital. The way these health messages and practices are conveyed and presented to the mothers may, however, be problematic and show little consideration of the hardships mothers of preterm infants face when caring, and specifically feeding, their infant. Findings from this study, as well as the research literature, support this statement.

Firstly, the participants felt bombarded with the message that they must express breastmilk and supply specified amounts of breastmilk for their infant. They described feeling *'pushed'* and '*forced*' as if '*the whole thing is just milk, milk, milk'*. They also described feeling judged by nursing staff if they were unable to provide their infant with their milk as they were told that breastmilk would make their infant go home sooner than formula milk. These experiences are upsetting, as it is mostly anticipated that mothers of preterm infants, especially extremely and very preterm infants, will struggle with the initiation of lactation (McInnes & Chambers, 2008). Maintaining lactation is a further challenge as infants are often not yet able to breastfeed, the interaction between mother and infant is limited, and mothers experience high levels of stress during their hospital stay (Lee & Gould, 2009). Although the use of expressed breastmilk is advantageous to the infant and should be encouraged, it seems that the manner in which HCPs encouraged the mothers to express and provide breastmilk allowed little accommodation for the physiological and psychological challenges they faced due to

preterm birth. Secondly, the big focus on weight gain and the daily monitoring of weight made mothers feel anxious and hopeless. The infant's weight was seen as a numerical measure of their progress towards discharge and the daily monitoring, therefore, had a strong influence on maternal mental health.

These findings are aligned with what Thoyre (2001) describes as a volume-driven approach to feeding, where the efficiency of feeding is valued over the experience of feeding. Thus, the goal is to take all feeds orally before discharge from the hospital. The success of oral feeding is measured by the completion of oral feeds and weight gain rather than the quality of the feeding experience. Thoyre (2001) warns that this approach may result in mothers ignoring infant stress cues during feeding times, and feed even when the infant is not ready to complete the oral feed. Eventually, this may result in mothers who convert to bottle feeding and abandon breastfeeding after discharge from hospital. This risk of the volume-driven approach was evident in this study, as all study participants converted to bottle and formula feeding once they returned home. Some of the participants explained that this shift was due to their return to work, while others stated that this was either the infant's or their own preference. The finding of mothers of preterm infants converting to bottle and formula feeding once they return home is consistent with the findings of Buys (2020) who conducted a similar study amongst isiXhosa speaking mothers within the same research setting.

The way that HCPs package and convey messages regarding feeding to the mothers of preterm infants should be considered carefully. Consideration must be given to two aspects in particular, namely the challenges of being a mother of a preterm infant, and the method with which HCPs motivate these mothers to follow the prescribed feeding practices. Firstly, HCPs must adjust the packaging of their message to accommodate the unique hardships that the members of this vulnerable population encounter. The following hardships were highlighted in the current study and are also supported by literature: high stress levels (van Schalkwyk et al., 2020); difficulty with initiating and maintaining lactation (Lee & Gould, 2009; Ericson & Palmér, 2019); reduced feeding abilities of the infant (Crapnell et al., 2013); limited reciprocal interaction with their infant (Pascoe et al., 2016); and being in an unfamiliar hospital environment for prolonged periods with limited support (Swift & Scholten, 2009).

Secondly, HCPs must find creative ways to motivate mothers to use expressed breastmilk and to breastfeed their infant as prescribed by the WHO and UNICEF (WHO, 2020). Participants explained that breastmilk was promoted to them as '*the thing that is going to send us home the quickest'*. Perhaps it is necessary to ask whether HCPs are promoting breastmilk and its advantages, or whether they are promoting discharge from hospital. An important factor to consider in conjunction with this question is the shortage of resources in the South African public healthcare sector. According to Lloyd and de Witt (2013), there is a shortage of neonatal facilities and staff in district, regional, and provincial hospitals in South Africa. The limited availability of NICU, KMC, and nursery beds may pressurise HCPs to eagerly promote and '*push*' for infants' discharge from hospital. Promoting the use of breastmilk and breastfeeding by focusing on the inherent advantages versus focusing on an expedited discharge may produce different long-term outcomes in adhering to these practices. The first option may increase internal motivation to follow the prescribed health behaviours due to the

advantageous nature of breastmilk and breastfeeding. The second option, however, runs the risk of producing an intense short-term motivation to use breastmilk and breastfeed as a means to an end (discharge from hospital). This risk, in conjunction with the fact that mothers of preterm infants and the infants themselves have a high risk to struggle with breastfeeding (Thoyre, 2001), may explain why the use of bottle and formula feeding after discharge was a common finding in this as well as previous studies (Buys, 2020). HCPs have the challenging task of finding ways in which to promote evidence-based feeding practices to the mothers of preterm infants in a way that will ensure that they are motivated and committed to these practices. A question that deserves our attention is, how can HCPs encourage mothers of preterm infants to use breastmilk or to breastfeed, in a way that is sensitive towards their unique realities and preferences, and ensures their commitment to these practices? Recent international research trends (Ericson & Palmér, 2019; Gianní et al., 2018; Yang, Brandon, Lu & Cong, 2019) specify increased breastfeeding support from HCPs as the starting point for improving mothers' breastfeeding skills, confidence, and commitment. Yang et al. (2019) also identified the need for increased paternal and peer support to improve breastfeeding outcomes for the mothers of preterm infants. Ericson and Palmér (2019) highlight that breastfeeding support should be based on mothers' perspectives in order to allow them to breastfeed according to their own desires. This is congruent with the current study's recommendation of seeking ways to encourage mothers of preterm infants to breastfeed in a manner that accommodates their unique realities and preferences.

A further important question to ask is why mothers were so desperately longing to be discharged from the hospital and to go home. The participants experienced the hospital setting as stressful and therefore discharge from hospital was seen as a reward. This experience of '*the hospital is no one's home'* echoes the report by Buys (2020) who found that an isiXhosa group of low-income mothers of preterm infants experienced the hospital setting as stressful, while their experience of caring for a preterm infant in the home setting was more positive. The current study found that various factors influence maternal experiences of being hospitalised. Although participants mostly perceived the hospital as stressful, certain aspects of their hospital stay were perceived as '*good*' or '*necessary*'. This finding is supported by a vast amount of research exploring specific barriers and facilitators that hospitalisation might present to the parents of preterm infants (Crisp, 2006; Leonard & Mayers, 2008; Mcinroy & Kritzinger, 2005; Nicolaou et al., 2009; Flacking et al., 2006; Kritzinger & Louw, 2003; Swift & Scholten, 2009). Participants naturally divided the factors that influenced their experiences of being hospitalised into two categories, namely experiences of the general hospital environment and experiences of HCP attitudes. Firstly, participants experienced the hospital setting as unknown and highly controlled. They perceived fixed feeding schedules and caregiving routines as unnatural and felt that they were unable to use their infant's '*signals*' to guide their caregiving attempts. The experience of the hospital as unknown is placed into context by considering Swift and Scholten's (2009) statement that a setting such as the NICU is novel to the majority of mothers and thus the mothers of preterm infants are bound to feel unfamiliar and uncomfortable while hospitalised. The findings of a scoping review (van Schalkwyk et al., 2020) also reveal that hospitalisation poses a major barrier to natural interaction for the mother-infant dyad due to the controlled nature of the setting. Secondly, participants in the current study experienced some HCPs, especially

nursing staff, as strict and impatient. Participants felt that they were unable to ask for support with caregiving tasks more than once, and breastfeeding was specifically highlighted as a task with which they required more support. This finding raises concern if one considers the important role that nursing staff should play in supporting vulnerable mothers to confidently fulfil their motherly role during an uncertain period (Aagaard & Hall, 2008). Additionally, breastfeeding is one of the main goals of the mother-infant dyad during this period and support should be readily available to encourage mothers to breastfeed.

Various aspects of a mother's life (such as personal needs, social and economic circumstances) will inevitably be altered while they are in hospital with their infant. Although participants did not prominently discuss these changes as factors influencing their experience of the hospital setting, the anxiety brought about by being away from their familiar living and working conditions for a substantial period of time are fundamental to consider when trying to determine why mothers so desperately longed to be discharged from the hospital. The following factors may add to the maternal anxiety experienced whilst in hospital with their infant: failure to provide care and comfort to other children at home; fear of losing their employment and income; being away from their home and belongings for a prolonged period (Tehrani, Haghighi & Bazmamoun, 2012). Maternal stress holds the potential risk of influencing the preterm infant in two ways, firstly by transferring stress to the infant, and secondly by compromising the mother's ability to care for her infant. Therefore, identifying and addressing the factors that contribute to maternal anxiety whilst hospitalised with their preterm infant should be a priority of health care facilities offering care to mother-infant dyads.

Despite the negative experiences described above, the participants felt that being in the hospital also had certain advantages. Firstly, the availability of HCPs to assist with and demonstrate caregiving tasks was perceived as useful. This demonstrates the contrasting experiences that participants had with regard to the attitude of HCPs. While some HCPs had a negative influence on maternal experiences of being hospitalised (as discussed in the previous paragraph), other HCPs had a positive influence. This is consistent with the findings of a qualitative study involving mothers of preterm infants, which investigated their experiences of breastfeeding support in the first twelve months of life. The researchers concluded that the participants felt as if they were 'being thrown into a lottery' (Ericson & Palmér, 2019, p. 134) with regard to the support they received. They perceived the support they received as genuine support, inadequate support, or a combination of the two. Their perception of the support they received was dependent on the knowledge and support style of the individual HCPs who worked with the mother-infant dyad. The need for unvarying maternal support that accommodates the unique needs of the mother-infant dyad (Ericson & Palmér, 2019) is highlighted by this finding.

Secondly, mothers felt reassured that their infant was receiving the necessary medical intervention. It can also be speculated that mothers felt relieved that all the required medical interventions were done during their hospital stay, thereby potentially limiting the need to return to the hospital in future. This speculation was not explicitly mentioned by participants during the interviews but is plausible if one considers the access and financial difficulties associated with travelling to and from hospital.

Lastly, mothers explained that they were willing to endure hospitalisation, if it was what was best for their infant. Mothers were evidently able to recognize the advantages of being hospitalised for both themselves and their infant, despite being faced with a stressful and unfamiliar environment. Mothers' willingness to learn in this challenging environment has positive implications and provides HCPs with an opportunity to engage in preventative and health promotion work with this vulnerable group. Kritzinger and Van Rooyen (2014) state that SLTs should utilise this window period (admission to NICU or KMC units) to provide mothers with information regarding typical hearing and communication development, as well as to promote the use of breastmilk and breastfeeding. Information tailored to the preterm infant population such as developmental stages, stress signs, feeding support and communication cues (Pike et al., 2017) should also be provided to mothers before their return to underserved and often hard to reach communities.

The participants experienced breastfeeding as '*amazing*' and described this activity as a significant contributor to their maternal identity. They experienced breastfeeding as having both physiological and psychological advantages for mother and child. Physiologically, the breastfeeding mothers experienced an increase in milk production, an increase in infant weight gain, and a generally healthy infant. Mothers experienced that shortly after they started breastfeeding, they were discharged from hospital and this further supported their positive perception of breastfeeding. Psychologically, mothers experienced increased proximity, bonding, and communication with their infant during breastfeeding. Breastfeeding was the factor that helped this vulnerable group to feel they were actively fulfilling their maternal role, despite being hospitalised. These findings are ironic if one considers that despite these positive experiences, all the study participants still converted to bottle and formula feeding once they returned home. The reasons why mothers of preterm infants shift from breastfeeding to bottle and formula feeding once they are no longer hospitalised, despite their initial positive experiences in this regard, may be a useful future research focus.

Positive maternal experiences regarding breastfeeding and KMC provide HCPs, and specifically SLTs, with an opportunity to provide ECI tailored to the preterm mother-infant dyad. The participants described that they felt physically and emotionally closer to their infant while breastfeeding. Furthermore, breastfeeding was described as a special time between mother and infant where most communication occurred. Breastfeeding and KMC were closely associated with each other due to the corresponding timelines of these practices. Once the mother-infant dyad was moved from the NICU to a general ward where they had to practice KMC, breastfeeding was also initiated. Mothers consequently experienced KMC and breastfeeding as co-existing practices. KMC has been described as a useful vehicle for ECI in high-risk neonates and as the ideal opportunity to implement communication intervention programmes aimed at the vulnerable mothers of such neonates (SASLHA, 2017). Kritzinger and Van Rooyen (2014) state that KMC prepares mothers for communication intervention as they are naturally more sensitive towards their infant during this practice. This finding is echoed in the current study as mothers explained that during breastfeeding (and KMC) they experienced intimate and reciprocal interaction with their infant. The intimate nature of breastfeeding naturally lends itself to feelings of bonding and motherhood. These feelings should be promoted during all stages of the preterm infant's hospital stay and not only when the infant progresses to a general ward and breastfeeding.

While the infant is in the NICU and dependent on tube feeding or cup feeding, HCPs should strive to facilitate bonding, interaction, and positive feeding experiences between the mother and infant. This may be achieved by actively including mothers in caregiving tasks; encouraging mothers to interact with their infant; assisting mothers to be sensitive and responsive toward their infant's cues; and providing mothers with the opportunity to practice KMC whilst in NICU (SASLHA, 2017). The experience of fulfilling a motherly role, as described by participants while breastfeeding, should be actively sought and worked towards from the start of the preterm infant's hospitalisation. Implementing this recommendation has various short- and long-term advantages for both infant and mother. Pleasurable mother-infant interactions from birth will positively influence the infant's physical, psychological, behavioural, and developmental wellbeing immediately and in future (Winston & Chicot, 2016). Additionally, supporting mothers towards the positive feeling of motherhood will increase their emotional wellbeing as well as confidence to intuitively interact with and care for their infant.

The findings and discussion of this study contribute some potential answers to the 'whom, when, how' (SASLHA, 2017, p. 3) questions regarding ECI for preterm infants belonging to socially marginalised and disadvantaged groups in South Africa. Exploring maternal experiences of feeding their preterm infant in the first months of life provided the researcher with insight into the provision of (especially) feeding support to a vulnerable maternal population whilst in hospital. The following section gives some answers to the 'whom, when, how' (SASLHA, 2017) questions of providing ECI support for the first months of life, to the mothers of preterm infants with low SES who belong to linguistic minority groups:

Whom? The preterm infant and the mother should be viewed as equal intervention targets. Mothers should enjoy increased support from HCPs to be able to confidently and competently complete caregiving tasks, while also maintaining their emotional wellbeing.

When? ECI should be implemented from the start of the mother-infant dyad's hospital journey. The goals of ECI might differ when the infant is in the NICU versus in a KMC unit; however, ECI should not only be reserved for KMC units and breastfeeding mother-infant dyads.

How? ECI aimed at the preterm population should acknowledge and accommodate the unique hardships that the mothers of preterm infants living in low socio-economic settings encounter. With regard to feeding support, mothers should be optimally supported during each phase of their infant's feeding journey (tube feeding, cup feeding, and breastfeeding). This should include repeated, patient, and empathetic physical demonstrations of how to manage each feeding method, and provide a platform where mothers can freely ask for support.

During the interviews, one participant explained that while she was in hospital, she was dependent on her husband or other mothers in the ward to convey HCPs' messages regarding the infant to her as she has limited comprehension of complex English conversations. It can be deduced that the participant had two options with regard to receiving counselling about her preterm infant's condition, namely to wait until her husband was present (delaying receiving much anticipated information); or to ask a stranger to assist (potentially sharing sensitive and private information). This was the only experience where a participant mentioned language or

culture as an influencing factor with regard to caring for their preterm infant, albeit a powerful example of receiving 'monolingual health services in a multilingual society' (Elkington & Talbon, 2016). Afrikaans-speaking mothers of preterm infants with low SES may be viewed as a minority group that is poorly represented in our health care constitution and relevant research fields. Although Afrikaans is the most spoken language in the Western Cape, linguistic and particularly culture differences are likely to exist between mothers and some HCPs. Certain characteristics of preterm mother-infant dyads are universal and already well-known to HCPs, for example it is well-known that the experience of having and caring for a preterm infant is stressful to mothers. Communication, language, and culture are intertwined, however (Health Professions Council of South Africa [HPCSA], 2019), and consequently there are bound to be differences in perceptions regarding communication development, interaction styles, and various other aspects surrounding communication between and even within cultures. South Africa celebrates a variety of cultures and languages, and HCPs need context-specific knowledge regarding the characteristics and experiences of preterm mother-infant dyads from socially marginalised and minority groups. Limited knowledge is available in this regard, and knowledge generation is required to enable HCPs to provide contextually relevant care to the mothers of preterm infants from various cultures. HCPs should be aware, however, of the risk of generalising such knowledge and stereotyping vulnerable populations accordingly. Besides the generation and awareness of context-specific knowledge, HCPs are also required to develop a skill set that enables them to provide appropriate care to *individual* clients and caregivers. An example of such a skill is ethnographic interviewing which aims to provide the HCP with a clear comprehension of how individual patients experience and comprehend certain contexts, thereby assisting the HCP to identify patient-specific needs (Westby, Burda & Mehta, 2003).

Implications and Recommendations

Broad implications and recommendations were made and discussed in the preceding sections. Specific implications and recommendations will now be discussed concerning future research, HCP education, and clinical practice.

Future research

Three recommendations are relevant based on the findings of this study. Firstly, further research is required to establish more comprehensively the 'whom, when, how' (SASLHA, 2017, p. 3) of ECI for the preterm infant population. This is in line with the recommendation by SASLHA (2017) that further research regarding ECI in high-risk neonates from varying cultural and linguistic backgrounds should be conducted in South Africa. The current study provides preliminary information for planning ECI for the preterm population from low-resource environments based on maternal experiences of feeding their infant in the first months of life and specifically while hospitalised. It is important to acknowledge that the attainment of a universal 'whom, when, how' (SASLHA, 2017, p. 3) of ECI in preterm infants is not a suitable goal for the South African context. The planning and development of contextually relevant ECI services that accommodate the unique linguistic, cultural, personal, and environmental factors of the family seeking intervention (HPCSA, 2019) should be sought actively through conducting further research. Therefore, this recommendation also adheres to the

recommendation by HPCSA (2019) to take steps to urgently address the need for research into speech-language development and difficulties in the local context, as well as relevant research that focuses on cultural and linguistic diversity.

Secondly, the reasons why mothers of preterm infants commonly stop breastfeeding and start bottle and formula feeding once in the home setting should be further explored. This may assist HCPs and other role players to develop a better understanding of how realistic and sustainable breastfeeding recommendations, as prescribed by the WHO and UNICEF (WHO, 2020), are to a population at-risk to struggle with breastfeeding. A thorough understanding of maternal perceptions will be a significant part of the relevant information.

Thirdly and related to the previous recommendation, seeking effective methods to promote the use of breastmilk and breastfeeding amongst mothers of preterm infants living in low socio-economic settings will be useful. These methods should aim to internally motivate this vulnerable group to follow the prescribed feeding practices while still accommodating the unique hardships they encounter.

HCP Education

The training of HCPs should focus on developing appropriate attitudes when working with preterm mother-infant dyads from diverse cultural and linguistic backgrounds. This includes cultural awareness, cultural sensitivity, cultural competence, and cultural humility (HPCSA, 2019). Education and training programmes should strive to develop HCPs that are motivated to seek the knowledge and skills of cultural competence, and to commit to improving their cultural competence through continued professional development (HPCSA, 2019). The research recommendation of building context-specific knowledge regarding the experiences of mothers of preterm infants applies to HCPs training; however, the generation of such knowledge is time-consuming and an endless process as cultures and languages are not static. Additionally, this recommendation runs the risk of creating cultural stereotypes which may further disadvantage marginalised groups. It is therefore important that the focus of HCP education is also on developing appropriate attitudes and skills, such as ethnographic interviewing skills, when working with mother-infant dyads from diverse backgrounds (Penn, 2014).

Clinical Practice

Five recommendations are relevant to adjust the way HCPs (including SLTs) are currently approaching ECI, and specifically feeding support, with this vulnerable group. Firstly, increased awareness and acknowledgement is required of the unique challenges the mothers of preterm infants from low socio-economic settings face. Secondly, HCPs should increase their focus on mothers as an equally important receiver of intervention while the mother-infant dyad is hospitalised. Thirdly, creative ways should be considered to provide emotional support and protect the mental health of these mothers while their infants are hospitalised. Potential ideas include in-hospital support groups; a system to flag mothers at risk of mental illness; and access to a counsellor, social worker, or psychologist if needed. Fourthly, bonding and the attainment of a maternal identity should be encouraged during all stages of the preterm infant's hospital stay and not only when the

infant can progress to a KMC unit and breastfeeding. This can be achieved by actively including mothers in all caregiving tasks, especially feeding tasks, from the start of the infant's journey in the NICU. Lastly, messages to encourage mothers to express breastmilk and to breastfeed should be focused on the advantageous nature of these practices for mother and child, rather than an expedited discharge.

Limitations

During the pilot study, the birthweights of the infants were specified as lower than 2500 gm (as part of the inclusion criteria) and the researcher did not record the exact birthweights. During the main study, the exact birthweights were recorded to classify infants as LBW, VLBW or ELBW. This allowed the researcher to provide a more detailed description of the preterm infants included in the study sample. This difference in recording the birthweight between the pilot study and the main study is a methodological discrepancy. The researcher is therefore able to provide only a limited description (gestational age only) of the preterm infants included in the pilot study and a more detailed description (gestational age and birth weight) of the preterm infants included in the main study. The study contributes to our knowledge of the experiences of poor Afrikaans-speaking mothers with regard to caring (specifically feeding whilst hospitalised) for their preterm infant. This contribution is specific to the population and the context specified. The findings of the study cannot and should not be transferred to the mothers of preterm infants from all cultures and/or socio-economic statuses. Some experiences of having and caring for a preterm infant will be shared across cultures and SESs. As discussed earlier in the chapter, the attainment of a universal 'whom, when, how' (SASLHA, 2017, p. 3) of ECI in preterm mother-infant dyads is not appropriate in a multicultural South Africa. Thus, the limited transferability of the study to other populations and contexts is not considered a significant limitation. Finally, all participants received in-patient care at the same public tertiary hospital in the Western Cape. Maternal experiences of caring for a preterm infant may differ according to the setting where they receive care, for example at a secondary versus a tertiary health care facility. The findings of the study are therefore not transferable to all health care facilities providing in-patient care to preterm mother-infant dyads in the Western Cape, or elsewhere in the country.

Strengths

The strengths of the study were identified and discussed throughout the methodology chapter. The following points summarise the most significant strengths:

- The researcher was responsible for conducting and transcribing all the interviews and thus had frequent interaction with the data in its various forms, thereby ensuring good familiarisation.
- The accuracy and quality of the transcriptions were confirmed approved by a doctoral Speech-Language Therapy student.
- The researcher attended two courses on qualitative research methodology during the time of the study.

- The pilot study was thoroughly considered and reviewed by the researcher, the research supervisor and an expert before commencing with the main study.
- The interviews yielded authentic and detailed narratives of the participants' experiences of caring for their preterm infant in the first few months of life.
- The presentation of the study findings and discussion were guided by the participants' experiences. Thus, feeding was explored in depth as this was a prominent point of discussion during all the interviews.
- The methodology is described comprehensively and explicitly. This allows for study replication and provides the reader with a clear lens through which to read and interpret the study.

REFERENCE LIST

Aagaard, H., & Hall, E. O. (2008). Mothers' experiences of having a preterm infant in the neonatal care unit: a meta-synthesis. *Journal of pediatric nursing*, 23(3), e26–e36. https://doi.org/10.1016/j.pedn.2007.02.003

Abrahams, N., Jewkes, R., Martin, L. J., Mathews, S., Vetten, L., & Lombard, C. (2009). Mortality of women from intimate partner violence in South Africa: a national epidemiological study. *Violence and victims*, *24*(4), 546-556.

Alant, E., & Lloyd, L. (Eds.). (2005). *Augmentative and alternative communication and severe disabilities: Beyond poverty*. John Wiley & Sons Incorporated.

Alhusen, J. L., Hayat, M. J., & Gross, D. (2013). A longitudinal study of maternal attachment and infant developmental outcomes. *Archives of women's mental health*, *16*(6), 521-529.

Ali, A. M., & Yusof, H. (2012). Quality in qualitative studies: The case of validity, reliability and generalisation. *Issues in Social and Environmental Accounting*, *5*(1/2), 25–64. Retrieved 22 June, 2020, from http://www.iiste.org/Journals/index.php/ISEA/article/view/952

American Speech-Language-Hearing Association [ASHA]. (2008). *Roles and responsibilities of speech-language pathologists in early intervention: Position Statement*. Retrieved 6 July, 2020, from www.asha.org/policy

Berry, L., Biersteker, L., Dawes, A., Lake, L., & Smith, C. (2013). *South African child gauge*. Cape Town: Children's Institute, University of Cape Town. Retrieved 4 August, 2020, from http://ci.org.za/depts/ci/pubs/pdf/general/gauge2014/ChildGauge2014_ibcover.pdf

Beuker, K., Rommelse, N., Donders, R., & Buitelaar, J. (2013). Development of early communication skills in the first two years of life. *Infant Behavior and Development*, *36*(1), 71-83. Retrieved 11 November 2019, from http://dx.doi.org/10.1016/j.infbeh.2012.11.001

Blencowe, H., Cousens, S., Oestergaard, M., Chou, D., Moller, A.B., Narwal, R., Adler, A., Vera Garcia, C., Rohde, S., Say, L. & Lawn, J. (2012). National, regional and worldwide estimates of preterm birth rates in the year 2010 with time trends for selected countries since 1990: a systematic analysis. *The Lancet*, 379(9832), 2162-72. doi: 10.1016/S0140-6736(12)60820-4

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, *3*(2), 77-101.

Brockmeyer Cates, C., Dreyer, B.P., Berkule, S.B., White, L.J., Arevalo, J.A., & Mendelsohn, A.L. (2012). Infant communication and subsequent language development in children from low income families:

The role of early cognitive stimulation. *Journal of Developmental and Behavioural Paediatrics*, 33(7), 577–585. doi:10.1097/DBP.0b013e318264c10f.

Brown, N. C., Inder, T. E., Bear, M. J., Hunt, R. W., Anderson, P. J., & Doyle, L. W. (2009). Neurobehavior at term and white and gray matter abnormalities in very preterm infants. *The Journal of pediatrics*, *155*(1), 32-38.

Buys, K. H. S. (2020). *Maternal experiences of prematurity, feeding and infant communication within a vulnerable population in South Africa*. Unpublished Master's Thesis. Stellenbosch: Stellenbosch University.

Clark, B., & Preto, N. (2018). Exploring the concept of vulnerability in health care. *CMAJ*, *190*(11), 308-309.

Craig, J.W., Glick, C., Phillips, R., Hall, S.L., Smith, J. & Browne, J. (2015). Recommendations for involving the family in developmental care of the NICU baby. *Journal of Perinatology*, *35*, 5-8. doi:10.1038/jp.2015.142.

Crapnell, T. L., Rogers, C. E., Neil, J. J., Inder, T. E., Woodward, L. J., & Pineda, R. G. (2013). Factors associated with feeding difficulties in the very preterm infant. *Acta Paediatrica*, *102*(12), 539-545.

Creswell, J. W., Klassen, A. C., Plano Clark, V. L., & Smith, K. C. (2011). Best practices for mixed methods research in the health sciences. *Bethesda (Maryland): National Institutes of Health*, *2013*, 541-545.

Creswell, J.W. (2007). *Qualitative Inquiry and Research Design: Choosing amongst five approaches.* Lincoln, Nebraska.

Crisp, L. (2006). *The communicative opportunities afforded parents of premature infants who had graduated from a Neonatal Intensive Care Unit (NICU)*. Doctoral dissertation, Stellenbosch University. Retrieved 25 June 2019, from http://web.b.ebscohost.com.ez.sun.ac.za/ehost/detail/detail?vid=5&sid=17c35f4a-8ace-4708-994b-79667adb7e58%40sessionmgr104&bdata=JnNpdGU9ZWhvc3QtbGl2ZSZzY29wZT1za XRl#AN=NX0153264&db=awn

Darcy, A. E. (2009). Complications of the late preterm infant. *The Journal of perinatal & neonatal nursing*, *23*(1), 78-86.

Davy, K., Bergh, A., & Van Rooyen, E. (2011). The neonatal nurse's role in kangaroo mother care: mother and child health. *Professional Nursing Today*, *15*(3), 32-37.

Dawes, A, Biersteker, L. and Irvine, M. (2008). What makes a difference to child outcomes in the period 0–4? *Inputs for quality ECD interventions: Scaling up ECD 0–4 years in South Africa*. Cape Town: HSRC

Dodrill, P., McMahon, S., Ward, E., Weir, K., Donovan, T., & Riddle, B. (2004). Long-term oral sensitivity and feeding skills of low-risk pre-term infants. *Early human development*, *76*(1), 23-37.

Elkington, E. J., & Talbot, K. M. (2016). The role of interpreters in mental health care. *South African Journal of Psychology*, *46*(3), 364-375.

Ericson, J., & Palmér, L. (2019). Mothers of preterm infants' experiences of breastfeeding support in the first 12 months after birth: A qualitative study. *Birth*, *46*(1), 129–136. https://doi.org/10.1111/birt.12383

Ertem, I.O., Atay, G., Dogan, D.G., Bayhan, A., Bingoler, B.E., Gok, C.G., et al. (2007). Mothers' knowledge of young child development in a developing country, *Child: Care, Health, Development*, 33(6), 728-737.

Fegran, L., Helseth, S., & Fagermoen, M. S. (2008). A comparison of mothers' and fathers' experiences of the attachment process in a neonatal intensive care unit. *Journal of clinical nursing*, *17*(6), 810-816.

Feldman, R., Eidelman, A. I., Sirota, L., & Weller, A. (2002). Comparison of skin-to-skin (kangaroo) and traditional care: parenting outcomes and preterm infant development. *Paediatrics*, *110*(1), 16-26. Retrieved from: https://www.ncbi.nlm.nih.gov/pubmed/12093942

Flacking, R., Ewald, U., Nyqvist, K. H., & Starrin, B. (2006). Trustful bonds: a key to "becoming a mother" and to reciprocal breastfeeding. Stories of mothers of very preterm infants at a neonatal unit. *Social Science and Medicine*, *62*(1), 70-80. Doi: 10.1016/j.socscimed.2005.05.026

Geertz, C. (1973). Thick description: Toward an interpretive theory of culture. *The interpretation of cultures: Selected essays*. New York: Basic Books.

Gianni, M. L., Bezze, E. N., Sannino, P., Baro, M., Roggero, P., Muscolo, S., et al. (2018). Maternal views on facilitators of and barriers to breastfeeding preterm infants. *BMC pediatrics*, *18*(1), 283.

Golafshani, N. (2003). Understanding reliability and validity in qualitative research. *The Qualitative Report*, 8(4), 597–607. Retrieved 3 May 2020, from http://www.nova.edu.

Goldenberg, R.L., Culhane, J.F., Iams, J.D. and Romero, R. (2008). Preterm birth 1: epidemiology and causes of preterm birth, *Lancet*, 371, 75-84.

Good Governance Learning Network (GGLN). (2014). *Putting participation at the heart of development / putting development at the heart of participation*. Retrieved August 4, 2020, from https://www.salga.org.za/Documents/Knowledge%20Hub/Good%20Governance%20Learning%20Network/GGLN-State-of-Local-Governance-Publication_2012.pdf

Graafmans, W. C., Richardus, J. H., Macfarlane, A., Rebagliato, M., Blondel, B., Verloove-Vanhorick, S. P., et al. (2001). Comparability of published perinatal mortality rates in Western Europe: the quantitative

impact of differences in gestational age and birthweight criteria. *BJOG: An International Journal of Obstetrics & Gynaecology*, *108*(12), 1237-1245.

Green, S. L., & Phipps, W. D. (2015). Interactional pattern analysis of mother-baby pairs: Kangaroo mother care versus incubator care. *South African Journal of Psychology*, *45*(2), 194-206. Doi: 10.1177/0081246314565961

Hagen, I. H., Iversen, V. C., & Svindseth, M. F. (2016). Differences and similarities between mothers and fathers of premature children: a qualitative study of parents' coping experiences in a neonatal intensive care unit. *BMC pediatrics*, *16*(1), 92.

Health Professions Council of South Africa (HPCSA), Professional Board for Speech, Language and Hearing Professions. (2019). *Guidelines for Practice in a Culturally and Linguistically Diverse South Africa.* Retrieved September 26, 2020, from https://www.hpcsa.co.za/Uploads/SLH/Guidelines%20for%20practice%20in%20a%20culturally%20and%20linguistically%20divers---.pdf

Huang, K., O'Brien Caughy, M., Genevro, J.L. & Miller, T.L. (2005). Maternal knowledge of child development and quality of parenting. *Applied Developmental Psychology*, 26, 149-170.

Huddy, C. L. J., Johnson, A., & Hope, P. L. (2001). Educational and behavioural problems in babies of 32–35 weeks gestation. *Archives of Disease in Childhood - Fetal and Neonatal Edition*, *85*(1), F23-F28.

Hussey, N. (2013). The language barrier: the overlooked challenge to equitable health care: Emerging Public Health Practitioner Awards. *South African health review*, *2012*(1), 189-195.

Kathard, H., & Pillay, M. (2013). Promoting change through political consciousness: A South African speech-language pathology response to the World Report on Disability. *International Journal of Speech-Language Pathology, 15*(1), 84-89.

Kerstjens, J.M., de Winter, A.F., Bocca-Tjeertjes, I.F., Bos, A.F. & Reijneveld, S.A. (2012). Risk of developmental delay increases exponentially as gestational age of preterm infants decreases: a cohort study at age 4. *Developmental Medicine & Child Neurology*, 54(12), 1096-1101.

Kritzinger, A., & Van Rooyen, E. (2014). The effect of formal, neonatal communication-intervention training on mothers in kangaroo care. *African Journal of Primary Health Care & Family Medicine*, *6*(1), 1-9. Doi: https://doi.org/10.4102/phcfm.v6i1.675 |

Kritzinger, B., & Louw, A. (2003). Clinical training of undergraduate communication pathology students in neonatal assessment and neonate-caregiver interaction in South Africa. *South African Journal of Communication Disorders, 50*(1), 5-14. Doi: http://journals.co.za/content/communication/50/1/AJA03798046_644

Laborde, D., Martin, W., & Vos, R. (2020). Poverty and food insecurity could grow dramatically as COVID-19 spreads. *International Food Policy Research Institute (IFPRI), Washington, DC*.

Lawn, J. E., Cousens, S. N., Darmstadt, G. L., Bhutta, Z. A., Martines, J., Paul, V., et al. (2006). 1 year after The Lancet Neonatal Survival Series—was the call for action heard? *The Lancet*, *367*(9521), 1541-1547.

Lee, H. C., & Gould, J. B. (2009). Factors influencing breast milk versus formula feeding at discharge for very low birth weight infants in California. *The Journal of pediatrics*, *155*(5), 657-662.

Leonard, A., & Mayers, P. (2008). Parents' lived experience of providing Kangaroo Mother Care to their preterm infants. *Health SA Gesondheid*, 13 (4), 16-28.

Levin, M. E. (2006). Language as a barrier to care for Xhosa-speaking patients at a South African paediatric teaching hospital. *South African Medical Journal*, *96*(10), 1076-1079.

Lewis, M. P., Simons, G. F., & Fennig, C. D. (2016). *Ethnologue: Languages of the world* (Nineteenth Edition). Dallas, TX: SIL International.

Lloyd, L.G., & de Witt, T.W. (2013). Neonatal mortality in South Africa: How are we doing and can we do better? *South African Medical Journal*, *103*(8), 518-519. Retrieved September 29, 2020, from http://www.scielo.org.za/scielo.php?script=sci_arttext&pid=S0256-95742013000800017&lng=en&tlng=en.

Machisa, M., & van Dorp, R. (2012). *The Gender Based Violence Indicators Study: Botswana*. African books collective.

Malterud, K., Siersma, V.D. and Guassora, A.D. (2016). Sample Size in Qualitative Interview Studies: Guided by Information Power. *Qualitative Health Research, 26*, 1753-1760. https://doi.org/10.1177/1049732315617444

McInnes, R. J., & Chambers, J. A. (2008). Supporting breastfeeding mothers: qualitative synthesis. *Journal of advanced nursing*, *62*(4), 407-427.

McInroy, A., & Kritzinger, A. (2005). A single case study of the communication development of a high-risk neonate from birth to discharge from a neonatal intensive care unit. S*outh African Journal of Communication Disorders*, *52*(1), 25-53. Retrieved 3 May, 2020, from https://www.ncbi.nlm.nih.gov/pubmed/17902399

Medoff-Cooper, B., & Ratcliffe, S. J. (2005). Development of preterm infants: feeding behaviors and brazelton neonatal behavioral assessment scale at 40 and 44 weeks' postconceptional age. *Advances in Nursing Science*, *28*(4), 356-363.

Mercer, R. T. (2004). Becoming a mother versus maternal role attainment. *Journal of nursing scholarship*, *36*(3), 226-232.

Mgoqi, M. (2017). *Nurses' experiences on the use of Afrikaans for nursing documentation and handovers at a central hospital in the Western Cape*. Unpublished Doctoral dissertation. Stellenbosch University.

Miles, M. S., & Holditch-Davis, D. (1995). Compensatory parenting: how mothers describe parenting their 3-year-old, prematurely born children. *Journal of Pediatric Nursing*, *10*(4), 243-253.

Minde, K. (2002). Prematurity and serious medical conditions in infancy: Implications for development, behavior, and intervention. In: Zeanah CH (ed.). *Handbook of Infant Mental Health*. The Guilford Press; New York: 2000. pp. 176–194.

Nicolaou, M., Rosewell, R., Marlow, N., & Glazebrook, C. (2009). Mothers' experiences of interacting with their premature infants. *Journal of Reproductive and Infant Psychology*, *27*(2), 182-194. Doi: https://doi.org/10.1080/02646830801922796

Oruche, U. M., Gerkensmeyer, J., Stephan, L., Wheeler, C. A., & Hanna, K. M. (2012). The described experience of primary caregivers of children with mental health needs. *Archives of Psychiatric Nursing*, *26*(5), 382-391.

Pascoe, M., Bissessur, D., & Mayers, P. (2016). Mothers' perceptions of their premature infant's communication: A description of two cases. *Health SA Gesondheid (Online)*, *21*(1), 143-154. Doi: 10.4102/hsag.v21i0.945

Pattinson, R.C., Bergh, A.M., Malan, A.F., & Prinsloo, R. (2006). Does kangaroo mother care save lives? *Journal of Tropical Pediatrics*, *52*(6), 438-441.

Patton, M. Q. (2002). Two decades of developments in qualitative inquiry: A personal, experiential perspective. *Qualitative social work*, *1*(3), 261-283.

Penn, C. (2007). Factors affecting the success of mediated medical interviews in South Africa. *Current Allergy & Clinical Immunology*, *20*(2), 66-72.

Penn, C. (2014). Asking new questions and seeking new answers: The reality of aphasia practice in South Africa. *Topics in language disorders*, *34*(2), 168-181.

Penn, C., & Watermeyer, J. (2018). *Communication across cultures and languages in the health care setting: Voices of care*. London: Palgrave Macmillan.

Petrou, S. (2005). The economic consequences of preterm birth during the first 10 years of life. *BJOG: An International Journal of Obstetrics & Gynaecology*, *112*, 10-15.

Pike, M., Kritzinger, A., & Krüger, E. (2017). Breastfeeding characteristics of Late-preterm infants in a Kangaroo Mother Care Unit. *Breastfeeding medicine*, *12*(10), 637-644.

Plüddemann, P., Braam, D., Broeder, P., Extra, G. & October, M. (2004). Language Policy Implementation and Language Vitality in Western Cape Primary Schools. *PRAESA Occasional papers, (15)*:1-64.

Polkinghorne, D. E. (1989). Phenomenological research methods. In *Existential-phenomenological perspectives in psychology* (pp. 41-60). Springer, Boston, MA.

Potjik, M.R., Kerstjens, J.M., Bos, A.F., Reijneveld, S.A. & de Winter, A.F. (2013). Developmental Delay in Moderately Preterm-born Children with Low Socio-economic status: Risks Multiply. *Journal of Pediatrics*, *163*(5), 1289-1295.

Pramitasari, P. A., Sidiartha, I. G. L., & Pratiwi, I. G. A. P. E. (2019). The effect of storage on energy, carbohydrate, fat, and protein content of breast milk. *Parity*, *1*(13), 48-1.

Rosa, E. M., & Tudge, J. (2013). Urie Bronfenbrenner's theory of human development: Its evolution from ecology to bioecology. *Journal of Family Theory & Review*, *5*(4), 243-258.

Rossetti, L. M. (2001). *Communication Intervention: Birth to Three, 2nd ed.* Clifton Park, NY: Delmar.

South African Speech-Language-Hearing Association (SASLHA) Ethics and Standards Committee. (2017). *Practice Guidelines for Audiologists and Speech-Language Therapists in Early Communication Intervention*. Retrieved 4 August 2020, from www.saslha.co.za

South African Speech-Language-Hearing Association (SASHLA). (2011b). *Guidelines: Early communication intervention*. Retrieved June 13, 2020 , from www.saslha.co.za

Statistics South Africa. (2017). *Poverty on the Rise in South Africa P10334*. Census 2015. Pretoria: Statistics South Africa. http://www.statssa.gov.za/?p=10334

Strasheim, E., Kritzinger, A., & Louw, B. (2011). The development of a neonatal communication intervention tool. *South African Journal of Communication Disorders*, *58*(1), 13-18.

Swift, M. C., & Scholten, I. (2009). Not feeding, not coming home: parental experiences of infant feeding difficulties and family relationships in a neonatal unit. *Journal of Clinical Nursing*, *19*(1-2), 249-258. Doi: https://doi.org/10.1111/j.1365-2702.2009.02822.x

Tanner, A. (2010). The effects of premature birth on language development. *Research Papers.* Paper 250. Available online at http://opensiuc.lib.siu.edu/gs_rp/250

Tehrani, T., Haghighi, M., & Bazmamoun, H. (2012). Effects of stress on mothers of hospitalised children in a hospital in iran. *Iranian journal of child neurology*, *6*(4), 39–45.

Thoyre, S.M. (2001). Challenges mothers identify in bottle feeding their preterm infants. *Neonatal Network, 20*(1), 41‑50.

van Schalkwyk, E., Gay, S., Miller, J., Matthee, E., & Gerber, B. (2020). Perceptions of mothers with preterm infants about early communication development: A scoping review. *South African Journal of Communication Disorders*, *67*(1), 1-8.

Viviers, M., Kritzinger, A., & Vinck, B. (2016). Development of a clinical feeding assessment scale for neonates in South Africa**.** *South African Journal of Communication Disorders 63*(1), 148. http://dx.doi.org/10.4102/sajcd.v63i1.148

Von Fintel, M. (2015). *Social mobility and cohesion in post-apartheid South Africa*. Unpublished Doctoral dissertation. Stellenbosch: Stellenbosch University.

Waisel D. B. (2013). Vulnerable populations in healthcare. *Current opinion in anaesthesiology*, *26*(2), 186–192. https://doi.org/10.1097/ACO.0b013e32835e8c17

Wang, ML., Dorer, D.J, Fleming, M.P. & Catlin, E.A. (2004). Clinical outcomes of near-term infants. *Pediatrics*, 114(2), 372-376.

Ward, R. M., & Beachy, J. C. (2003). Neonatal complications following preterm birth. *BJOG: An International Journal of Obstetrics & Gynaecology*, *110*, 8-16.

Watt, N., Wetherby, A., & Shumway, S. (2006). Prelinguistic predictors of language outcome at 3 years of age. *Journal of Speech, Language, and Hearing Research*, 49, 1224–1237. doi:10.1044/1092-4388(2006/088)

Westby, C., Burda, A., & Mehta, Z. (2003). Asking the right questions in the right ways: strategies for ethnographic interviewing. *The ASHA Leader, 8*(8). https://doi.org/10.1044/leader.FTR3.08082003.4

Williams, M., & Bekker, S. (2008). Language policy and speech practice in Cape Town: An exploratory public health sector study. *Southern African Linguistics and Applied Language Studies*, *26*(1), 171-183.

Winston, R., & Chicot, R. (2016). The importance of early bonding on the long-term mental health and resilience of children. *London Journal of Primary Care (Abingdon)*. 2016; 8(1): 12–14. Published online 2016 Feb 24. doi: 10.1080/17571472.2015.1133012

World Health Organisation (WHO). (2017). *Preterm birth: Fact Sheet No.363*. Retrieved September 18, 2019, from http://www.who.int/mediacentre/factsheets/fs363/en/

World Health Organisation (WHO). (2018). *Preterm birth.* Retrieved June 30, 2019, from https://www.who.int/news-room/fact-sheets/detail/preterm-birth

World Health Organisation (WHO). (2020). *Infant and young child feeding.* Retrieved October 3, 2020, from https://www.who.int/news-room/fact-sheets/detail/infant-and-young-child-feeding

Yang, Y., Brandon, D., Lu, H., & Cong, X. (2019). Breastfeeding experiences and perspectives on support among Chinese mothers separated from their hospitalised preterm infants: a qualitative study. *International breastfeeding journal*, *14*(1), 1-7.

APPENDIX A: BUYS'S (2020) QUESTIONNAIRE

A. Biographical Information: Not on voice-recording

Date:

Setting:

Mother's information:

Name:

Surname:

Birth date:

Age at the birth of her first child:

Number and ages of children:

Were there any other children born prematurely?

If yes, at what age, complications etc:

File number:

Home address:

Type of housing:

No. of people living in the house, and whom:

Are there other people or family members that help with caregiving?:

Other preterm children?

- if so, what was the gestational age, health and developmental status.

Highest level of education achieved:

SES bracket (TBH classification):

Marital status:

What language/s are spoken at home:

Language(s) spoken with child:

Language of interview:

Ethnic/cultural group:

Home environment:

Infant information:

Date of birth:

Age at time of interview:

Gestational age at birth:

Other relevant medical history:

The following discussion consists of core areas that centre around each research aim, with possible prompting questions that may be used to introduce the topic or gather more specific information.

B. Perceptions of prematurity

1. This is a premature baby. Tell me what that means for you?
2. What do you believe was that reason for the baby to come early?
3. What do you believe the difference between a baby that is born early and a baby that is born at the usual time?
    a. Do you have worries about the way that your baby will grow and learn new things (development)?

C. Experiences of giving birth prematurely and caring for a preterm infant

4. Tell me about what was most difficult for you to have a premature baby?
    a. *If the mother has previously had full-term children - How did the prematurity change the way you cared for your baby?
    b. How did you feel when you found out that you were going to have your baby early?
    c. How did you feel when you could take your baby home from the hospital?
    d. Did you get any information or support while you were at the hospital (KMC?)
5. Tell me about how are you doing/coping now?
    a. What is difficult for you in caring for this baby?
    b. What do you enjoy about caring for this baby?

D: Communication and interaction:

6. Tell me about how you and your baby interact
    a. Do you talk to your baby?
    b. How do you place your baby when you talk to him or her? (where, how)
    c. Care-taking moments (nappy changes, bathing)
    d. How do you spend your day?
    e. What does your baby do when you talk to him/her?
    f. Tell me about your baby's communication
    g. How does your baby communicate with you?
    h. E.g. how does your baby tell you that they are hungry or needs something? (nappy change –
    i. Are the communications different for the different needs? (or different cries)
    j. Does your baby smile
    k. How do others communicate with your baby

7. What do you think will be the next things that your baby will learn to do?
    a. When do you believe your baby will learn to sit
    b. When do you believe your baby will learn to walk
    c. What do you think your baby will start making sounds that sound like the sounds we make, for example 'ba'.
    d. When do you think your baby will say his/her first word?
8. Do you think that being born early will affect/change anything with the baby's communication (talking)?

E. Roles

9. What do you believe are your most important roles in your child's life?
10. Who else are very important people in your child's life?
11. What roles do you feel you play in helping your child develop their communication skills?

F. Feeding

12. Tell me about your baby's feeding?
    a. Is your baby breastfed or bottle fed?
    b. Was your baby fed through a tube in the hospital? – do you know why?
    c. When you started to feed your baby, what was hard for you?
        i. Why?
        ii. what or who did you need to make this feeding easier?
13. (if they had a child previously: How was feeding your small baby different?

G. Other

14. If you think back to when you left hospital for the first time with your baby, what information do you think you needed to help you at home with the baby?
15. How would you have liked this information?
    Prompts: a pamphlet with pictures? A small book? A DVD/CD? A website? An app? What would have worked the best for you?
16. Where do you find information about your baby's development?
    Prompts: who do you ask when you want to know something about your baby's development
    What do you do when you want to find out something about your baby's development?
    Prompts: who you you ask? Where do you look for information?

This questionnaire was developed after a review of the available materials as well as materials used in preveous studies. Information was taken largely from the Rosetti-Infant Toddler Scale, Pascoe, Bissessur & Mayers' study, and Ertem et al.'s study.

Ertem, I.O., Atay, G., Dogan, D.G., Bayhan, A., Bingoler, B.E., Gok, C.G., Ozbas, D., Haznedaroglu, D. & Isikli, S. (2007). Mothers' knowledge of young child development in a developing country, *Child: Care, Health, Development*, 33(6), 728-737.

Pascoe, M., Bissessur, D. & Mayers, P. (2016). Mothers' perceptions of their premature infant's communication: A description of two cases. *Health SA Gesondheid, 21*, 143-154.

Rossetti, L. M. (1990). *The Rosetti Infant-Toddler Language Scale: A Measure of Communication and Interaction*. East Moline, IL: LinguiSystems.

APPENDIX B: DISCUSSION SCHEDULE

(Please note that this section will be in Afrikaans only as this is the language that was used during the interviews)

Inleidende vraag: Algemene ervaring

Vertel my meer oor u ervaring as die moeder van ‘n premature baba?

Afdeling 1: Prematuriteit

U baba is prematuur gebore. Wat beteken dit vir u?

Opvolg: rede / verskille van voltermyn baba

Afdeling 2: Sorggewing

Vertel my meer van u ervaring om ‘n premature baba te hê en te versorg?

Opvolg: aanvanklik / huidiglik / aanpassings nodig

Afdeling 3: Kommunikasie (Interaksie)

Vertel my meer oor u interaksies (defineer: gesels, speel, boodskappe uitruil) met u baba?

Opvolg: moeder se pogings (hoe en wanneer) / baba se respons / baba se pogings (hoe en wanneer) / moeder se respons / verskille van voltermyn baba / struikelblokke (maak dit moeilik) / fasiliteerders (maak dit maklik)

Afdeling 4: Voeding

Vertel my meer oor u baba se voeding?

Opvolg: metode / ervaring: goed, sleg, moeilik, maklik / verskille van voltermyn baba

Afdeling 5: Moederlike rol/verantwoordelikhede

U is die moeder van hierdie baba. Wat beteken hierdie rol vir u?

Opvolg: verantwoordelikhede (wat moet u vir u baba doen) / verantwoordelikhede wat slegs u kan vervul

Afdeling 6: Addisionele rolspelers

Vertel my meer van die ander persone wat belangrik is in u baba se lewe?

Opvolg: verantwoordelikhede teenoor baba / verantwoordelikhede teenoor u

Afdeling 7: Inligtingsbehoeftes

As u terug dink aan die afgelope paar maande vanaf u baba se geboorte – vertel my meer oor die tipe inligting/hulp wat die proses vir u makliker sou maak?

Opvolg: formaat van inligting / deur wie oorgedra / huidige inligtingsbronne (waar, wie, hoe)

APPENDIX C: EXAMPLE OF TRANSCRIPT

MAIN STUDY PARTICIPANT FIVE (M5)

23/10/2019, 12:15 pm

Interviewer = I, Participant = P

The interview commenced 12:15 pm on 23/10/2019 in a private and quiet consulting room in Tygerberg Hospital next to the High Risk Clinic (HRC) following the P's follow-up appointment with a paediatrician. The P was selected as she is an Afrikaans speaking mother of a preterm infant between three and six months of age. The necessary ethical information was provided to the P in verbal and written formats and consent was obtained. The P and the infant were present during the interview. The infant was in a calm-alert state and no interruptions occurred during the interview which lasted for approximately 35 minutes. The P is a 36-year-old female with two children in total. This includes a 17-year-old boy and a six month-old boy. The last mentioned was born very preterm at 29 weeks with a very low birth weight of 1000 gram. The mother-infant dyad was hospitalised for approximately a month and a half following birth. The P had no prior experience with preterm infants before her last born. She resides with her mother and two aunts. Her relationship status is single. She is in contact with the infant's father and he recently started supporting her financially. She receives extensive support from her family members with regard to the caregiving of her infant. Her highest education level is grade ten and she is currently employed as a clerk at a computer company. Afrikaans is her home language. The P was eager to engage with the I and enjoyed reflecting on her past and present experiences. She appeared calm and confident during her interactions with her infant and the I. It was clear that she enjoys the motherly role thoroughly as she spontaneously cuddled and kissed her infant multiple times during the interview. The I found it easy to engage with the P and could elicit lengthy descriptions with minimal prompting.

I: Goed, ons het nou so begin gesels oor Q wat te vroeg gebore is. So vertel my hoe was dit vir jou om vir hom te hê en te versorg sover?

P: Hmmmm. In die begin, OK van die dag wat hy gebore is het ek nou maar self vir hom gesorg. Daar was nog nie 'n helper in sy pa nie, sy pa het nou maar eers nou die dag in die prentjie gekom. So vir my was dit *tough*… jy weet, maar ek het deurgedruk en ek het darem *support* gehad van my *family* en *support* van my kerkmense. So hulle was *amazing* en ek kan nie sê dit was 'n *tough* ding *financially* nie, maar uhm toe ek vir hom kry op die dag… die 22ste en toe die 24ste is die eerste keer wat ek toe weer vir hom gesien het en ek het nog nie daai *bond* gehad nie, ek het niks gevoel nie. Ek weet nie ek het net *mixed feelings* gehad (laughs and puts hand over mouth) amper soos ek kan nie met hom wees nie want hy is nou al gebore en wat moet ek nou met hom maak! So *feeling* het ek gehad en uhm die *struggle* was gewees *obviously* as jy nou 'n c-*section* het is dit verskriklik baie seer. Daar waar ek gelê het was die *service* baie *poor*. Hulle het jou nie gehelp met enige iets nie. Die enige tyd wanneer ek hulp gekry het was toe my niggie inkom hospitaal toe en toe kom sy en help vir my op want ek moet mos nou *move*. Daai was die enigste tyd wat ek eintlik help gekry het, jy moet self sien en kom klaar en daai was vir my 'n bietjie *hard*. Uhm en toe die Woensdag is ek ontslaan uit die hospitaal

uit want ek kan toe mos nou te beginne beweeg op my eie… swaar, maar ek moes dit gedoen het. Net eers die Woensdag toe besef ek maar joh, ek het mos ‘n babatjie in die hospitaal. Toe kom dit eers by my op, *you know* die *morphine* is uitgewerk en alles is *back to normal*. Maar ek het mos ‘n babatjie in die hospitaal…toe hulle my nou ontslaan die dokters toe gaan ek nou om na my babatjie toe en toe sien ek hom nou vir die eerste keer na hy gebore is. En daai is die tyd wat ons toe nou te beginne *bond*, *you know*… (laughs). *But* ek kan niks sê, niks slegs sê van enige iemand nie, hulle het vir my baie *nice* gehelp. Ek *mean* ek was dan vandag daar by hulle om vir hom te gaan wys en hulle was *crazy* oor hom. Ek sê vir sister T, want sy was nou my *best friend*… of sy was nie my *best friend* nie want sy het my ‘n harde tyd gegee. Ek het baie gehuil! *Anyway* toe sê sy nou sien, ons moet vir jou so harde tyd gee want kyk hoe pragtig is jou babatjie nou! *You know*, so ek kan nie eintlik sê ek het ‘n *bad experience* hier gehad nie. Die *bad experience* was net hy is vroeg gebore en die c-section is *terrible* gewees en *stuff like that*. Ek dink daai is daai…ek het nie eintlik *complaints* of so nie. Al wat ek verlang is hulle moet *try* om die mense te help. Want jy kan nie ‘n *c-section* hê en jy moet net aangaan nie. Daai is my enigste ding dat hulle ons meer moet help as ons klaar is met ons c-*sections*. Van daar af – *no problems*!

I: Sjoe, jy het nou vir my ‘n baie mooi antwoord gegee. Dit was bietjie moeilik want jy is in pyn en jy is geskuif van jou baba en jy is nog nie heeltemaal seker oor hierdie baba nie. Maar die band het later gekom en ek kan sien jy is baie lief vir jou baba nou…

P: Joh, ek is baie lief vir die kind. Joh!
I: Vertel my bietjie wat gehelp het om daai band te vorm?

P: Ek dink dit was meer, toe ek hom nou sien en ek besef dat die Here het vir my ‘n kans gegee. Dit was alles die Here se plan. Daar is niemand anders vir wie ek kan dankie sê of vir wie ek die eer kan gee nie. Hy (points to sky), Hy het dit gedoen. En ek het baie gebid en my kerkmense het baie gebid vir my, daar het gebede uitgegaan vir my en vir hom soos nooit van te vore nie. So ek het maar net besef dat dit is my *miracle baby* en die Here het my *gebless* met die kind so hoe kan ek dan nou nie baklei vir die kind nie en hy baklei dan om gesond te raak. En van daar af toe baklei ek vir my kind se gesondheid.

I: Wow, dis baie mooi. Ek kan hoor jy het ‘n *mindshift* gemaak en besluit dat jou baba ‘n wonderwerk is en dis jou werk om hom verder te help.

P: Ja, en hy is so pragtig soos nog iets!
I: Ja, hy is pragtig (laughs). Jy het baie gesels oor jou kerkmense en jou familie. Ek kan hoor jy het ‘n baie goeie ondersteuningsnetwerk. Vertel my meer hiervan? Daar is mos baie ander mense wat vir jou en vir hom help?

P: *Oh*, daai is nou my ma en my antie. Ek het nou drie weke gelede weer begin werk en uhm ek weet nie of ek vir hom in ‘n crèche wou gehad het of iets nie, maar ek het my ma uitge*try* om te sien wat sy gaan sê. En nooit nie – nooit sal ek my kleinkind in ‘n crèche sit nie. My ma is *disabled* en sy het vir my grootgemaak en sy maak my kind groot en toe sê sy vir my nooit gaan jy my kleinkind vir ander mense gee nie. Hy bly net hier

by ons. Maar hulle kyk so mooi na hom, hy is hulle… soos as ek in die aande by die huis is dan sal my antie vir my sê wat is die dag se roetine nou. Hy het nou so gemaak en hy het so gemaak, ons het vir hom bietjie op sy maag gelê dat hy kan bietjie *balance* kry en al die dinge. So hulle is 'n groot help vir my! Daar is 'n tydjie wat ek so bietjie gehaak het en dan het my antie nou vir my *financially* ook gehelp, *you know*. So ek het nooit 'n tekort gehad aan kimbies en melk nie want ek het eerste gesorg dat daai reg is, maar nou vir my myself… sy was altyd daar, sy is altyd daar vir ons almal. Vir my en vir my kinders en vir my ma. So ek het 'n baie, baie lieflike *support system* by die huis. As ek nou sê ek wil gou winkel toe gaan en dan sal hulle nou sê, nee los hom hierso en dan gaan jy maar gou winkels toe. So hulle *support* vir my deur en deur.

I: Wow, dis fantasties. Jy is baie gelukkig om so goeie ondersteuningsstelsel te hê. En sê vir my in die begin in die hospitaal? Hoe was dit toe?

P: Dit was *nice*. Hulle het gekom… ek onthou die dag, die Dinsdag maar toe het hulle hospitaal toe gekom my ma, my antie, my niggie-hulle, my werksmense hulle het almal gekom. Ek onthou ek het opgestaan en ek het so gesukkel om te loop en ek het toe maar uitgeloop want hulle kan nie inkom nie. En toe my ma my sien toe huil sy en my niggie sê toe moenie huil nie, jy gaan vir haar ook *emotional* maak – sy is mos nou seer en dis rou en dis seer. Ek toe sê toe mammie, ek is *fine*, mammie hoef nie te huil nie. Ek is my mammie se enigste kind *so by the way!* (laughs). Ek het net baie pyn, maar dis oraait. En my ma en my antie het geloop uit die Elsies uit Tygerberg toe… geloop! Ek sê vir hulle hoe kan jy daai wil doen. Hulle sê hulle moes kom. Ek het mos die Maandag gekraam, maar ek het nie kontak gehad met niemand nie. Met niemand van die familie nie want my *phone* het pap gegaan. Toe weet hulle niemand wat aangaan nie en my antie wat my nou so *support* om na hom te kyk sy bel Tygerberg toe en sy kom deur by niemand nie want almal sê vir haar *hold* vir daai, *hold* vir daai en dan raak die *airtime obviously* mos nou op. En uhm my niggie-hulle het begin *worry* en begin *stress* want hulle weet nie wat aangaan nie. Toe het my niggie nou, ons het 'n sister wat hier werk by Tygerberg wat by ons kerk gaan,vir haar gebel en gesê sy moet net gou kyk want hulle is baie bekommerd. Toe het sy nou ingebel hospitaal toe en het hulle *confirm* dat ek nou wel klaar die babatjie gekry het. En toe is my niggie-hulle so verlig! So ja, ek het 'n *support system* wat skrik vir niks!

I: Jy is regtig gelukkig. Ons het nou baie gesels oor al die ander rolspelers. Maar jy bly mos nou sy ma en die *sole provider*. So wat beteken dit vir jou om 'm ma te wees – watter verantwoordelikhede of pligte?
P: Dit beteken alles. Soos die *experience* wat ek nou gehad het, vir my is dit *like* soos die Here het met my gepraat op 'n harde manier. So vir my is dit en ek het vir almal gesê ek gaan my kind as een van die Here grootmaak. En daar is nie 'n ander manier nie *cause* die wêreld is woes daar buite en ek wil net die beste hê vir my babatjie. So vir my beteken dit ek moet sorg vir hom, hom lei op die regte pad en sorg dat hy uitgesorteer is. Dat hy die liefde en aandag kry wat hy moet kry en wat hy verdien om te kry. Want hy verdien alles! (kisses baby and laughs). So ja, dit is vir my net – daai is wat ek gaan doen.

I: Dis regtig baie mooi en jy verduidelik dit baie mooi. En jy het baie gepraat oor die langtermyn dinge wat jy moet doen. As ons gesels oor die dinge waarmee jy hom nou moet help – wat is dit vir jou? 'n Baba het mos maar baie goedjies waarmee jy moet help.

P: In terme van wat nou?

I: Sorggewing. *Nappy changes*, alles?

P: Ek doen alles vir hom (gasps)… joh, somtyds dan *joke* ek met hom en dan sê ek joh Q, *you don't even say thank you for the things mommy does – you just take it as you must have it!* Okay, so ek sorg vir hom. Ek bad vir hom, maar okay nou nie in die week nie want dan werk ek en ek moet kosmaak en ek moet kyk na my oudste seun. So ek moet maar sulke tydjies maak vir alles, maar hy kom mos nou eerste want hy kan nog nie na homself kyk nie. En my oudste seun verstaan, gelukkig verstaan hy. Want partykeer dan voel ek so *confused* en dan weet ek nie wat om te maak nie want almal sê ek moet nou nie my oudste seun afskeep nie. Want dis omtrent 17 jaar terug vandat ek 'n kind groot gemaak het so die is nou weer 'n nuwe aanpassing – partykeer kan ek nie lekker onthou hoe om alles reg te doen nie. Maar okay, K verstaan dat Q is die *baby* en hy makeer nou baie meer aandag as hy. So K sal ook vir hom bad en die *nappy changes* doen en hy sal bietjie met die *bottle feed* en bietjie sit met hom. Hy maak vir my baie moeg somtyds jong! Glo my as ek nou vir hom 5 *minutes* vir hom neersit dan begin hy huil, maar okay dan sal die ander hom bietjie vat want ek is moeg. Maar in die aande het ons twee *bonding* time – ons gaan slaap, maar ons moet eerste speel. So uur voor ons gaan slaap dan moet ons eers speel. So ons moet speel en lag en hande klap en te kere gaan. Daai is ons manier van *bond*!

I: Ag, dis dierbaar! En in daai *bonding* time is daar baie kommunikasie wat plaasvind tussen jou en Q.

P: Ja, ons sal gesels en so aan. Dan kom my antie-hulle in die kamer aan en dan lag hulle vir hom wat so aangaan en vir my wat so aangaan met hom. So ja, ek moet *basically* alles doen. Ek doen sy *shopping*, sy melkies en kleretjies sal ek nou koop en partykeer kom die pa ook by en dan gee hy geld. Maar *obviously* doen die ma die meeste. Vanselfsprekend doen die ma die meeste. Maar ek gee nie om nie want hy is my gogga (kisses baby and laughs). Hy is so lief vir daai woord – gogga (exaggerated pronunciation). As ek dit so sê dan lag die kind!

I: Wow, ek kan sien hoe lief jy is vir hom. Jy het nou so mooi verduidelik hoe julle twee kommunikeer met mekaar deur te lag en gesels en speel. Vertel my meer daarvan - wat doen jy en wat doen hy?

P: Ek sal nou byvoorbeeld vir hom *come clap handies* sing en hy sal nou lag en *excited* raak. En as soos vir hom droogmaak dan soen ek soos sy magie en dan lag hy want hy hou van die snaaksigheid. En dan sal vir hom droogmaak en dan sal hy so *stretch* – hy *love* dit om te *stretch*. En dan sal ek sy beentjies so bietjie beweeg en daai *excersises* gee en dan sal hy lag vir al die snaakse goed wat sy ma aanvang. En ek sal hom so bietjie in die lug inhou en dan beweeg ek hom so bietjie en dan lag hy. Hy lag vir enige ding wat ek met hom doen (starts breastfeeding comfortably).

I: Dis oulik. Ek sien hy borsvoed baie lekker – kom ons gesels bietjie oor die voeding. Van die begin af tot waar hy nou is.

P: Okay, so in die begin was dit mos nou… ek mos nou nie melk gehad om vir hom te gee nie want hy is mos nou vroeg gebore en dit was nog dit tyd gewees dat ek melk het. So toe was dit nog *donor* milk wat baie gehelp het en uhm ek het seker op so paar weke oud ge*try* om vir hom op die bors te kry, maar dit het nie so lekker gewerk nie want daar het niks uitgekom nie. Toe het hulle maar nou vir hom op die boksmelk gesit, op die *Infacare*. So dit was moeilik in die hospitaal, maar toe ons nou by die huis is toe begin dit reg kom. So ek het hom elke dag geborsvoed en die melk gemaak en ek was mos nou maar by die huis. Ek het nou eers weer drie weke gelede begin werk. So toe kon ek mos nou lekker borsvoed en die melk het lekker deurgekom. So uhm hy is nou nog op die bors en op die *infacare*. Ons het nou gister begin met die pap en hy eet die pap baie *nice*. Ons gaan nou vandag begin met die groente en vrugte want dokter het gesê ons moet nou begin met daai ook. Verder is alles *fine*, sy oë blink soos jy kan sien. Maar ja, hy is baie lief vir tiet. As ek by die huis is dan gee ek vir hom meer tiet as *bottle because* die … daar het baie vir my gesê jy moet nou ophou borsvoed en toe sê ek sal dit nooit doen nie want my oudste kind het gedrink tot op drie jaar oud so ek sal nooit dit doen nie. Ek voel baie beter as hy drink aan my as wat hy aan ‘n *bottle* drink.

I: En hoekom dink jy voel jy so?
P: Want borsvoed is *amazingly* gesond. Dit het alles in. Dis hoekom ek nie *much* is oor die boksmelk nie. Ek sal vir hom baie meer dit gee as daai. Maar *obviously* moet ek vir hom daai gee as ek nie by die huis is nie.
I: Okay, so die borsvoeding is vir jou ‘n lekker ervaring.
P: Dis *amazing! I love it*! En ek het nie daarvan gehou met my eerste kind nie. Ek kon dit nie vat nie. Maar met hom is dit so *different.* Ek sê vir hulle daai is my en my kind se *bonding*.
I: Okay, dis baie goed. En borsvoeding is baie goed vir jou baba. So in die begin kon hy mos nou nog nie borsvoed nie, hoe was die voeding toe vir jou?

P: Uhm dan is mos nou die buisie wat hulle nou… met al die voeding goeters het my kind se gewig baie mooi opgetel. So vir my was daai nie ‘n problem nie. Dis net die *cup feed* was i*rritating* – ugh, ek haat die *cup feed*! Ek het dit gehaat. Want meeste van die tyd met die cup feed dan het hy verstik en daai kan ek nie vat nie. So toe ek by die huis kom toe stop ek die *cup feed*. Want ek is nie nou by die hospitaal nie so ek gaan *bottle feed*. En ek maak seker sy bottels is *gesterilise*. So vir my was dit okay gewees in die begin, dit was net *sad* omdat ek nou nog nie vir hom kon *gebreastfeed* het nie. Ek het baie gehuil oor ek nie kon *gebreastfeed* het nie want ek het gedink my kind gaan nooit die bors vat nie. Maar toe het hy en nou drink hy aan die bors!
I: Okay so die buis was vir jou okay want hy het gewig opgetel en jy wil hê hy moet gewig optel en die cup was so bietjie moeilik want jy weet nie of gee jy te veel of gee jy te min nie en toe was die borsvoeding bietjie stresvol want jy het nie geweet of gaan hy borsvoed of nie.

P: Ja, toe hy nog nie kon borsvoed nie was dit stresvol. Ek het baie gehuil. Ek het gedink ek en my kind gaan nooit *bond* nie (laughs). Maar toe ons by die huis kom toe verander alles. Ek was baie ge*stress* in die hospitaal

omdat ek is nie ‘n hospitaal *person* nie en ek ken nie van ‘n hospitaal nie. Ek het baie ge*stress* want ek en my oudste kind is baie *close* en ek en my ma is ook baie *close* so ek het altyd *geworry* is hulle *okay even* as ek geweet het hulle is *okay*, het ek *geworry*. So ek wou nooit by die hospitaal gebly het by hom nie want ek het *geworry* oor my ander kind ook. Want onthou ek het nog ‘n kind en ek het ‘n ma ook. En uhm hulle het altyd verstaan want hulle het gesê as jy voel jy wil bietjie huis toe gaan is dit oraait, ons kyk na jou kind hier. En hulle het baie mooi na my babatjie gekyk. So ja, alles is vir my *perfectly fine except* die *cup feed* ding en so. Hy vat die *bottle* lekker en so, so ja.

I: Okay, ons gesels nou nog heeltyd oor die aanpassings wat jy moes maak en hoe die *journey* vir jou was omdat Q te vroeg gebore is. So as jy nou hierdie word *premature* hoor – wat beteken dit vir jou?

P: Ek het, jy weet om die waardheid te sê – vir my was dit so *weird* omdat ek ‘n *premature* baba gehad het. Dit kom nog altyd by my op. Vir my is dit so *weird* dat ek het ‘n *premature baby* gekry want my vriendin is ‘n bietjie ouer as my en ons was saam swanger en sy het nie ‘n *premature baby* gekry nie, haar *baby* was *perfectly healthy*. Hoe gebeur dit? *You know*, sulke dinge kom op by my brein. En ek het *actually* gisteroggend by die werk toe *Google* ek *premature babies* en ek beginne huil en ek sê vir myself joh, ek was ook daar met die kind. En het gehuil en gebid en ek bid sommer vir die *premature* babatjies hier in die hospitaal. En ek kan nie glo dat dit ek was ses maande gelede nie! Vir my is dit *like* – gaan die kind *survive*? Daai is die eerste ding gewees. Kom ek sê gou vir u iets. Toe hulle vir my sê hulle moet ‘n *emergency c-section* doen – daar het niks by my mind opgekom nie. Niks. Ek het dit vir die Here gegee en U se wil, nie myne nie. En as ek soos nou sien of soos vanoggend toe ek nou weer al die *premature babies* sien toe stap ek tot by ‘n meisie en haar baby is op 28 weke gebore… kleintjies, nog nie eers ‘n kilogram geweeg nie. En ek wou nou net vir haar gesê het, meisie weet jy wat help baie? Is om te bid. Dit help baie. En as jou kind gesond hier uit kom dan kan jy nie net hom sommer so grootmaak nie. Dit is die Here se kind. En dit was lekker, ek is daar weg en kon iemand bemoedig het. Daai is maar wat ek doen, ek bemoedig mense. In die *ward* ook – ek het mense bemoedig en dan huil ek weer want ek is ge*stres*s. En dan bemoedig mense en dan huil ek weer want ek is so *frustrated*. So het dit gegaan by die hospitaal – ek was ‘n wrak. Die dokters het vir my gesê ek gaan nie melk uitkry nie want ek *stress* te veel. So dan as ek huis toe gaan gaan dit beterder gaan want dan is ek meer *stress free*. En dit het net so gewerk. So…

I: Vertel my wat in die hospitaal het jou so laat *stress* of *frustrated* voel?

P: Tygerberg! (Laughs). Dis net… nie die mense nie, net die hospitaal self. Ek hou nie van ‘n hospitaal nie. Ek is net nie oor ‘n hospitaal nie. En die feit dat ek nog nooit weg gewees het van my kind af nie, is vir my *hard*.

I: Okay en so rukkie terug het ons nou gepraat oor *premature babies* wat *miracle babies* is. So dink jy hoe jy

sorg vir die *miracle baby* verskil van hoe jy sorg vir ‘n voltermyn baba?
P: Ek dink daar is ‘n verskil ja. Want wat ek gedoen het met hom – kyk, hy was nou in die winter gebore so dis koud. En daai is die tye wanneer die kinders afsterwe want dis koud. Wat ek gedoen het en ek het die raad gekry by my *neighbour* want hulle ken ook van ‘n *premature baby*. Sy het vir raad gegee om *cotton wool* te vat en vir hom toe te maak so dat hy daarin kan broei. Ek het nie meer ge*kangaroo* by die huis nie, ek het eerder daai gedoen. En dan in die aand as ons gaan slaap is hy bloedrooi van die broei. En so het hy vining groot geword. Ek het net *cotton wool* gebruik om hom… ek het nou nog *cotton wool*! Ek gebruik dit nie meer nie. En hy het nou verander want ek dink hy was te warm toe hy klein was en nou hou hy nie van klere nie. En hy sweet baie, maar die dokter sê dis *normal*.

I: Okay, dis interessant. Die laaste deeltjie waaroor ek met jou wil gesels is oor die hele ervaring. Jy het gesê dit was moeilik by tye, maar dit was ook goed en jy was geseën met jou seuntjie. So is daar enige iets wat die ervaring vir jou beter sou kon maak? Enige iets?

P: Net daai stukkie wat ek mos vir u gesê het van die *nurses* wat daar sit en nie *worry* of jy daar lê na jou *birth* nie. Hulle help jou nie. En hulle is immers daar om mense te help. Jy kan mos nie iemand net daar laat lê in hulle bloed en dan niks doen vir die persoon nie. Ek dink daai is baie verkeerd en ek het nie daarvan gehou nie. Dit was die enigste ding.

I: Okay, dis goed. En toe jy moes huis toe gaan – het jy gevoel jy is gereed om huis toe te gaan?

P: *Yes, I was born ready*! Ons het die vierde *June* huis toe gegaan, uit *ICU* uit na sy *ordeal* met die blou trekkery. En toe ek nou ontslaan raak met hom toe sê die dok maar hulle weet nie of hulle my nou gaan ontslaan en of hy nog twee of drie dae moet bly nie. Toe voel ek nie baie *happy* nie, maar okay in U se wil. En kyk sy gewig is al reg, dis al 1,9. En ek wil huis toe gaan, ek wil nie hier bly nie! Dokters het toe gegaan en gesê okay, ons kan maar gaan. En toe sê ek – dankie Here! *But* ek was gereed. En dit het daai dag hard gereën toe ons huis toe gaan. My antie het alles reggemaak by die huis vir ons. En ek was reg en hy is *all good.* (Ending)

APPENDIX D: THEMATIC MAP

Theme 1: Feeding as a progressive task that always entails "something more"

This theme describes maternal experiences of the feeding task which is always changing to work towards a specific set of goals.

CODES	DEFINITIONS	EXAMPLES
Progressive: feeding method	The infant progress from tube feeds whilst in an incubator and in NICU/high-care to syringe feeds (rarely done) to cup feeds and eventually to breastfeeding in the KMC or general ward with the mother and infant sharing a bed. TARGET: Breastfeeding	MS_P3: sy het 'n *tube* in haar mond gehad so sy het daardeur gevoed. Van die *tube* het sy na die *cup* gegaan… en sy het van die *cup* bietjie gedrink… *she actually drank very well from the cup*… en toe die *bottle*. *Because* sy nooit *milk* van soos die *breast* gedrink het nie, sy het nie geweet hoe om te *like suck properly* van die *teat* so sy moes dit leer.
Progressive: feeding volume	The number of millilitres consumed during a feed increases frequently. Thus moms must supply more breastmilk.	MS_P7: Die melk en voeding wat hulle kry, het elke dag opgegaan. So jy moet nou meer melk gee en mos nou ge-*express* het, maar ek het darem gelukkig… PS_P2: En soos dit aan gaan, dan haar ml's elke dag hoër en hoër. Dan moet mens elke keer meer en meer potjies melk maak. Maar ek het altyd meer potjies melk in die *fridge* ge-het. Want hoe meerder sy begin te drink het, haar *percentage* het gou opgegaan.
Progressive: weight gain	The infant is expected to gain weight consistently. This is monitored daily. TARGET: 1,8 kilograms	PS_P2: En dan werk 'n mens heeltyd na die mikpunt waar hulle 1.8 is die gewig. Want dan kan hulle mos huis toe gaan. MS_P7: Toe voel dit net vir my soos ek gaan nooit daar uitkom nie en dis nog ver want hulle het gesê hy moet 'n sekere gewig weeg vir ons om te kan skuif
Progressive: discharge	This is the ultimate goal and one that mothers work toward tirelessly. This requires the infant to	PS_P2: En dan werk 'n mens heeltyd na die mikpunt waar hulle 1.8 is die gewig. Want dan kan hulle mos huis toe gaan.

	- Maintain a minimum weight of 1,8kg - Be able to feed orally, preferably breastfeeding	MS_P8: Ja, in die begin is die babatjie nie by jou nie. Hy is in die broeikas. Dit moet nou so wees want die babatjie is mos nog te klein. En dan begin te voed jy, hulle leer jou hoe om te voed die babatjie. Koppie voed en na koppie voed dan gaan jy weer na 'n saal toe waar die babatjie by jou is. En van daar af gaan jy huis toe.

Theme 2: Feeding as a cause of negative emotions, especially "in the beginning"

This theme describes the various factors contributing to the negative emotions mothers experience with regard to feeding.

CODES	**DEFINITIONS**	**EXAMPLES**
Stress: infant growth	Mothers found it stressful to wait and observe how their infants grow.	PS_P2: dis baie *stress*vol eintlik. Om te kyk hoe hulle moet groei. MS_P7: Ja, soos ons kyk elke dag in die lêers hoeveel hulle weeg. Of jy kan vra vir die suster of so. Maar nou is jy deurmekaar want jy vra wat moet jy doen dat die kind gewig optel, wat presies moet jy doen. Dan sê hulle nou jy moet die kind KMC, jy moet melk *express* en jou eie melk gee, maar vir my was dit ek het alles daai gedoen en ek het amper heeldag by hom gesit. Ek het in die middag dan het ek besluit, OK, ek gaan nou nie meer slaap nie. Ek gaan nou net by hom wees sodat hy nou net gouer kan optel en toe verstaan ek nie want ek doen dan nou alles reg, maar nog altyd.
Stress: breastmilk supply	Mothers experienced breastmilk supply and specifically the lack thereof to be a great stressor. (The reasons for this will be discussed in a separate theme)	MS_P3: Vir my was die ervaring… *it was fine when I found out I was pregnant, but afterwards it was horrible! It was horrible!* Want ek het niks *milk* gehad nie en ek het nie geweet wat om te doen nie… want sy huil die hele tyd en hulle *force* my vir *milk* en ek was net soos **ek het nie *milk* nie**! So die dokter het vir my 'n pil of iets gegee om *milk* te maak, *but* dit het ook nie gehelp nie so… *I was like… I was at a point where I was crying because she was crying!* Ek het nie geweet wat om te maak nie!
Stress: not breastfeeding	Mothers found it stressful/sad when their	PS_P2: Dit was baie *stress*vol. Baie, baie baie. *Because* ek het geweet die bors is wat vir haar gaan laat huis toe gaan. En haar gewig was al

	infants were unable to breastfeed.	1,8 al en toe kon sy nog nie gaan nie want sy het nog nie gebors nie. MS_P5: So vir my was dit okay gewees in die begin, dit was net *sad* omdat ek nou nog nie vir hom kon *gebreastfeed* het nie. Ek het baie gehuil oor ek nie kon *gebreastfeed* het nie want ek het gedink my kind gaan nooit die bors vat nie.
Stress: infant regression in feeds	Mothers found regressions in their infants feeds stressful, or were anxious about a potential regression.	*PS_P2: Cause* as sy gaan afval dan moet hulle die *tubie* terugsit en dan gaan ek nog langer bly en ek wil net huis toe gaan MS_P5: so daai was baie hard gewees want hy het nie elke dag opgetel ook nie so die een dag is ek *excited* want hy het nou opgetel, maar die volgende dag is ek nou weer af want…
Stress: messy feeds	Mothers found the messing during feedings times stressful.	MS_P3: So dit was baie *messing* en nuwe klere aantrek en *all that*! MS_P4: . Sy het vir die eerste paar dae gemors – uitgespoeg, het nie geweet hoe om dit regtig te sluk nie en toe agterna toe raak dit vir my makliker

Theme 3: Breastmilk supply as the "the biggest thing" that causes stress

Mothers described breastmilk supply as the biggest "problem" during their hospital stay. This theme explores the various reasons why insufficient milk supply was perceived as a major stressor.

CODES	DEFINITIONS	EXAMPLES
Milk supply stress: breastmilk best	Mothers want an infant to drink "my own milk" as this is the best for the infant.	MS_P7:in die begin toe hy gebore was het ek gesukkel met die melk en dit het ook vir my so bietjies uitge*stress* want hulle het vir my gesê hy moet my melk kry want dit gaan vir hom gouer help en daai was seker so vir die eerste week wat ek gesukkel het toe. PS_P2: Op'n tyd het my melk opgedroog ook en dit was s*tress*vol *cause why*, ek wou nie gehad het sy moet ander melkies inkry nie.

		Maar sy het darem die hele pad my eie melk gekry
Milk supply stress: sufficient supply	Even if mothers had breastmilk, they were concerned about whether they have enough milk (seeing as feeding volumes keep on increasing).	MS_P6: Ek het al sommer gebid vir die Here, gebid vir my my vir melk want ek was al op daai stadium die kinders *need* melk want hulle moet groei. MS_P6: Maar eintlik al ding van hulle is net – jy moet jou melk gee. Daai was vir my net so groot stres, die melk. Ek dan skuif hulle dit so op, hulle skuif dit so op op op – op die ou einde is dit so baie melk dat jy nie eers kan amper daai totaal gee nie want ek het eerste in die begin by die huis geslaap dan los ek miskien nou 'n dag se melkies, maar dan skuif hulle dit nou opper en opper en opper. Dan kan ek nou nie meer daai totaal nie
Milk supply stress: expressing is difficult	Mothers did not know how to express milk or found expressing difficult/hard.	MS_P6: Joh want jy moet *express* en baie van ons weet mos nou nie hoe om te *express* nie en dis seer en jou melk kom nie
Milk supply stress: infant intestines immature for formula	Not having milk made mothers anxious as formula may harm the infant's immature intestines	MS_P3: En hulle wou nie vir haar *formula* gee nie want sy is te jonk so hulle is bang vir haar *intestines* en *all that*.
Milk supply stress: forced to express	Mothers felt forced / "pushed" to express milk and perceived hospital staff to obsess over expressing breastmilk.	MS_P6: Ja, want hierso is dit so hulle *push* jou so vir melk dat die hele ding is net melk, melk, melk. MS_P3: En hulle was net *like* jy moet *breastfeed*, jy moet melk uitdruk en ek was *like* ek kan nie. En *even* daai soos wat jy elke twee ure moet wakker word om te *express*, ek moes daai doen *even* al het ek nie milk nie en daar kom niks nie!
Milk supply stress: judged if no milk	Mothers felt judged by nursing staff if they were unable to provide milk for their infant	MS_P3: en dit was soos *hell* daar *cause* die *nurses gossip*, die hele milk ding, ek het nie milk nie so hulle sal soos *gossip* en my *force* vir milk en *all that.* So dit was regtig *horrible*!

Milk supply stress: stress inhibits production	This is quite an ironic code. Mothers were stressed about the fact they shouldn't be stressed to produce milk.	MS_P6: Jy is al so ge*stress* want jy wil ook hê jou babatjie moet groei en nie siek raak nie en jy moet melk hê so jy kan nie *stress* nie. MS_P6: Daar was dae wat ek nie geweet het moet ek huil, moet ek lag… want aan die een kant, ek kan nie *stress* nie want my kinders drink my melk so ek moet nou kalmte wees anders het ek nie melk vir hulle nie. En joh, dit was moeilik.

Theme 4: Succesful breastfeeding as an all-round "amazing" experience with multiple advantages

This theme explores the different positive perceptions mother has regarding breastfeeding and the advantages it entails for mother or/and infant.

CODES	**DEFINITIONS**	**EXAMPLES**
BF = amazing	Mothers experience breastfeeding as positive and enjoyable.	PS_P3: Saterdag toe die suster nou vir my sê ek moet vir hom borsvoed toe is dit so 'n *amazing* gevoel dat hy aan my borste is... ek kan dit vir niemand *explain* daai *amazing* gevoel nie, dit soos *butterflies* wat ek in my binneste gevoel het toe hy die eerste keer aan my gedrink het.
BF = best weight increase	Mothers believe that breastmilk leads to increased weight gain.	PS_P2: *Because why* sy gaan nou groei MS_P7: Omdat hulle gesê het hy tel gouer op en die melk wat ek moes *express* moet in die yskas so dis nou nie vars melk wat hulle vir hom gee nie. So toe voel ek net *excited* oor die melk wat hy van my af kry want dis mos nou vars melk en ja
BF = bonding opportunity	Mothers experience breastfeeding as an opportunity to bond with their infant.	PS_P3: maar waar ek die moeder en kind gevoel gekry het was toe ek hom die eerste keer hier (wys na bors) by my gehad het. Toe voel ek daai tussen ons twee MS_P5: Ek sê vir hulle daai is my en my kind se *bonding*

BF = increased communication	Mothers experience breastfeeding as an opportunity to interact and communicate with their infant.	PS_P3: Die *main* ene is hoe ek met hom kommunikeer is deur dat ek kom borsvoed. Daai is vir my ‘n baie spesiale tyd met my kind. Want dan is dit vir my hy drink ‘n deel van my. Van alles en alles... daai is vir my baie spesiaal.
BF = healthy	Mothers believe breastmilk to be healthy and good for their infant	MS_P5: Want borsvoed is *amazingly* gesond. Dit het alles in. Dis hoekom ek nie *much* is oor die boksmelk nie. Ek sal vir hom baie meer dit gee as daai. Maar obviously moet ek vir hom daai gee as ek nie by die huis is nie.
BF = discharge home	Mothers feel that breastfeeding will enable the infant to go home. Perhaps this is linked to their perceptions of breastfeeding that increases weight gain and that is “the best” for the infant.	PS_P2: *Because* ek het geweet die bors is wat vir haar gaan laat huis toe gaan.
BF = increased breastmilk supply	Mothers feel that breastmilk supply increases as they start to breastfeed. This causes relief about sufficient milk supply.	MS_P6: Toe kom die melk nou ‘n bietjie beter, toe beginne kom dit. Want die een ling was huis toe gestuur voor die ander enetjie en toe hy nou kan beginne drink toe stimuleer die bors mos nou en toe kom die melkies beter.
BF = increased proximity	Mothers perceive breastfeeding as an opportunity to be close to their infant.	PS_P3: Dit was net *amazing* want hy moet hier (wys na bors) heeldag by my sit
BF = mother	Mothers perceived breastfeeding as the thing that made them feel like a mother at last.	PS_P3: toe is dit nou *kangaroo* en borsvoed. En hy moet nou *straight* drink van my bors af. Daar het dit vir my nou begin insink... hier my by (wys na kop) MS_P7: Dit het my goed laat voel want soos nou voel dit vir my OK, ek is nou ‘n ma uiteindelik (laughs). Ek is nou ‘n ma want hy drink nou aan my. MS_P7: ja so vir my was dit ook eintlik nou voor hy nou aan my bors begin drink het het ek ook gevoel ek voel nie regtig soos ek is nou eintlik ‘n ma nie want ek

		bedoel maar hy was nog in die broeikassie en ek moet nou net daar sit en ja.

Theme 5: The hospital environment as both a facilitator and barrier to positive feeding experiences

This theme explores the different factors in the hospital that mothers experienced as a facilitator and/or barrier. The hospital environment is perceived as being advantageous and disadvantageous simultaneously.

CODES	**DEFINITIONS**	**EXAMPLES**
Hospital +: teaching of tasks	Hospital staff (doctors and nurses) provided great help to the mothers as they taught them how to perform caregiving tasks.	PS_P3: Dokter... die dokter daar by die *KMC* het vir die mammies baie mooi gewys. Sy het ‘n pop daar gehad en vir ons gewys hoe om die babatjie te draai, eers dit en dan daai... (wys met hande). Hoe om hom aan te trek, altyd te voel of die waswater reg is en dan eers die babatjie daar in te sit... ja. En hoe om hom aan te trek, eers dit en dan daai (wys met hande). MS_P4: so dan sal sy nou met ons kom sit en met ons gesels en verduidelik die babatjie moet so gehou word en jy moet so maak met die babatjie en as die babatjie verstik dan moet jy hier jou hand so hier sit en die neus toe hou en die kop ophou. So daar was dit baie beter, hulle het ons baie gehelp.
Hospital -: stressful environment	The hospital environment in itself is a stressful, intimidating and novel context.	MS_P5: Maar toe ons by die huis kom toe verander alles. Ek was baie ge*stress* in die hospitaal omdat ek is nie ‘n hospitaal *person* nie en ek ken nie van ‘n hospitaal nie
Hospital -: controlled environment	The hospital environment is governed by a schedule for feeding, washing, sleeping and other care-giving tasks. This creates a controlled environment with little room for spontaneous interaction with the infant.	MS_P3: Dit was *actually* moeiliker in *hospital than* wat dit is by die huis… ek dink dis omdat die *hospital* is baie *controlled like* jy **moet** *feed* op die tyd, jy **moet** die *nappy change* as jy haar *feed*, jy **moet** dit doen… maar by die huis is dit meer soos hulle gee *signals* as die *nappy* nat is of… *like* sy huil net as sy honger is of as haar *nappy* nat is.

Hospital -: impatient nursing staff	Hospital staff (especially nurses) are perceived to be impatient and unwilling to demonstrate tasks multiple times.	MS_P7: Maak ‘n voorbeeld, soos ek sal miskien nou vra hoe moet ek nou maak met die of hoe met ek nou maak met daai? Dan voel hulle miskien nou, nee man, ek het nou al hoeveel keer al verduidelik al vir die een en vir daai een. Dan sal hulle miskien nou raas op jou en jy weet nou nie hoekom hulle so sê of hoekom hulle so lelik is nie.
Hospital -: strict nursing staff	Hospital staff (especially nurses) are perceived to be strict with the mothers.	PS_P2: Dis net somtyds was die nurses so bietjie… as ons voed. Maar hulle is eintlik streng.
Hospital -: single demonstrations	Mothers perceived the teaching of care-giving tasks to be done only once.	PS_P2: Hulle was amper soos jy moet net weet hoe nou… amper soos hulle doen al jare die werk so hulle wys nou net een keer vir jou en jy moet al weet hoe die volgende keer.
Hospital -: Breastfeeding support	Mothers needed more support on how to breastfeed their infant.	PS_P2: Ja, dis net met die *breastfeeding*. Ek het altyd gedink iemand kan kom en vir mens leer en vir mens sê hoe die *breastfeeding* werk *cause why* die babatjie vat altyd in die begin die bors sommer net so en so bietjie sukkel.

Theme 6: Feeding as a task where both mother and infant gradually become more skilled and comfortable over multiple exposures

This theme describes how both mother and infant gradually become more skilled in the task of feeding. This includes the how and what of their learning.

CODES	**DEFINITIONS**	**EXAMPLES**
Mother learning method: observation	Mothers learn by observing others (other mothers in the ward, nursing staff, doctors) as well as their infant	PS_P2 Ek het dit alles hier geleer. Ek het niks geweet van *premature* nie. Ek het alles dag-na-dag geleer… die *nurses* dopgehou, geluister wat die dokters praat, en dan het ek net vir haar ook beginne dop te hou en so het ek geleer. MS_P4 Ek het myself gewys en myself gehelp. OK, ek het bietjie in die rondte

		gekyk hoe dit gedoen moet word… vir my was dit nou ek is nie seker of ek dit so moet doen of so nie, maar OK ek gaan dit op my eie manier probeer doen en dan werk dit!
Mother learning method: direct instruction	Mothers learn from direct instructions provided by the medical staff	MS_P5: Ons het nou gister begin met die pap en hy eet die pap baie *nice*. Ons gaan nou vandag begin met die groente en vrugte want dokter het gesê ons moet nou begin met daai ook.
Infant learning method:	Infants learn and develop their oral-motor feeding skills through practice	MS_P4: Sy het vir die eerste paar dae gemors – uitgespoeg, het nie geweet hoe om dit regtig te sluk nie en toe agterna toe raak dit vir my makliker want so meer ek vir haar uit die koppie gee, so meer het sy gewoond geraak aan die koppie.
Mother learn: hunger cues	Mothers learn to recognize their infants hunger cues.	MS_P3: *Like I will know*… sy sal suig aan haar hand as sy honger is PS_P2: Ja, en sy huil as sy honger is of as die stertjies drooggemaak wil word. Of as sy die handjie te begin te in die mond sit en suig dan is sy honger of dors
Mother learn: infant preferences	Mothers learn their infant's specific preferences (what work and what doesn't work)	MS_P3: Is net *bottle*. Ek gee net *bottle* nou ook, uhm, sy weet nou hoe om te *suck*… maar sy *suck* net aan soos *round teats like* een wat soos 'n *nipple* is. *Cause* ek het ge*try* om een te koop wat die meeste soos 'n *nipple* lyk laat sy kan leer om te *suck.* PS_P2: maar dan hang dit ook nou van die babatjie af. Of die babatjie dit wil hê of nie wil hê nie. Die suster het toe later gesien sy is nie soos die ander kinders nie, sy vat nie die koppie nie
Mother learn: physical handling	Mothers learn how to handle and position their infant	PS_P3: In die begin was dit vir my baie *awkward* gewees want dis my eerste babatjie, ek weet nie hoe om hom te

		hanteer nie, hoe om vir hom te vat nie en netnou maak ek hom seer...
Mother learn: bottles	Mothers gain general knowledge about bottles – how to make a bottle feed, how to clean bottles.	MS_P3: So dit was *like* baie moeilik vir my want ek het nie geweet om die goed te doen nie en nou moet ek leer en dan raak ek *irritated*… soos ek moes leer oor *like bottles* en *all that – making bottles, cleaning bottles*.
Infant learn: drinking and sucking	The infant doesn't drink (suck) immediately and gradually learns to drink (suck) from the breast	MS_P7: die dokter gesê ek moet probeer om vir hom aan die bors te sit, maar hy gaan nie dadelik drink aan dit nie maar net dit vir sy brein of eintlik vir my brein 'n aanduiding gee maar hier is nou 'n babatjie, die melk moet sirkuleer en daar moet melk wees. En toe het ek hom nou begin aansit en so en hy het lekker geleer en darem lekker beginner drink en so. MS_P6: Hulle binnegoed is amper mos soos nie volheid ge-ontwikkel nie soos waar 'n volle nege maande baba as jy geboorte gee, hulle gee die baba vir jou en jy sit vir baba op die bors en die baba *click* dadelik ek moet nou drink en so aan. Die *difference* met hulle is, hulle kan nie sommer drink as hulle uitkom nie, hulle is *like* hulle weet nie hulle moet drink nie.

Theme 7: Maternal perceptions regarding tube feeds, cup feeds, breastfeeding and bottle feeds

Tube feeds, cup feeds and bottle feeds will be discussed here. Breastfeeding was discussed in a separate theme. This summary will be of interest to SLT's working in the field of paediatric dysphagia who have firm beliefs regarding the different methods of feeding from a theoretical point of view.

For example, SLT's typically advise that bottle feeds should be avoided and exclusive breastfeeding encouraged; in practice, however, it becomes clear that bottle feeds do have merits and advantages for working mothers or infants that struggle with breastfeeding.

CODES	**DEFINITIONS**	**EXAMPLES**
Tube feeds +	Mother had a positive experience of tube feeding.	PS_P3: Die voeding het ek mos nou deur die pypie gegee en dit was vir my... eintlik maklik gewees

(Majority of moms)	Reasons for this: - Easy (limited effort from mom or infant needed) - Effective for weight gain	MS_P5: Uhm dan is mos nou die buisie wat hulle nou… met al die voeding goeters het my kind se gewig baie mooi opgetel. So vir my was daai nie ‘n *problem* nie.
Tube feeds – (Single mom)	Mother had a negative experience of tube feeding Reasons for this: - Tube through the nose is unnatural	? I have no good quotation for this. It was implied by the mother's gestures and I did not explore it further in my interview. MS-P2: Toe hy in die broeikas gelê het, toe was hy klein en dan moet ek vir hom melk deur die pypie gegee het deur sy neus…
Cup feeds + (Equal)	Mother had a positive experience of cup feeding Reasons for this: - Infant managed this feeding method well	MS_P4: sy het nie geborsvoed nie, sy wou nie geborsvoed het nie en toe moes ek mos nou vir haar voer uit ‘n koppie uit en sy het gedrink uit die koppie uit baie sterk. MS_P3: en sy het van die *cup* bietjie gedrink… *she actually drank very well from the cup*
Cup feeds – (Equal)	Mother had a negative experience of cup feeding Reasons for this: - Infant struggled with this feeding method - Infant often choked with this method - Infant messed with this method	MS_P5: Dis net die *cup feed* was i*rritating* – ugh, ek haat die *cup feed*! Ek het dit gehaat. Want meeste van die tyd met die cup feed dan het hy verstik en daai kan ek nie vat nie. So toe ek by die huis kom toe stop ek die *cup feed*. PS_P2: Ek het meestal ge*stress* oor dit want sy kon nie lekker gekoppie nie. PS_P2: Met die koppie het ek mos bietjie gesukkel. En toe sien hulle eers agterna dis sy en nie ek nie.
Bottle feeds + *Interesting that no moms had negative	Mothers had a positive perception regarding bottle feeds and actively uses this method to feed their infant at home.	MS_P2: Toe ek vir hom beginne têt gee en toe wil hy nie die têt vat nie en toe het ons vir hom die bottel koop en die melk en toe is dit bietjie beterder. Nou as ek wil loop dan neem ek hom net na my antie toe en dan neem ek die melk en die bottel. So as

perceptions regarding bottle feeds. Some were very positive about bottle feeds (especially younger moms). Others were neutral but used bottles at home nonetheless (this was the older moms).	Reasons for this: - Infant prefers bottle to breast - Infant prefers formula to breastmilk - Mom more mobile (can work, has some free time) - Family members can take care of the infant	hy nou têt gedrink het dan kan ek nie vrye tyd gehet het nie… MS_P4: En toe koop ek vir haar ‘n bottel en van daar af drink sy nou bottel en sy drink ook nie borsmelk nie, sy wil nie borsmelk drink nie. Net formule. Want ek het probeer om vir haar bors te gee en sy wil dit nie hê nie. Sy wil nie suig nie. Sy suig net een keer en dan *worry* sy nie meer nie en toe sien ek sy wil seker nie borsmelk hê nie so ek gaan nou die formule melk probeer.

APPENDIX E: HREC APPROVAL LETTER

UNIVERSITEIT STELLENBOSCH UNIVERSITY

Approval Letter
Amendment

09/04/2019

Project Reference #: 6707

Ethics Reference #: S18/04/068

Project Title: The perceptions of mothers of preterm infants regarding communication, feeding and general caregiving, within low socioeconomic settings in the Western Cape.

Dear Miss Kristen Buys ,

Your amendment request dated 28 March 2019 refers.

The Health Research Ethics Committee (HREC) reviewed and approved the amended documentation through an expedited review process.

The following amendment was reviewed and approved:

- Additional co-investigator - Elanie van Schalkwyk

Where to submit any documentation

Kindly note that the HREC uses an electronic ethics review management system, *Infonetica*, to manage ethics applications and ethics review process. To submit any documentation to HREC, please click on the following link: https://applyethics.sun.ac.za.

Please remember to use your project ID 6707 and ethics reference number **(S18/04/068)** on any documents or correspondence with the HREC/UREC concerning your research protocol.

Yours sincerely,

Health Research Ethics Committee 2

National Health Research Ethics Council (NHREC) Registration Number:

REC-130408-012 (HREC1)•REC-230208-010 (HREC2)

Federal Wide Assurance Number: 00001372
Office of Human Research Protections (OHRP) Institutional Review Board (IRB) Number:
IRB0005240 (HREC1)•IRB0005239 (HREC2)

The Health Research Ethics Committee (HREC) complies with the SA National Health Act No. 61 of 2003 as it pertains to health research. The HREC abides by the ethical norms and principles for research, established by the World Medical Association (2013). Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects;the South African *Department of Health (2006). Guidelines for Good Practice in the Conduct of Clinical Trials with Human Participants in South Africa (2nd edition)*; as well as the Department of Health (2015). Ethics in Health Research: Principles, Processes and Structures (2nd edition).

The Health Research Ethics Committee reviews research involving human subjects conducted or supported by the Department of Health and Human Services, or other federal departments or agencies that apply the Federal Policy for the Protection of Human Subjects to such research (United States Code of Federal Regulations Title 45 Part 46); and/or clinical investigations regulated by the Food and Drug Administration (FDA) of the Department of Health and Human Services.

APPENDIX F: NHRD (TYGERBERG HOSPITAL) APPROVAL LETTER

Western Cape Government
Health

TYGERBERG HOSPITAL
REFERENCE:
Research Projects
ENQUIRIES: **Dr GG Marinus**
TELEPHONE:**021 938 5752**

Ethics Reference: **S18/04/068**

TITLE: **The perceptions of mothers of preterm infants regarding communication, feeding and general caregiving, within low socio economic settings in the Western Cape.**

Dear Ms Kristen Buys

PERMISSION TO CONDUCT YOUR RESEARCH AT TYGERBERG HOSPITAL.

1. In accordance with the Provincial Research Policy and Tygerberg Hospital Notice No 40/2009, permission is hereby granted for you to conduct the above-mentioned research here at Tygerberg Hospital.

2. Researchers, in accessing Provincial health facilities, are expressing consent to provide the Department with an electronic copy of the final feedback within six months of completion of research. This can be submitted to the Provincial Research Co-Ordinator (Health.Research@westerncape.gov.za).

DR GG MARINUS
MANAGER: MEDICAL SERVICES

DR D ERASMUS
CHIEF EXECUTIVE OFFICER
Date: 13 July 2018

Administration Building, Francie van Zilj Avenue, Parow, 7500 Private Bag X3, Tygerberg, 7505
tel: +27 21 938-6267 fax: +27 21 938-4890 www.capegateway.go.v.za

Ethics Reference: **S18/04/068**

TITLE: **The perceptions of mothers of preterm infants regarding communication, feeding and general caregiving, within low socio economic settings in the Western Cape.**

BY _____
An authorized representative of Tygerberg Hospital

NAME Dr DS Erasmus

TITLE CEO

DATE 13 July 2018

APPENDIX G: INFORMATION AND CONSENT FORM

INLIGTINGSBLAD EN TOESTEMMINGSVORM VIR DEELNEMERS

Titel van die navorsingsprojek:	
Die persepsies van moeders van premature babas aangaande kommunikasie, voeding en algemene sorgewing in lae sosio-ekonomiese gebiede in die Wes-Kaap.	
INLIGTING OOR HOOFNAVORSER (HN):	
Titel, voornaam, van: **Me. Elanie van Schalkwyk**	**Verwysingsnommer vir etiese goedkeuring:** **#6707**
Volledige posadres:	**HN se kontaknommer:**

Ons wil jou graag nooi om aan ’n navorsingsprojek deel te neem. Lees asseblief rustig deur die inligting hier onder, want dit verduidelik wat hierdie projek presies behels. Vra gerus die projekpersoneel as daar enige deel van die projek is wat jy nie heeltemal verstaan nie. Dit is baie belangrik dat jy moet voel jy weet presies waaroor die navorsing gaan en wat dit gaan beteken as jy daaraan deelneem. Onthou ook, jou deelname is **heeltemal vrywillig**, en jy mag weier om deel te neem. Met ander woorde, jy kan kies of jy wil deelneem of nie. As jy nee sê, sal daar niks slegs van kom nie. Dit sal jou op geen manier benadeel nie. As jy kies om nie deel te neem nie, sal dit geensins veroorsaak dat jy benadeel word, sekere voordele verloor of swakker versorg word as waarop jy andersins geregtig sou wees nie. Jy kan ook op enige tydstip sê jy wil nie verder aan die projek deelneem nie, selfs al het jy aan die begin ja gesê. ‘n Stemopname sal van die onderhoud gemaak word. Jy mag vir die onderhoudvoerder vra om die stemopname te stop of om dit te vernietig.

Die **Universiteit Stellenbosch se Gesondheidsnavorsingsetiekkomitee** (GNEK) het hierdie navorsingsprojek goedgekeur. Die projek sal uitgevoer word volgens die etiese riglyne en beginsels van die internasionale Helsinki-verklaring, die Suid-Afrikaanse riglyne vir goeie kliniese praktyk (2006), die Mediese Navorsingsraad (MNR) se riglyne vir etiese navorsing en die Departement Gesondheid se dokument ‘Etiek in Gesondheidsnavorsing: Beginsels, Prosesse en Studies’ (2015)

Waaroor gaan hierdie navorsingsprojek?

- Die studie sal plaasvind by die Hoë Risiko Opvolg Kliniek by Tygerberg Hospitaal. Afrikaanssprekende moeders van premature babas tussen drie en ses maande oud sal genooi word om deel te neem in die studie. Ons sal moeders uitnooi om deel te neem in die studie totdat ons voel ons

opregte insigte tot hulle ervarings en persepsies van die kommunikasie, voeding en algemene sorggewing van hulle premature baba (data versadiging) verkry het.

- Die studie probeer om te beskryf wat die moeders van premature babas dink en voel oor kommunikasie, voeding en algemene sorggewing met hulle premature baba. Moeders van premature babas ervaar dikwels moeilike emosies en situasies gedurende en na die hospitalisasie van hul premature baba. Dit sluit uitdagings tydens alledaagse take soos optel, voeding, aantrek, skoonmaak, speel en praat met hulle baba in. Deur die inligting in te samel kan ons die uitdagings wat hulle ervaar beter verstaan en aanspreek. Die studie wil dus moeders van premature babas help deur hulle te voorsien met die unieke inligting en ondersteuning wat hulle voel hulle benodig tydens die eerste jaar van die premature baba se lewe.

- Afrikaanssprekende moeders van premature babas wat die Hoë Risiko Opvolg Kliniek by Tygerberg Hospitaal bywoon, sal genooi word om deel te neem aan die studie. Die studie sal aan die moeder verduidelik word op ‘n manier wat sy verstaan. As die moeder bereid is om in die studie deel te neem sal sy ‘n onderhoud voer met ‘n enkele persoon in ‘n stil en privaat kamer. Die onderhoud sal nie langer as een uur wees nie en ‘n stemopname sal gemaak word. Die onderhoudvoerder sal vir die moeder vra oor haar ervaringe van kommunikeer, voed en sorg vir haar premature baba.

- Na die onderhoud sal die stemopname neergeskryf word. Jou naam sal geskei word van die inligting wat jy tydens die onderhoud verskaf het sodat jy anoniem bly.

Hoekom nooi ons juis vir jóú om deel te neem?

- Jy is ‘n Afrikaanssprekende moeder van ‘n premature baba wat die Hoë Risiko Opvolg Kliniek by Tygerberg Hospitaal bywoon. Jou baba is tussen drie en ses maande oud en het geen ander mediese diagnose buiten die geskiedenis van prematuriteit nie. Jy het ervaar hoe dit is om geboorte te skenk aan ‘n premature baba en hoe dit is om vir die baba te sorg (voed, aantrek, speel, was, gesels) in die hospital en by die huis. Ons wil meer weet van hierdie ervaringe.

Wat gaan ons van jou verwag?

- Jy word verwag om deel te neem in die onderhoud deur die vrae van die onderhoudvoerder na die beste van jou vermoë te antwoord.

Watter voordeel is daar vir jou as jy aan hierdie projek deelneem?

- Jy sal geen direkte voordele ontvang deur aan die studie deel te neem nie. Deur te gesels oor jou ervaringe mag dalk help om betekenis te gee aan die uitdagings wat jy beleef het in die afgelope paar maande. Hierdie studies sal wel toekomstige moeders van premature babas ondersteun deur die lewering van goeie en gepaste dienste spesifiek vir hierdie teikengroep te fasaliteer.

Watter gevare is daar vir jou as jy aan hierdie projek deelneem?

- Daar is geen fisiese risikos verbonde aan die deelname in die studie nie.
- Refleksie op uitdagende ervaringe mag dalk ‘n emosionele of traumatiese ervaring wees vir sommige deelnemers. Die nodige ondersteuning sal dan verskaf word.

As jy besluit om nié deel te neem nie, watter ander moontlikhede is daar vir jou?

- As u besluit om nie deel te neem aan die studie nie sal daar geen negatiewe gevolge wees nie. Jy sal dus kan huis toe gaan na jou mediese afspraak.

Wie sal kan sien wat in jou mediese lêer staan?

- Alle inligting (stemopnames en geskrewe material) sal as konfidensieel behandel word en veilig gestoor word. Hierdie inligting sal vernietig word sodra die studie voltooi is. U biografiese inligting sal geskei word van die res van die onderhoud om te verseker dat jy anoniem bly. Die onderhoudvoerder en haar navorsingstoesighouer is die enigste persone wat toegang tot die oorspronklike data sal hê. Items (tesis, artikels, aanbiedings) wat uit die studie ontstaan sal gedeel word met die groter navorsingsgemeenskap op verskillende platforms, maar u sal altyd anoniem bly.

Die kanse is baie skraal dat dit sal gebeur, maar wat as jy tóg op die een of ander manier beseer word omdat jy aan hierdie projek deelgeneem het?

- Die Universiteit Stellenbosch word deur omvattende skuldlose versekering gedek, en sal enige mediese koste betaal wat vir persone veroorsaak is omdat hulle aan hierdie projek deelgeneem het (ongeag of hulle die medikasie vir hierdie proefneming gebruik het, en of hulle op ’n ander manier deelgeneem het). Skuldlose versekering beteken jy hoef nie te bewys dat die borg (die Universiteit) skuld het aan die gebeure wat die kostes vir jou veroorsaak het nie.

Sal jy betaal word om aan hierdie projek deel te neem, of sal jý iets moet betaal?

- U sal nie betaal word vir jou deelname aan die studie nie, alhoewel verversings beskikbaar sal wees om u te bedank vir u ty den bereidwilligheid om aan die studie deel te neem.
- U sal nie vir u reiskoste Tygerberg Hospitaal toe vergoed word nie, aangesien die aanvanklike en hoof rede vir u besoek die bywoon van die mediese afspraak is.

Is daar enigiets anders wat jy moet weet of doen?

- Jy kan vir Elanie van Schalkwyk bel by 071 869 8052 indien daar enige verdere navrae is.
- Jy kan die Gesondheidsnavorsing Etiekomitee bel by 021 938 9677/9819 indien daar iets is wat die navorser nie vir jou verduidelik het nie, of as jy ‘n klag wil lê.

- Jy sal ‘n kopie van die inligting ontvang om te bewaar.

Verklaring deur deelnemer

Deur hier onder te teken, stem ek, ……..……., in om aan ’n navorsingsprojek met die titel (vul die projektitel hier in) deel te neem.

Ek verklaar soos volg:

- Ek het hierdie inligtingsbrosjure en toestemmingsvorm gelees, of iemand het dit aan my voorgelees, en dit is geskryf in ’n taal wat ek maklik praat en verstaan;
- Ek het kans gekry om vrae te stel, en al my vrae is duidelik genoeg beantwoord.
- Ek verstaan dat ’n mens **vrywillig** aan hierdie studie deelneem, en niemand het my gedwing om deel te neem nie.
- Ek besef ek kan op enige tydstip ophou om aan die projek deel te neem sonder dat ek enigsins gestraf of benadeel sal word.
- Ek verstaan dat ‘n stemopname van die onderhoud gemaak sal word en dat ek die navorser mag vra om dit te stop of vernietig.

Geteken te (*plek*) .....…..…….. op (*datum*) ……...…….. 2019.

Deelnemer se handtekening Getuie se handtekening

Verklaring deur navorser

Ek, *(naam)* ……..……, verklaar soos volg:

- Ek het die inligting in hierdie dokument op ’n eenvoudige en duidelike manier aan …….. verduidelik.
- Ek het die persoon aangemoedig om vrae te stel, en het genoeg tyd daaraan afgestaan om dit te beantwoord.
- Ek is tevrede dat die deelnemer alle aspekte van hierdie navorsing, soos dit hier bo uiteengesit is, ten volle verstaan.
- Ek het nie ’n tolk gebruik nie.

- Ek het ‘n stemopname van die onderhoud geneem.

Geteken te (*plek*) .....….....…….. op (*datum*) ……...…….. 2016.

Navorser se handtekening **Getuie se handtekening**

APPENDIX H: NUMBERED QUOTATIONS IN AFRIKAANS AND ENGLISH WITH PARTICIPANT SPECIFIED

NUMBER	AFRIKAANS	ENGLISH	PARTICIPANT
1.	Sy het 'n *tube* in haar mond gehad so sy het daardeur gevoed. Van die *tube* het sy na die *cup* gegaan…	She had a tube in her mouth so she fed through the tube. After the tube, she went to the cup…	MS_P3
2.	Toe is dit nou *kangaroo* en borsvoed. En hy moet nou *straight* drink van my bors af.	Then it is kangaroo and breastfeeding. And she must now drink straight from my breasts.	PS_P3
3.	*Because* ek het geweet die bors is wat vir haar gaan laat huis toe gaan.	Because I knew the breast is the thing that is going to let her go home.	PS_P2
4.	Ja, in die begin is die babatjie nie by jou nie. Hy is in die broeikas. Dit moet nou so wees want die babatjie is mos nog te klein. En dan begin te voed jy, hulle leer jou hoe om te voed die babatjie. Koppie voed en na koppie voed dan gaan jy weer na 'n saal toe waar die babatjie by jou is. En van daar af gaan jy huis toe.	In the beginning, the infant is not with you. He is in the incubator. For now, it must be like this because he is still too small. And then you start to feed, they teach you how to feed the baby. Cup feeding and after cup feeding, you go to another ward where your baby is with you. And from there you go home.	MS_P8
5.	En soos dit aan gaan, dan haar ml's elke dag hoër en hoër. Dan moet mens elke keer meer en meer potjies melk maak. Maar ek het altyd meer potjies melk in die *fridge* ge-het. Want hoe meerder sy begin te drink het, haar *percentage* het gou opgegaan.	And as it goes on, then her ml's [millilitres of milk required] goes higher and higher every day. Then you must make more and more pots of milk every time. But I always had more pots of milk in the fridge. Because	PS_P2

		the more she started to drink, the quicker her percentage [weight] went up.	
6.	En dan werk ‘n mens heeltyd na die mikpunt waar hulle 1.8… is die gewig. Want dan kan hulle mos huis toe gaan.	And then you always work towards the goal where they are 1,8 [kilograms]… the weight. Because then you can go home.	PS_P2
7.	Toe voel dit net vir my soos ek gaan nooit daar uitkom nie en dis nog ver want hulle het gesê hy moet ‘n sekere gewig weeg vir ons om te kan skuif.	To me it just felt like I was never going to get there [referring to 1,8 kilograms] and it’s still far because they said he must be this certain weight before we can move [go home].	MS_P7
8.	Dis baie *stress*vol eintlik. Om te kyk hoe hulle moet groei.	It’s actually very stressful… to watch how your infant must grow.	PS_P2
9.	So daai was baie hard gewees want hy het nie elke dag opgetel ook nie… so die een dag is ek *excited* want hy het nou opgetel, maar die volgende dag is ek nou weer af want…	So it was very hard because he didn’t pick up weight everyday… so the one day I’m excited because he picked up weight but the next day I’m off [sad] because [referring to no or poor weight gain]…	MS_P5
10.	Ja, soos ons kyk elke dag in die lêers hoeveel hulle weeg. Of jy kan vra vir die suster of so. Maar nou is jy deurmekaar want jy vra wat moet jy doen dan die kind gewig optel, wat presies moet jy doen. Dan sê hulle nou jy moet die kind KMC, jy moet melk *express* en jou eie melk gee, maar vir my was dit ek het	Every day we look in the files to see how much they weigh. Or you can also ask the sister or so. But then you are confused because you ask – what must I do for the child to pick up weight, what exactly must I do?	MS_P7

	alles daai gedoen en ek het amper heeldag by hom gesit. Ek het in die middag dan het ek besluit, OK, ek gaan nou nie meer slaap nie. Ek gaan nou net by hom wees sodat hy nou net gouer kan optel en toe verstaan ek nie want ek doen dan nou alles reg, maar nog altyd.	Then they say you must KMC the child, you must express your milk and give your own milk but for me, it was like I'm doing all of those and I was sitting with him for almost the whole day. In the afternoon I would decide, OK, I'm not going to sleep anymore. I'm only going to be with him so he can pick up quicker [referring to weight gain] and then I didn't understand because I'm doing everything right, but still [referring to the infant not gaining weight].	
11.	*Cause* as sy gaan afval dan moet hulle die *tubie* terugsit en dan gaan ek nog langer bly en ek wil net huis toe gaan.	'Cause if she drops [referring to weight] then they have to put the tube back in and then I will stay here even longer and I just want to go home.	PS_P2
12.	Ek het al sommer gebid vir die Here, gebid vir my my vir melk want ek was al op daai stadium die kinders *need* melk want hulle moet groei.	I started praying to the Lord, I prayed for my milk because at that stage I was like the children need milk because they must grow.	MS_P6
13.	Vir my was die ervaring… *it was fine when I found out I was pregnant, but afterwards it was horrible! It was horrible!* Want ek het niks *milk* gehad nie en ek het nie geweet wat om te doen nie… want sy huil die hele tyd en hulle *force* my vir *milk* en ek was net soos **ek**	To me the experience was… it was fine when I found out I was pregnant but afterwards, it was horrible! It was horrible! Because I had no milk and I didn't know what to do…	MS_P3

	het nie *milk* nie! So die dokter het vir my 'n pil of iets gegee om *milk* te maak, *but* dit het ook nie gehelp nie so… *I was like… I was at a point where I was crying because she was crying!* Ek het nie geweet wat om te maak nie!	because she cries the whole time and they are forcing me for milk and I was just like I don't have milk! So the doctor gave me a pill or something to make milk but it also didn't help so… I was like… I was at a point where I was crying because she was crying. I didn't know what to do!	
14.	Dit was baie *stress*vol. Baie, baie baie. *Because* ek het geweet die bors is wat vir haar gaan laat huis toe gaan. En haar gewig was al 1,8 al en toe kon sy nog nie gaan nie want sy het nog nie gebors nie.	It was very stressful. Very, very, very. Because I knew the breast is what's going to let her go home. And her weight was already 1,8 [kilograms] and then she still couldn't go because she couldn't breast [breastfeed].	PS_P2
15.	So vir my was dit okay gewees in die begin, dit was net *sad* omdat ek nou nog nie vir hom kon *gebreastfeed* het nie. Ek het baie gehuil oor ek nie kon *gebreastfeed* het nie want ek het gedink my kind gaan nooit die bors vat nie.	So to me it was okay in the beginning, it was just sad that I couldn't breastfeed him. I cried a lot because I couldn't breastfeed him because I thought my child is never going to take the breast.	MS_P5
16.	Sy het vir die eerste paar dae gemors – uitgespoeg, het nie geweet hoe om dit regtig te sluk nie en toe agterna toe raak dit vir my makliker.	She messed for the first few days – spit it [milk] out, didn't really know how to swallow it. And then afterwards it got easier for me.	MS_P4
17.	In die begin toe hy gebore was het ek gesukkel met die melk en dit het ook vir	In the beginning when he was born, I struggled with	MS_P7

	my so bietjies uitges*tress* want hulle het vir my gesê hy moet my melk kry want dit gaan vir hom gouer help.	the milk and that stressed me out a bit because they told me that he must get my milk because it will help him quicker.	
18.	Maar eintlik al ding van hulle is net – jy moet jou melk gee. Daai was vir my net so groot stres, die melk. Ek dan skuif hulle dit so op, hulle skuif dit so op op op – op die ou einde is dit so baie melk dat jy nie eers kan amper daai totaal gee nie… want ek het eerste in die begin by die huis geslaap dan los ek miskien nou 'n dag se melkies, maar dan skuif hulle dit nou opper en opper en opper. Dan kan ek nou nie meer daai totaal nie.	But actually the only thing about them [nursing staff] is – you must give your milk. That was such a big stress to me, the milk. And then they move it up, they move it up up up – at the end, it is so much milk that can't even almost give that total… because in the beginning, I slept at home and then maybe I leave a day's milk but then they move it upper and upper and upper. Then I can't give that total anymore.	MS_P6
19.	Joh want jy moet *express* en baie van ons weet mos nou nie hoe om te *express* nie en dis seer en jou melk kom nie.	Because you must express and many of us don't know how to express and it's sore and your milk doesn't come.	MS_P6
20.	Ja, want hierso is dit so hulle *push* jou so vir melk dat die hele ding is net melk, melk, melk!	Yes because here it's like they push you for milk and the whole thing is just milk, milk, milk!	MS_P6
21.	En hulle was net *like* jy moet *breastfeed*, jy moet melk uitdruk en ek was *like* ek kan nie. En *even* daai soos wat jy elke twee ure moet wakker word om te *express*, ek moes daai doen *even* al het ek nie milk nie en daar kom niks nie!	And they were just like you must breastfeed, you must express milk and I was like I can't. Even that where you must wake up every two hours to express, I had to do	MS_P3

		that even though I didn't have milk and nothing comes!	
22.	En dit was soos *hell* daar *cause* die *nurses gossip*, die hele milk ding, ek het nie milk nie so hulle sal soos *gossip* en my *force* vir milk en *all that.* So dit was regtig *horrible*!	And it was like hell there cause the nurses gossip, the whole milk thing, I don't have milk so they will gossip and force me for milk and all that. So it was really horrible!	MS_P3
23.	Daar was dae wat ek nie geweet het moet ek huil, moet ek lag… want aan die een kant, ek kan nie *stress* nie want my kinders drink my melk so ek moet nou kalmte wees anders het ek nie melk vir hulle nie. En joh, dit was moeilik.	There were days that I didn't know must I cry, must I laugh… because on the one side, I can't stress because my children are drinking my milk so I must be calm otherwise I won't have milk for them. And wow, this was hard.	MS_P6
24.	En hulle wou nie vir haar *formula* gee nie want sy is te jonk so hulle is bang vir haar *intestines* en *all that*.	And they didn't want to give her formula because she was too young and they are scared for her intestines and all that.	MS_P3
25.	Saterdag toe die suster nou vir my sê ek moet vir hom borsvoed toe is dit so 'n *amazing* gevoel dat hy aan my borste is... ek kan dit vir niemand *explain* daai *amazing* gevoel nie, dit soos *butterflies* wat ek in my binneste gevoel het toe hy die eerste keer aan my gedrink het.	The Saturday when the sister told me I must breastfeed him it was such an amazing feeling that he was on my breasts… I can't explain it to anyone that amazing feeling, it's like butterflies that I felt inside of me when he drank from me the first time.	PS_P3

26.	Toe kom die melk nou ‘n bietjie beter, toe beginne kom dit. Want die een ling was huis toe gestuur voor die ander enetjie en toe hy nou kan beginne drink toe stimuleer die bors mos nou en toe kom die melkies beter.	When the milk came a bit better, then it started coming. Because the one was sent home before the other [mother of twins] and then he could start drinking and it stimulated the breast and then the milk came better.	MS_P6
27.	*Because why* sy gaan nou groei	Because why, she is going to grow now.	PS_P2
28.	Omdat hulle gesê het hy tel gouer op en die melk wat ek moes *express* moet in die yskas so dis nou nie vars melk wat hulle vir hom gee nie. So toe voel ek net *excited* oor die melk wat hy van my af kry want dis mos nou vars melk.	Because they said he picks up quicker and the milk that I had to express had to go in the fridge so it’s not fresh milk that they give him. So then I felt excited about the milk that he is getting from me because now it is fresh milk.	MS_P7
29.	Want borsvoed is *amazingly* gesond. Dit het alles in. Dis hoekom ek nie *much* is oor die boksmelk nie. Ek sal vir hom baie meer dit gee as daai. Maar obviously moet ek vir hom daai gee as ek nie by die huis is nie.	Because breastfeeding is amazingly healthy. It has everything in. That’s why I’m not much about box milk. I’ll give him much more of this [points to breast] than that. But obviously, I have to give him that if I'm not at home.	MS_P5
30.	*Because* ek het geweet die bors is wat vir haar gaan laat huis toe gaan.	Because I knew the breast is what’s going to let her go home.	PS_P2
31.	Maar waar ek die moeder en kind gevoel gekry het was toe ek hom die eerste keer	Where I got the mother-and-child feeling the first time was when I had him	PS_P3

	hier (wys na bors) by my gehad het. Toe voel ek daai tussen ons twee.	here [points to chest] by me. Then I felt it between us two.	
32.	Dit was net *amazing* want hy moet hier (wys na bors) heeldag by my sit	It was just amazing because he has to sit here [shows to breasts] with me the whole day.	PS_P3
33.	Die *main* ene is hoe ek met hom kommunikeer is deur dat ek kom borsvoed. Daai is vir my 'n baie spesiale tyd met my kind. Want dan is dit vir my hy drink 'n deel van my. Van alles en alles... daai is vir my baie spesiaal.	The main one of how I communicate with him is by breastfeeding him. That is a very special time with my child. Because then it is to me like he's drinking a part of me. All and all (Van alles en alles) … that is very special to me.	PS_P3
34.	Dit het my goed laat voel want soos nou voel dit vir my OK, ek is nou 'n ma uiteindelik (laughs). Ek is nou 'n ma want hy drink nou aan my.	It made me feel good because now it feels to me like okay, now I am a mother at last (laughs). I am now a mother because he drinks from me.	MS_P7
35.	Ja, so vir my was dit ook eintlik nou voor hy nou aan my bors begin drink het het ek ook gevoel ek voel nie regtig soos ek is nou eintlik 'n ma nie want ek bedoel maar hy was nog in die broeikassie en ek moet nou net daar sit en ja.	Yes, so to me it actually was like before he started drinking from my breasts I felt like I'm not really like I'm not actually a mother because I mean he was still in the small incubator and I must just sit there and yes.	MS_P7
36.	Dis net…. Dis niemand se huis nie. Dis net anders as wat dit by die huis is.	It's just... (The hospital) isn't anybody's home. It's just different from what it would be like at home.	MS_P8

37.	Maar toe ons by die huis kom toe verander alles. Ek was baie ge*stress* in die hospitaal omdat ek is nie ‘n hospitaal *person* nie en ek ken nie van ‘n hospitaal nie.	But when we got home then everything changed. I was really stressed in the hospital because I’m not a hospital person and I don’t know hospitals.	MS_P5
38.	Dit was *actually* moeiliker in *hospital than* wat dit is by die huis… ek dink dis omdat die *hospital* is baie *controlled like* jy **moet** *feed* op die tyd, jy **moet** die *nappy change* as jy haar *feed*, jy **moet** dit doen… maar by die huis is dit meer soos hulle gee *signals* as die *nappy* nat is of… *like* sy huil net as sy honger is of as haar *nappy* nat is.	It was actually harder in hospital than it was at home… I think it's because the hospital is very controlled like you must feed at this time, you must change the nappy when you feed her, you must do it… but at home, it's more like they give signals when the nappy is wet or… like she will cry when she's hungry or if her nappy is wet.	MS_P3
39.	As jy moet bly, moet jy bly – dis jou kind se gesondheid. Jy kan ook nie teenstrydig wees nie.	If you must stay, you must stay – it is your child’s health. You can’t be against it.	MS_P8
40.	Dis net… wat jou gelukkig ook maak en so om te weet jou babatjie is gesond. Want baie toetse en goed word, en jy sê vir jouself ‘n gesonde babatjie wil ek hê, ‘n baba wat se brains reg is. Jy wil net het hê al die toetse wat hulle met jou babatjie doen moet oraait wees so jy bly en jy kyk al die toetse wat dokter doen is oraait. Jy moet eintlik met ‘n goeie hart huis toe gaan, jy moet weet alles is nou normaal met my babatjie. Nie jy wil huis toe gaan en oh jissie, ek weet nie of my kind normaal gaan dink nie. Gaan my	It’s just that what makes you happy is knowing your baby is healthy. Because lots of tests and stuff are done and you tell yourself I want a healthy baby, a baby whose brains are right. You want all the tests they do with your baby to turn out fine, so you stay, and you check that all the tests that the doctor does are okay. Actually, you must go home	MS_P8

	kind kan sien en dis al daai. Maar dis lekker as dokter vir jou kan sê, nee alles is normaal met die babatjie. Jy stap met 'n normale babatjie huis toe, al het hy voor die tyd gekom.	with a good heart, you must know that everything is now normal with your baby. Not go home and then oh no, I don't know if my child is normal. Will my child be able to see and all that. But it is nice when the doctor tells you, now everything is normal with the baby. You walk away with a normal baby, even if he came before the time	
41.	So dan sal sy nou met ons kom sit en met ons gesels en verduidelik die babatjie moet so gehou word en jy moet so maak met die babatjie en as die babatjie verstik dan moet jy hier jou hand so hier sit en die neus toe hou en die kop ophou. So daar was dit baie beter, hulle het ons baie gehelp.	So then she will come and sit and talk to us and explain the baby must be held like this and you must do this with the baby and if the baby chokes then you must put your hand here and close the nose and hold the head up. So there it was much better, they helped us a lot.	MS_P4
42.	Dis net somtyds was die nurses so bietjie… as ons voed. Maar hulle is eintlik streng.	It's just sometimes the nurses were a little… when we feed. They were actually strict.	PS_P2
43.	Hulle was amper soos jy moet net weet hoe nou… amper soos hulle doen al jare die werk so hulle wys nou net een keer vir jou en jy moet al weet hoe die volgende keer.	They were almost like you must just know how… almost like they are doing this work for years so now they show you only once and you must already know the next time.	PS_P2

44.	Maak ‘n voorbeeld, soos ek sal miskien nou vra hoe moet ek nou maak met die of hoe met ek nou maak met daai? Dan voel hulle miskien nou, nee man, ek het nou al hoeveel keer al verduidelik al vir die een en vir daai een. Dan sal hulle miskien nou raas op jou en jy weet nou nie hoekom hulle so sê of hoekom hulle so lelik is nie.	Make an example, like I will maybe ask now how must I do with this or how must I do with that? Then they [nursing staff] maybe feel like, no man, I have explained this how many times already to this one and to that one. Then they will maybe scold you and then you don’t know why they are saying so or why they are so rude.	MS_P7
45.	Dis net met die *breastfeeding*. Ek het altyd gedink iemand kan kom en vir mens leer en vir mens sê hoe die *breastfeeding* werk *cause why* die babatjie vat altyd in die begin die bors sommer net so en so bietjie sukkel.	It’s just with the breastfeeding. I always thought that someone can come and teach us and tell us how the breastfeeding works ‘cause why the baby just takes the breast in the beginning and struggles a bit.	PS_P2
46.	*Like now I will know*… sy sal suig aan haar hand as sy honger is.	Like now I will know… she will suck on her hand if she’s hungry.	MS_P3
47.	Is net *bottle*. Ek gee net *bottle* nou ook, uhm, sy weet nou hoe om te *suck*… maar sy *suck* net aan soos *round teats like* een wat soos ‘n *nipple* is. *Cause* ek het ge*try* om een te koop wat die meeste soos ‘n *nipple* lyk laat sy kan leer om te *suck*.	It’s just bottle. I just give bottle now too, uhh, she knows how to suck now… but she only sucks on rounds teats like the one that is like a nipple. Cause I tried to buy one that looks the most like a nipple so she can learn how to suck.	MS_P3

48.	In die begin was dit vir my baie *awkward* gewees want dis my eerste babatjie, ek weet nie hoe om hom te hanteer nie, hoe om vir hom te vat nie en net nou maak ek hom seer...	In the beginning, it was very awkward for me because it's my first baby, I don't know to handle him, how to take him and just now I hurt him…	PS_P3
49.	So dit was *like* baie moeilik vir my want ek het nie geweet om die goed te doen nie en nou moet ek leer en dan raak ek *irritated*… soos ek moes leer oor *like bottles* en *all that – making bottles, cleaning bottles*.	So it was like very difficult for me because I didn't know how to do the stuff and now I must learn and then I become irritated… like I had to learn about like bottles and all that – making bottles, cleaning bottles.	MS_P3
50.	Ek het dit alles hier geleer. Ek het niks geweet van *premature* nie. Ek het alles dag-na-dag geleer… die *nurses* dopgehou, geluister wat die dokters praat, en dan het ek net vir haar ook beginne dop te hou en so het ek geleer.	I learned everything here. I didn't know anything about premature. I learned everything day after day… observed the nurses, listened to what the doctors are talking, and then I also started watching her and this is how I learned.	PS_P2
51.	Ons het nou gister begin met die pap en hy eet die pap baie *nice*. Ons gaan nou vandag begin met die groente en vrugte want dokter het gesê ons moet nou begin met daai ook.	We started with the porridge yesterday and he eats the porridge very nicely. We are going to start with the vegetables and fruits now because the doctor said we must now also start with that.	MS_P5
52.	Ek het myself gewys en myself gehelp. OK, ek het bietjie in die rondte gekyk hoe dit gedoen moet word… vir my was dit nou ek is nie seker of ek dit so moet	I showed myself and helped myself. Okay, I did look around a little bit to see how it must be done…to me, it	MS_P4

	doen of so nie, maar OK ek gaan dit op my eie manier probeer doen en dan werk dit!	was that I'm not sure if I must do it so or so but okay I'm going to try doing it my own way and then it works!	
53.	Hulle binnegoed is amper mos soos nie volheid ge-ontwikkel nie… soos waar 'n volle nege maande baba as jy geboorte gee, hulle gee die baba vir jou en jy sit vir baba op die bors en die baba *click* dadelik ek moet nou drink en so aan. Die *difference* met hulle is, hulle kan nie sommer drink as hulle uitkom nie, hulle is *like* hulle weet nie hulle moet drink nie.	Their insides are almost like not fully developed… like where a full nine-month baby when you give birth, they give your baby to you and you put baby on the breast and the baby clicks immediately I must drink now and so on. The difference is with them that they can't just drink when they come out, they are like they don't know that they must drink.	MS_P6
54.	En toe het ek hom nou begin aansit en so en hy het lekker geleer en darem lekker beginner drink en so.	And then I started putting him on [referring to breastfeeding] and so and he learned nicely and luckily started drinking nicely and so.	MS_P7
55.	Die voeding het ek mos nou deur die pypie gegee en dit was vir my... eintlik maklik gewees.	The feeding I gave through the tube and to me that was … actually it was easy.	PS_P3
56.	Uhm dan is mos nou die buisie wat hulle nou… met al die voeding goeters het my kind se gewig baie mooi opgetel. So vir my was daai nie 'n problem nie.	Uhm then it is the little tube that they… with all the feeding things my child's weight picked up nicely. So to me, that wasn't a problem.	MS_P5

57.	Ek moes mos nou vir haar voer uit 'n koppie uit en sy het gedrink uit die koppie uit baie sterk.	I had to feed her with a cup and she drank from the cup very strongly.	MS_P4
58.	Dis net die *cup feed* was i*rritating* – ugh, ek haat die *cup feed*! Ek het dit gehaat. Want meeste van die tyd met die cup feed dan het hy verstik en daai kan ek nie vat nie. So toe ek by die huis kom toe stop ek die *cup feed*.	It's just the cup feed was irritating – ugh, I hate the cup feed! I hated it. Because most of the time with the cup feed then he chokes and that I can't take. So when I got home I stopped the cup feed.	MS_P5
59.	En toe koop ek vir haar 'n bottel en van daar af drink sy nou bottel en sy drink ook nie borsmelk nie, sy wil nie borsmelk drink nie. Net formule. Want ek het probeer om vir haar bors te gee en sy wil dit nie hê nie. Sy wil nie suig nie. Sy suig net een keer en dan *worry* sy nie meer nie en toe sien ek sy wil seker nie borsmelk hê nie so ek gaan nou die formule melk probeer.	And then I bought her a bottle and since then she drinks bottle and she also doesn't want breastmilk. Only formula. Because I tried to give her breast and she didn't want it. She doesn't want to suck. She only sucks once and then she doesn't worry anymore and then I saw that she probably doesn't want the breastmilk so I'm going to try the formula.	MS_P4
60.	Toe ek vir hom beginne têt gee en toe wil hy nie die têt vat nie en toe het ons vir hom die bottel koop en die melk en toe is dit bietjie beterder. Nou as ek wil loop dan neem ek hom net na my antie toe en dan neem ek die melk en die bottel. So as hy nou têt gedrink het dan kan ek nie vrye tyd gehet het nie…	When I started giving him breast and then he didn't want to take the breast and then we bought him the bottle and the milk and then it went a little better. Now if I want to walk then I take him to my auntie and then I take the milk and the bottle.	MS_P2

		So if he drank breast then I couldn't have free time…	