

Maternal experiences of prematurity, feeding and infant communication within a vulnerable population in South Africa

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DECLARATION

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ABSTRACT

Background

The concept of vulnerability, as defined by Adger (2006), relates to an individuals' "state of susceptibility to harm, powerlessness, and marginality" (p. 286). Respectively, the 'vulnerable' participants consisted of mothers of preterm infants, belonging to a largely marginalised indigenous cultural community (isiXhosa-speaking), living within low socioeconomic circumstances. Preterm birth remains a rising global threat to maternal and infant mortality and morbidity, with preterm birth accounting for 5-18% of births worldwide. Mothers, and other primary caregivers of preterm infants, face many day-to-day caregiving challenges. These mothers' experiences are influenced both positively and negatively by a myriad of factors, including traditional/cultural, socioeconomic and contextual influences. Understanding the daily realities these mothers face is thus essential in designing and providing interventions that are contextually appropriate for the patient populations. A need for and striving towards culturally competent healthcare is being globally recognised, but studies with such vulnerable populations are difficult to source. Such knowledge is necessary for evidence-based practice, however, a notable knowledge gap in terms of such vulnerable populations is evident.

Aims and Objective

The main objective of this study was to describe and explain the maternal experiences of having, caring for, feeding and communicating with their (the mothers') preterm infants in low socioeconomic circumstances in South Africa. The study explored such experiences of those isiXhosa-speaking mothers; a vulnerable population about whom limited knowledge is available. This objective was achieved through eight sub-aims.

Participants and Methodology

The study employed a qualitative cross-sectional design that was explorative in nature. A semi-structured discussion schedule was used to guide 15 in-depth interviews that were later thematically analysed. The participants were vulnerable mothers of preterm infants who were born and received follow-up appointments at the tertiary hospital serving as the research site. The participants' infants were of stable medical health and between the ages of three and six months chronological age (term – three months corrected age) and had spent a minimum of one week at home after hospital discharge.

Findings

Briefly, caring for a preterm infant was difficult, with concerns about medical stability and negative perceptions of tube feeding contributing to this negative initial experience. In-hospital support systems such as nursing staff, kangaroo mother care (KMC), information sessions and religious services provided positive influences throughout the hospital stays. Furthermore, home-based support systems (for example, with caregiving and chore-based, emotional and financial support) appeared to be one of the most positive aspects of mothers' overall experiences. Additionally, prematurity influenced maternal decision-making and mothers showed high perceptions of infant vulnerability. It was also found that the hospital staff's poor understanding and knowledge of cultural traditions surrounding infant birth impacted mothers' abilities to participate in certain traditional practices such as *Imbeleko* (the first ceremony that is performed when a baby is born).

Conclusion

The findings highlighted both universally shared and population-specific aspects of having and caring for a preterm infant. Important information emerged regarding influential factors within such maternal experiences, as well as information that may assist healthcare workers in providing mothers with premature infants with culture-specific care.

UITTREKSEL

Agtergrond

Die konsep van kwesbaarheid, as omskryf deur Adger (2006), hou verband met 'n individu se 'toestand van vatbaarheid vir skade, magteloosheid en marginaliteit' (p. 286). Die 'kwesbare' deelnemers bestaan uit moeders van vroeggebore babas, wat deel uitmaak van 'n grootliks gemarginaliseerde inheemse kultuurgemeenskap (isiXhosa-sprekend), wat onder lae sosio-ekonomiese omstandighede leef. Premature geboortes hou wêreldwyd toenemend 'n bedreiging in vir moeder- en babasterftes en -mortaliteit, met 5% tot 18% van alle babas oor die wêreld wat prematuur gebore word. Moeders en ander primêre versorgers van premature babas kom daaglik voor talle versorgingsuitdagings te staan. 'n Menigte faktore, met inbegrip van tradisionele/kulturele, sosio-ekonomiese en kontekstuele invloede, het 'n positiewe sowel as 'n negatiewe invloed op hierdie moeders se ervarings. Gevolglik is dit noodsaaklik om die daaglikse werklikhede waarmee hierdie moeders gekonfronteer word, te verstaan ten einde ingrypings te ontwerp en te voorsien wat kontekstueel geskik is vir die pasiëntbevolking. 'n Behoeftes aan en 'n strewe na kultuurgeskikte gesondheidsorg word wêreldwyd erken, maar dit is moeilik om studies oor sulke kwesbare populasies te vind. Ofskoon dié kennis noodsaaklik is vir bewysgebaseerde versorging, is dit duidelik dat daar ongetwyfeld 'n tekort aan kennis betreffende sulke kwesbare bevolkingsgroepe bestaan.

Doelstelling en doelwitte

Die hoofdoelstelling van hierdie studie was die beskrywing en verduideliking van moeders in swak sosio-ekonomiese omstandighede in Suid-Afrika se ervaring daarvan om premature babas te hê, hulle te versorg en te voed, en met hulle te kommunikeer. Hierdie studie het sulke ervarings van Xhosa-sprekende moeders ondersoek; 'n kwesbare groep oor wie slegs 'n beperkte hoeveelheid inligting beskikbaar is. Hierdie doelstelling is deur agt sekondêre doelwitte bereik.

Deelnemers en metodologie

'n Kwalitatiewe deursnee-ontwerp wat verkennend van aard is, is in die studie gebruik. 'n Semigestruktureerde besprekingskedule is as riglyn gebruik vir 15 diepgaande onderhoude wat later tematies ontleed is. Die deelnemers was kwesbare moeders van vroeggebore babas wat gebore was en opvolgbehandeling ontvang het in die tersiêre hospitaal wat as die navorsingsterrein gedien het. Al die deelnemers was vroue met 'n lae sosio-ekonomiese status

(soos bepaal deur opvoedkundige status en finansiële inkomste) wat in die omgewing van die tersiêre hospitaal gewoon het. Die deelnemers se babas was stabiel en gesond en hulle chronologiese ouderdom was tussen drie en ses maande (termyn – drie maande reggestelde ouderdom) en was reeds vir minstens ’n week tuis nadat hulle uit die hospitaal ontslaan is.

Bevindings

Kortliks, dat dit moeilik is om ’n premature baba te versorg, en dat kommer oor mediese stabiliteit en negatiewe persepsies van buisvoeding bygedra het tot die aanvanklik negatiewe ervaring. Die hospitaal se interne ondersteuningstelsels soos verpleegpersoneel, kangaroo-moederversorging (KMV), inligtingsessies en religieuse dienste was dwarsdeur die hospitaalverblyf positiewe invloede. Verder het tuisgebaseerde ondersteuningstelsels (byvoorbeeld ondersteuning met versorging en daaglikse huiswerk, asook emosionele en finansiële steun) geblyk een van die positiefste aspekte van die moeders se algehele ervaring te wees. Verder het die premature geboortes die moeders se besluitneming beïnvloed en hulle het sterk persepsies van die babas se kwesbaarheid getoon. Ook is daar gevind dat die hospitaalpersoneel se swak begrip en gebrekkige kennis van kulturele tradisies betreffende kindergeboorte ’n impak gehad het op die moeders se vermoë om deel te neem aan sekere tradisionele gebruike soos *Imbeleko* (die eerste seremonie wat plaasvind nadat ’n baba gebore is).

Slotsom

Die bevindings onderstreep sowel universele as bevolkingspesifieke aspekte daarvan om ’n premature baba te hê en te versorg. Belangrike inligting het aan die lig gekom oor faktore wat ’n invloed uitoefen op sulke ervarings van moeders, asook inligting wat gesondheidsorgwerkers kan help in die voorsiening van kultuurgeskikte sorg aan moeders van premature babas.

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LIST OF ABBREVIATIONS

AAP – American Academy of Pediatrics

ADHD – Attention Deficit and Hyperactivity Disorder

ART – Anti-Retroviral Treatment

ASHA – American Speech-Language-Hearing Association

EBP – Evidence Based Practice

ELBW – Extremely Low Birth Weight

HIV – Human Immunodeficiency Virus

LBW – Low Birth Weight

NICU – Neonatal Intensive Care Unit

PEG tube – Percutaneous Endoscopic Gastrostomy

SES – Socio-Economic Status

SLP – Speech-Language Pathologist

SLT – Speech-Language Therapy

SSB cycle – Suck Swallow Breathe cycle

TB - Tuberculosis

TBM – Tuberculosis Meningitis

TPN – Total Parenteral Nutrition

VLBW – Very Low Birth Weight

WHO – World Health Organization

PTSD – Post Traumatic Stress Disorder

UNAIDS – United Nations (Programme) on HIV and AIDS (Acquired Immune Deficiency Syndrome)

NEC – Necrotising Enterocolitis

GT – Grounded Theory

HREC – Health Research Ethics Committee

NHRC – National Health Research Committee

NHRD – National Health Research Department

CAQDAS – Computer Assisted Qualitative Data Analysis Software

Chapter 1:

INTRODUCTION

1.1 Introduction

Technological advances in the areas of general medicine, neonatal care and early complication detection technologies have resulted in the rise in the number of preterm infants who are surviving at younger gestational ages with lower birth weights (Preterm birth: Factsheet, WHO, 2017). Although there is currently no statistical data available regarding this phenomenon in South Africa, Beck et al. (2010) reported that premature birth rates tend to be higher in the global south¹, with 60% of these premature births occurring in Africa and Asia (Blencowe et al. 2012). Additionally, studies have linked incidence of preterm birth and low socioeconomic status (SES) (Potjik et al., 2013), which unfortunately affects a large portion of the South African population as recent statistics show that over 55% currently reside in poverty-stricken circumstances (Statistics South Africa, 2017). Preterm infants are at risk for a host of medical and developmental complications that may influence development in many areas, such as that of feeding and communication (Tanner, 2010). The risk of developmental delays for preterm infants is said to be twice that of infants born at a normal gestational age (Potjik et al., 2013). In discussions of risks related to childhood development, it is important to acknowledge the influence of external factors posing as additional risks as well as protective influences. In the South African setting, the general population is exposed to a unique burden of disease (such as HIV and tuberculosis), as well as poverty-related difficulties such as poor housing environments and difficulty accessing healthcare. Such factors may influence preterm infants either directly or indirectly, through maternal involvement. Mothers are often the primary caregivers and thus the individual with whom the infant or child spends most of their time. Mothers can therefore be described as the infants' most direct 'access point' to a world of influence. Thus, mothers may provide protection against or mediation of possible developmental risks, such as illness, or create contexts posing as further risk to development and infant wellbeing (for example poor infant nutritional support, failure to provide necessary medication, or poor developmental stimulation²). Mothers are therefore highly important components within infant and child interventions. The wellbeing of the mother is therefore also important, not just as a prime influence in the infant's life but also due to her intrinsic worth as a person. Over widespread literature it is commonly

¹ 'Global south': This term refers to the North-South divide, which is broadly considered that of a socioeconomic divide. The 'global south' refers to those low-to middle-income countries, generally located in the southern hemisphere, such as Southern African and Asian countries. The 'global north' refers to more westernized and industrialized countries, which are generally located in the northern hemisphere, such as the United States of America.

² Developmental stimulation refers to those caregiver-child interactions intended to assist with an aspect of development, for example teaching the children new words and expanding their vocabulary or teaching them new skills.

found that having a preterm infant is traumatic and stressful for the mother (Steyn et al., 2017). Furthermore, mothers of preterm infants are found to have increased risk of developing anxiety and depression (Allen et al., 2004). Such experiences may influence maternal interactions and caregiving patterns with their preterm infants, thereby influencing infant development.

Speech-Language Pathologists (SLPs) play an important role in the prevention, assessment, diagnosis, and management of communication and swallowing disorders in preterm infants, as well as the education and training of caregivers from the time of the child's birth (ASHA, 2004). The importance of the SLP's role within the preterm population is becoming increasingly emphasized as the incidence of premature births and accompanying possible complications increase. Maternal (or primary caregiver) perceptions, interaction styles and caregiving behaviours within the first year of life are powerful influences on the development of prelinguistic skills (early communication development). Similarly, maternal developmental knowledge is important for the early identification of communication and feeding difficulties. Early identification and stimulation act as protective and preventative factors regarding potential communication and feeding difficulties. Maternal knowledge, beliefs, behaviours and experiences of having and caring for a premature child may affect mother/caregiver-child interaction within the premature child's first year of life as well as the wellbeing of the mother herself. In the global south, in countries such as South Africa, many mothers and caregivers from different linguistic and cultural backgrounds are subjected to a combination of stressors such as low levels of education, low socioeconomic status (SES), and other environmental stressors (Walker et al., 2011). These factors interact to affect the experience of caring for a premature infant in a unique manner. Like all forms of speech-language therapy (SLT) services, intervention strategies at the prelinguistic stage of development (typically the first year of infant life) should be sensitive to the perceptions, preferences, practices and needs of the client. However, there exists limited information about maternal experiences, beliefs and knowledge about prematurity (and development) within the South African population.

Past research has been largely conducted within middle-class western populations, which is not applicable to the majority of South Africa. South Africa, home to a celebrated variety in language and culture, thus houses many unique groups that are not well presented in such literature. Due to this poor representation, such groups are likely to be vulnerable to knowledge gaps and poor access to healthcare resources ill equipped to effectively service such populations. The HPCSA calls healthcare providers to improve their "cultural competence", which can be described as "the

process by which individuals and systems respond respectfully and effectively to people of all cultures, languages, classes, races and ethnic backgrounds in a way that recognizes, affirms, and values the worth of the individual and protects and preserves the dignity of each” (Govender et al., 2017, p. 2). In order to improve one’s cultural competence, knowledge of the respectful populations is sought. Therefore, the generation of knowledge of such vulnerable groups (through respectful research) is necessary in order to address such knowledge gaps.

1.2. Rationale

It is evident that the role of the SLP within the wellbeing of preterm infants is increasing. Preterm infants are at an established risk for developmental delays which if untreated may affect other aspects of child wellbeing. There is a strong awareness and acceptance of the importance of the prevention efforts and early intervention of communicative disorders, and with this, an international trend shifting focus from a rehabilitative approach to one focussed on prevention. In order for any health professional to fulfil their role adequately, one must make an effort to understand their client population to the best of the professionals’ ability. Understanding the client population includes awareness of and respect for cultural/ethnic perceptions, knowledge and practices as well as their daily living experiences. Exploration of maternal knowledge and experiences of preterm infants’ communication and feeding, including cultural knowledge and beliefs, is extremely important in multicultural South Africa. With mothers having a large influence on their infants’ wellbeing and development, exploring their experiences and knowledge would be helpful in improving intervention plans for those at-risk preterm infants. Although there are many studies that have explored preterm infant development and maternal milestone knowledge of full-term infants, local studies investigating mothers’ experiences of having preterm infants are scarce, specifically within vulnerable populations. Exploration of such information within the South African context would likely bring to light valuable knowledge to practitioners in the line of cultural competency, stimulate further research, as well as provide evidence for use within educational efforts that are relevant and accessible. Knowledge specific to neglected and vulnerable groups in South Africa is needed.

When searching for poorly represented or vulnerable groups of people, the grouping term ‘culture’ comes to mind, often used as a descriptor of a group of people with similar beliefs, values and traditions. However, it is acknowledged that a person’s ‘culture’ is an ever-changing system that is difficult to accurately describe due to the many evolving influences. It would be

more accurate to describe every individual as holding his or her own unique culture. Thus, the term ‘culture’ is used with inverted commas throughout in acknowledgement of its reference to a group of defined people (defined within the study) as opposed to a true culture in all sense of the word. Those persons belonging to the isiXhosa speaking communities are one of the largest linguistic and/or broad ‘cultural’ groups that are poorly represented in available literature. Therefore, in a combination of multiple descriptive factors to describe a chosen vulnerable population group, the following study invited candidates from a vulnerable population that can be described as isiXhosa-speaking individuals living within urban low socioeconomic circumstances in the Western Cape, South Africa.

This research study therefore aims to generate knowledge about isiXhosa-speaking mothers’ perceptions and experiences with their premature infants in a low SES group in the Western Cape province of South Africa (referred to as ‘the mothers’ below). In order to do so, more specific aims were outlined, as illustrated below:

1. To describe and explain the perceptions of a group of mothers regarding prematurity;
2. To describe and explain the mothers’ experiences of giving birth to and caring for a preterm infant;
3. To describe and explain the interactions between preterm birth, the mothers’ maternal beliefs and traditional practices;
4. To describe and explain the mothers’ perceptions and experiences of feeding their preterm infant;
5. To describe and explain the mothers’ perceptions and experiences of communication with their infant;
6. To describe and explain the mothers’ perceptions of their role in their child’s caregiving and early communication development;
7. To describe and explain the mothers’ perceptions of other important role-players in their child’s caregiving and early communication development; and
8. To describe and explain the information that the mothers of preterm infants feel they need after hospital discharge.

1.3. Brief outline of the chapters presented

Chapter 1: Chapter 1 serves to introduce the research topic, provide a short rationale for the study and a first glance at the research aims.

Chapter 2: Literature review regarding prematurity and the possible sequelae affecting development. The review of prematurity is followed by that of theoretical perspectives and the presentation of the theoretical perspective adopted for the study.

Chapter 3: Chapter 3 discusses the South African context, including a brief exploration of culture, healthcare and the role of the SLP. The research problem, question and aims are then repeated.

Chapter 4: Chapter 4 focuses on the methodological aspects of the research with an ontological and epistemological introduction, followed by the research aims, design and procedure.

Chapter 5: Herein lie the findings of the research, first presented in an article format, followed by an additional discussion of the themes.

Chapter 6: The discussion is sectioned into three, in which the findings in relation to the aims of the study are first analysed, followed by a discussion of themes that did not fall directly within an 'aim', and finally the relation of the findings back to the theoretical perspective of the study.

Chapter 7: The concluding chapter houses a short conclusion, recommendations for future research and clinical implications of the findings.

Chapter 2:

LITERATURE REVIEW

2.1. Prematurity

2.1.1. The effects of Prematurity on the development of an infant and child

Preterm (or premature) births stand as one of the world's major health problems, with incidences ranging from 5% to 18% over 184 countries, accounting for roughly 9.6% of all births worldwide (WHO, 2018; Soleimani, Zaheri, & Abdi, 2014). Furthermore, preterm birth complications were said to be the leading cause of death in children under the age of 5 in 2015 (Liu et al., 2016). Preterm birth is thus discussed regularly with regards to global health concerns.

Rossetti (2001) describes preterm infants as those who are born before 37 weeks gestational age. There exists three subcategories of preterm birth based on gestational age, namely, moderate to late preterm (infants born between 32 – 37 weeks); very preterm (28 – 32 weeks); and extremely preterm (less than 28 weeks) (Preterm birth: Factsheet, WHO, 2017). Birth weight is an additional descriptive category accompanying prematurity, consisting of Low Birth Weight ('LBW' –infants born with a weight below 2500 grams); Very Low Birth Weight ('VLBW' –less than 1500 grams) and Extremely Low Birth Weight ('ELBW'- less than 1000 grams) (Hack et al., 1991). In a general pattern, as gestational age decreases, typically so does the birth weight of the infant. However, even when weight is appropriate for gestational age, preterm infants may still suffer from medical complications due to lack of prenatal development (Rossetti, 2001). The health risks of these preterm infants present inversely to that of birth weight and gestational age; as the gestational period and birth weight of these infants decrease, the possible health and developmental risks incurred increase exponentially (Kerstjens, de Winter, Bocca-Tjeertjes, Bos, & Reijneveld, 2012). Soleimani, et al., (2014) found that underweight and premature infants experience two- to three-times the complications pertaining to health and development, disability, and long- and short-term social and psychological functioning, as opposed to those encountered by full-term infants with healthy gestational weights. Complications (such as developmental delay and disability) associated with prematurity range across the various areas of physical and motor development, sensory development, attachment, social and behavioural development, cognition (including attention, memory and information processing), communication, and feeding development (Bhutta, Cleves & Casey, 2002; Forcada-Guex et al., 2006). The development of these systems coincide with one-another, for example communication development relies on simultaneous cognitive and motor development, thus rendering all of these areas important

developmental areas for the SLP. The American Academy of Pediatrics (AAP) recommends that health care providers view and assess the development of a child that was born preterm from an 'adjusted/corrected age' - which is their age starting from their expected birth date - until the child has reached two years of chronological age (Bernbaum, Campbell & Imaizumi, 2009). However, large numbers of children continue to show signs of developmental delays after this correction period.

When it comes to feeding, the ability to ingest nutrients is vital for any infant's survival, and is often compromised by complications arising from prematurity. Medical complications commonly suffered by preterm infants include, but are not limited to, increased incidence of respiratory distress, jaundice, temperature instability, hypoglycaemia as well as sepsis (Wang et al., 2004). The above-named factors, along with decreased muscle tone, poor endurance, and a less coordinated suck-swallow-breathe pattern following underdeveloped physical and neurological systems, contribute to the likelihood of feeding and swallowing difficulties in preterm infants (Ludwig, 2007). Feeding and swallowing difficulties may be detrimental to the infant's health. Possible consequences of feeding and/or swallowing difficulties include dehydration, compromised nutrition (failure to thrive), aspiration pneumonia or compromised pulmonary status. Furthermore, compromised feeding abilities may lead to the need for enteral (gastrointestinal, PEG tubes or nasogastric/orogastric tubes) or parenteral (e.g. TPN – total parenteral nutrition) feeding, as well as feeding and swallowing difficulties that may persist into childhood and even adulthood (Prasse & Kikano, 2009; Arts-Rodas & Benoit, 1998).

The majority of preterm infants are admitted into the NICU (Neonatal Intensive Care Unit) in hospitals in order to care for them due to their often-compromised health status. Amongst those high-risk infants, it has been found that recently more infants have been presenting with neurodevelopmental problems. On average, 20-80% of these high-risk infants present with feeding difficulties during infancy, with approximately 26% of these infants showing signs of dysphagia (Field, Garland & Williams, 2003; Rommel, De Meyer, Feenstra & Veereman-Wauters, 2003). Furthermore, approximately 31% of those infants with signs of dysphagia have respiratory complications within their first year of life (Mercardo-Deane et al., 2001). NICU discharge is often delayed due to the infants' inability to feed safely by oral ingestion. In accordance with the AAP, infants should be able to feed orally independently before hospital discharge, thus the longer the transition from tube-feeding to safe oral feeds takes, the longer the hospital stay. Extended hospital stays are thus a common occurrence with preterm infants due

to feeding difficulties as well as additional medical complications. Extended periods of hospitalization, in itself, may pose as a risk factor for attachment difficulties, social developmental difficulties and communication delays (Arvedson & Brodsky, 2002). The following indicates a few common neurological and physical characteristics of preterm infants that will affect feeding.

Table 1: Common neurological and physical characteristics of preterm infants and the resulting effects on feeding ability

Common characteristics of preterm infants	Effect on premature infants' feeding abilities
Compromised respiratory status	Preterm infants often present with respiratory problems. A mature respiratory system with appropriate functioning is important for the development of a safe suck-swallow-breathe pattern that allows the infant to feed without the risk of aspiration (Ludwig, 2007). Breathing difficulties in infancy have been noted to affect speech production later on (Rvachew, Creighton, Feldman & Suave, 2005).
Low muscle tone and muscular weakness	Muscle tone is important for stability throughout the body, which will ensure efficiency of feeding: "the less postural stability the infant possesses, the less efficient the oral feeding process" (Ludwig, 2007, p 73). "Oral muscle weakness influences the oral preparatory phase, resulting in weak sucking, weak mastication, or an inability to suck or chew. Weak sucking in the neonatal period often leads to (supplementary) tube feeding, which hampers the development of oral feeding." (Jadcherla, 2016, p 363). Furthermore, weak musculature at the level of the pharyngeal and oesophageal phase may lead to nasal regurgitation and insufficient bolus clearance potentially contributing to indirect aspiration (Weir, McMahon, Taylor & Chang, 2011). Low tone in the lips of preterm infants result in an inability to maintain adequate lip-seal for breast or bottle-feeding. Inadequate lip seal results in reduced ability to create negative pressure within the oral cavity to draw milk from the breast or bottle (Lau, 2016).

Poor endurance	Endurance is an important neuromuscular characteristic that allows the infant to drink/ingest appropriate volume for growth and development (Ludwig, 2007). Poor endurance may lead to insufficient nutrient intake.
Diffuse sleep cycle	Immature neurological systems cause premature infants' sleep cycle to be more diffuse in comparison to full-term infants. Preterm infants are thus more easily fatigued and less able to maintain an alert state during feeding, negatively affecting feeding interest and performance (McCain, 1997.)
Smaller anatomy	Premature infants have smaller buccal pads than full-term infants, meaning that creating intraoral suction in order to draw milk from the breast/bottle is more difficult for them to accomplish (Ludwig, 1997). Additionally, preterm infants' small anatomy may not be adequate to house the mother's nipple effectively.
Motor control	Safe swallowing relies on accurately timed and coordinated movements supported by an in-tact sensory system. According to Lewis et al. (2002), premature infants often have poor motor coordination and control due to immature neurological and physiological systems. During infancy, motor control is necessary for latching, suckling, sucking and swallowing with adequate airway protection. Compromised control and coordination of the oral and pharyngeal musculature may lead to compromised safety of swallowing, and less effective feeding. Such difficulties may ultimately lead to compromised infant nutrition and hydration. Additionally, as the infant gets older, more refined motor skills are necessary for the safe development of more complex eating manoeuvres such as sucking from a straw and chewing (Groher & Crary, 2016).
Depressed oral reflexes	Suckling is an inherent reflex, which may be observed in-utero as early as 16-24 weeks. However, active and safe sucking functioning to maintain feeding only fully develops between the gestational age of 34-37 weeks. Thus preterm infants often do not have a fully developed swallowing reflex, which may compromise swallowing

	safety (Winstock, 2005).
Sensitive respiratory system	Additional concerns regarding the safety of the swallow includes the swallows' effect on the respiratory system. When infants are born term, they develop a suck-swallow-breathe (SSB) cycle that allows the infant to feed (suck) whilst getting enough oxygen. However, according to Lau (2016, p 620S) "preterm infants primarily swallow during deglutition apnea and inhalation, increasing their risk of oxygen desaturation and laryngeal penetration/aspiration, respectively".

Communication is another highly important developmental domain that is often affected by prematurity. Communication development is influenced by, and influences, many other developmental areas, such as cognition (Owens, 2005), and is said to be the most common symptom of a developmental delay within the age group of 0-30 months (Rossetti, 2001). Unfortunately, communication delays are often not identified at this early stage in comparison with delayed physical milestones, such as walking or sitting. Early identification of communication difficulties is crucial in minimising the effect that it may have on an individual's functioning, and in the case of preterm infants, may lead to the early identification and intervention within other important domains (e.g. identifying sensory difficulties). The table below summarises the speech and language difficulties most often experienced by the preterm population.

Table 2: Common speech and language difficulties experienced by children born prematurely

Area of speech and/or language development	Premature infants' speech language characteristics
Prelinguistic stage (i.e. before the infant's first words.	A study conducted by Rvachew, Creighton, Feldman & Suave (2005) found that premature infants produced less 'canonical babbling' than that of full-term infants (the important prelinguistic stage where infants form connection between articulation trials and auditory results). Furthermore, the preterm infants remained at the babbling stage of speech development for a longer duration of time, thus delaying the time of their first word production.

Vocabulary development	Preterm children, even those categorized as medically ‘low risk’, show delays with vocabulary expansion as early as 1-2 years of age (Cattani, Bonifacio, Fertz, Iverson, Zocconi & Caselli, 2010; Caravale, Tozzi, Albino & Vicari, 2005).
Language development	Generally, children born prematurely show higher rates of language difficulties in comparison to that of full-term children. Studies have found that premature infants/children at the age of 26 months corrected age showed a language delay of 3-5 months (Cusson, 2003). In early childhood those children born prematurely show developmental delays within the areas of metalinguistic skills, language comprehension and production, even with ‘corrected’ milestones (Cattani et al., 2010). Additionally, children born prematurely are more likely to present with poorer grammatical abilities at early primary school level in comparison to their full-term peers (Sansavini et al., 2007).
Narrative development	Children born prematurely showed increased difficulty in forming full oral narratives than that of their full-term peers at primary school level (Crosbie, Holm, Wandschneider, & Hemsley, 2011).
Articulation	Several studies have revealed that those children born prematurely may be at higher risk of having poorer articulatory skills in early childhood compared to their full-term counterparts. This is due to premature infants and children often showing poorer fine and gross motor skills than those children born at full-term (Lewis et al., 2002).

Communication development does not begin when a child utters his/her first word, but rather very early on in the developmental process, arguably even before birth (Panthuramphorn, 1998). The prelinguistic stage is the time period before the child says their first meaningful word, or during which children make use of nonverbal means of communication before the transition to first words (Watt, Wetherby, & Shumway, 2006). Interaction at this prelinguistic stage involves communicating through actions, behaviours and voicing (for example cooing) (Rosetti, 2001). According to Brockmeyer-Cates et al. (2012) there is a large amount of evidence suggesting that early aspects of infant communication play a rather important role in shaping language-learning trajectories. Appropriate intervention at this prelinguistic stage has also been shown to benefit

subsequent speech-language intervention at later developmental ages (Rosetti, 2001). Prelinguistic communicative skills rely on a fully functional auditory and information processing system (i.e. a fully developed neurological system) (Jansson-Verkasalo et al., 2010). Thus, the prelinguistic stage from birth to a child's first word is an important stage of communication development, and one that is often overlooked or misunderstood. The table below outlines other cognitive and sensory abilities that may be affected by prematurity. Such abilities influence, and are influenced by, communication.

Table 3: Cognitive and sensory areas affected by prematurity that influence communicative abilities

Area of development	Premature infants' characteristics and the effect on communication.
Cognitive development and information processing	Studies indicate that preterm birth relates to slower information processing in comparison to that of full-term controls (Bhutta et al., 2002). Effective communication relies on the processing of simultaneous stimuli (for example: spoken words, facial expression, tone of voice and body posture and movement), thus slowed information processing may affect one's ability to listen, observe, comprehend and react appropriately to important communicative instances.
Attention	Increased activity and poor attention are the most common behavioural anomalies found in those children born prematurely (Nosarti, Rifkin, & Murray, 2003). Bhutta et al. (2002) found that those children born prematurely showed higher rates of ADHD (attention deficit-hyperactivity disorder) in comparison to those children born full-term. ADHD impairs a child's ability to concentrate and take-part in activities and may affect scholastic performance at a later stage. It is important to acknowledge that ADHD may also affect a child on an emotional level, which may affect development in many areas.
Memory	Nosarti et al., (2003) suggest that preterm children (specifically with

	VLBW) show deficits in many different areas of memory, including spatial memory ³ and episodic memory ⁴ . The authors relate these memory deficits to underdevelopment of the brain in preterm children, specifically the hippocampus.
School experience	Along with the above-mentioned factors, children born prematurely often have difficulties with performance in language and mathematics subjects at school. The combination of many difficulties affects a child's ability to cope with school, not only the academic curriculum, but the social, emotional and behavioural aspects of schooling. Many studies have shown that difficulties experienced at a school level may also continue affecting one's life in adulthood (Wolke, & University of Warwick, 2016).
Auditory difficulties	<p>Premature birth carries with it the risk of congenital hearing loss (Wróbel, Grecza & Szyfter, 2014). Additionally, certain factors associated with premature birth place an infant at risk for hearing impairments. Such risk factors include ototoxic medication (specifically treatment for hyperbilirubinemia) which may lead to sensory-neural hearing loss, low birth weight and prolonged mechanical ventilation (Rechia, Oliveira, Crestani, Biaggio & de Souza, 2016; American Academy of Pediatrics, 2007). Those children with a hearing loss are especially vulnerable to communication delays and disorders (Wroblewska-Seniuk, Greczka, Dabrowski, Szyfter-Harris & Mazela, 2017). Common speech and language difficulties linked to hearing loss include speech misarticulations, language delays, small vocabularies and difficulties with phonological processing necessary for reading and writing skills (Rechia, Oliveira, Crestani, Biaggio & de Souza, 2016).</p> <p>In addition to hearing loss, premature infants are also at increased risk of developing auditory processing difficulties which may affect their auditory memory span, an important tool in communication and</p>

³ Spatial Memory: Can simply be described as a form of memory relating specifically to the spatial structure of the environment. (Allen, 2004).

⁴ Episodic Memory: "Knowledge of personal information and events" (Radomski & Latham, 2014, p124)

academic performance (Bamiou, Musiek & Luxon, 2001).
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It is evident that prematurity effects many areas of physical, neurological, feeding, communication and cognitive development, however there is an important additional developmental area that is often overlooked, namely socio-emotional development. In infancy, emotional development is nurtured through mother or caregiver attachment. Attachment can be described as “one specific and circumscribed aspect of the relationship between a child and caregiver that is involved with making the child safe, secure and protected” (Benoit, 2004, p. 541). The quality of the infant-caregiver attachment is largely determined by the caregivers’ response when the infant is distressed. Around the age of six months, the infants learn to anticipate this response from the caregivers, and consequently begin shaping their own behaviour accordingly. These responses have been classified as illustrating four different types of attachment patterns, namely secure, avoidant, anxious and disorganised attachment. Research conducted by Diane Benoit (2004) strongly suggests, “The quality of the infant-parent attachment is a powerful predictor of a child’s later social and emotional outcome” (p 543). Healthy premature infants exhibit higher stress levels and appear to have different regulatory and interactive patterns in comparison to that of full-term infants (Montirosso, Borgatti, Trojan, Zanini & Tronick, 2010). Preterm infants, as well as their parents, are considered “particularly vulnerable” for developing malattachment patterns. Possible sequelae of attachment difficulties in those born prematurely include higher risks of emotional regulation difficulties, attention deficits and a variety of psychological issues (Ruiz et al., 2018). Those infants with poor attachment have also shown to be less responsive to interaction at 9 months of (corrected) age, vocalize less frequently, and exhibit more disorganized behavioural and temperamental difficulties. These early interaction difficulties in preterm infants show strong relationships to early communication delays (Rosetti, 2001).

As mentioned above, parents or caregivers of preterm infants are also ‘particularly vulnerable’ to emotional difficulties. Common emotional difficulties faced by parents of preterm infants include a persistent perception of vulnerability⁵ related to the child, higher risk of anxiety, depression and post-traumatic stress disorder PTSD (Ruiz et al., 2018). The aforementioned difficulties often

⁵ “The term means that parents perceive a child as vulnerable although there is no reason even though there might have been one in the past” (Ruiz et al., 2018, p 2).

affect the manner in which people interact with others, and thus may affect the manner in which the caregiver interacts with the infant.

2.1.2. Caregiving and prematurity

Health care professionals attending to premature infants, or children that were born prematurely, should also take into consideration the state of the mother and other important caregivers in order to provide holistic and family-centred care. Prelinguistic development (along with general communication and socio-emotional development) is fostered by caregiver attachment, interaction and adequate stimulation. Leonard and Mayers (2008) have described that the birth of a preterm infant is a crisis for the new parents. It is suggested that this could be due to the fact that the parents are robbed of time to prepare themselves for the child, both physically and psychologically. Klaus and Kennell (1982), suggested that attachment process begins and grows throughout the pregnancy, wherein a large portion of maternal psychological preparation occurs within the last trimester. When the infant is born prematurely, the mother may not yet have reached the last stages of their psychological preparation. This incomplete preparation may thus bring on feelings of loss, grief, failure and concern. Furthermore, directly after preterm birth mothers are often unable to hold their infants and cannot breastfeed the infant straight away - two very important first steps to forming a strong bond between mother and child. Thus, mothers are often faced with the first interaction with their child being in the NICU where the infant is in an incubator with monitors, tubes and needles, a sight which may be concerning to the mothers. Adding to these feelings and emotions is the stress of caring for a smaller infant who is often burdened with complex medical and developmental needs and interventions. Furthermore, Klaus and Kennell (1976) suggest that mother-child bonding is a process influenced by the mothers' own upbringing, the events surrounding the pregnancy, postpartum experiences and the first few months after the birth. This draws further attention to all these areas affected by preterm birth (e.g. a stressful birth and difficult post-partum period in the hospital with a vulnerable infant) as well as highlighting the importance of maternal beliefs and perspectives gained from her own upbringing. These influential factors, amongst others, may combine to affect the nature and quality of caregiver-child interaction and attachment patterns, which are an essential component in the fostering of development, specifically within the realm of communication and socio-emotional development (Twohig et al., 2016). Although there are many existing studies on interventions directed at preterm infants themselves, few focus on the mother or primary caregiver, a crucial influence in the process of development of the infant.

2.2. Theoretical perspectives on childhood development

It is evident that the relationship between prematurity and communication development/difficulties is complex. There are a multitude of factors affecting a child's development, more than merely biological factors (Lewis et al., 2002). Thus, in order to acknowledge, group and discuss different influential factors within childhood development in an ordered manner, a theoretical framework (or model) must be adopted. The following section will introduce and discuss two popular models of childhood development, namely the bio-ecological systems theory and the transactional model. A third model will then be presented as the framework that was used in the current study to understand and organise the external influences on childhood development of premature infants/children within low socioeconomic circumstances in South Africa.

2.2.1. The bio-ecological systems theory

Bronfenbrenner's 'ecological systems theory' is a well known and widely taught conceptual model that describes influences on childhood development occurring at different systems within the child's environment. The ecological systems theory was developed by Urie Bronfenbrenner in the late 1970's and first published in 1979. The theory was later renamed the 'bio-ecological systems theory' in order to highlight the influence of the child's own biological factors on their development (Berk, 2000). The bio-ecological systems theory proposes a relatively broad approach in understanding the environmental influences acting upon a child's development. The model advocates for a broad-spectrum view of development, in that development cannot merely be explained by a single factor (for example biology), but rather a more multidimensional system (Krishnan, 2010). According to Bronfenbrenner (1979), a child's development is shaped by various systems within the specific child's environment, as well as the reciprocal interrelationships between these systems.

There are four major processes within Bronfenbrenner's ecological systems theory. The processes are as follows: 1. The interaction between the child and other persons; 2. The interaction between the child and the physical environment; 3. The interaction between the child

and the context; 4. The interaction between the child and time. These processes form interactions between persons, place, context and time to influence a child's development (Wachs & Evans, 2010). The process of the child's interaction with the 'context' is focussed on and further broken down. Within a certain context, there exists the persons, environments and time-factors of the context itself. The 'context' process is comprised of four systems, namely the micro-, meso-, exo-, and macrosystems. Some later versions of the model added a fifth system, the chronosystem, which depicts changes within the context that occur over time (Krishnan, 2010). An important acknowledgement within the bio-ecological theory is the bidirectional property of the system, as one system influences the child, so can the child influence the system. The first system is the closest to the child, that with which the child has direct access, the *microsystem*. The *microsystem* focuses on those interactions and relationships that the child is exposed to within their immediate environment, such as parental, familial and childcare relationships and contexts (e.g. the relationship that the child has with his/her parents, caregivers and even within the day-care or the school environment). The next layer, the *mesosystem*, focuses on connections between two or more of the elements in the *microsystem*. An example within the *mesosystem* would be the relationship between the child's parents and the child's school, or teacher. The *mesosystem* is followed by the third layer, the *exosystem*. The *exosystem* involves contexts that children themselves are not a part of, but nonetheless influence the child's development, for example employment policies at the workplace of the child's parents. Employment policies may influence the time and amount of interaction the parent have with the child. The outermost and last layer (or system) is that of the *macrosystem*. This system has been described as the 'societal blueprint' and 'cultural milieu' that influences the systems beneath (Parilla et al., 2002; Krishnan, 2010). Influencing factors at this level include cultural characteristics, opportunity structure, the economic environment and material resources (Bronfenbrenner 1994). An example of an influence at this level could be a belief held within a certain cultural group against certain medicines or vaccinations of children. Such a belief might result in non-vaccination of a group of children against certain diseases such as measles. Should such a child develop one of the diseases, childhood development may be affected (such as polio affecting physical abilities). Thus, factors at the level of the *macrosystem* resultantly affect all systems below. Within this example it is clear to understand the value of insight into parental beliefs and values within early childhood development and intervention. The four systems are presented in Figure 1 below.

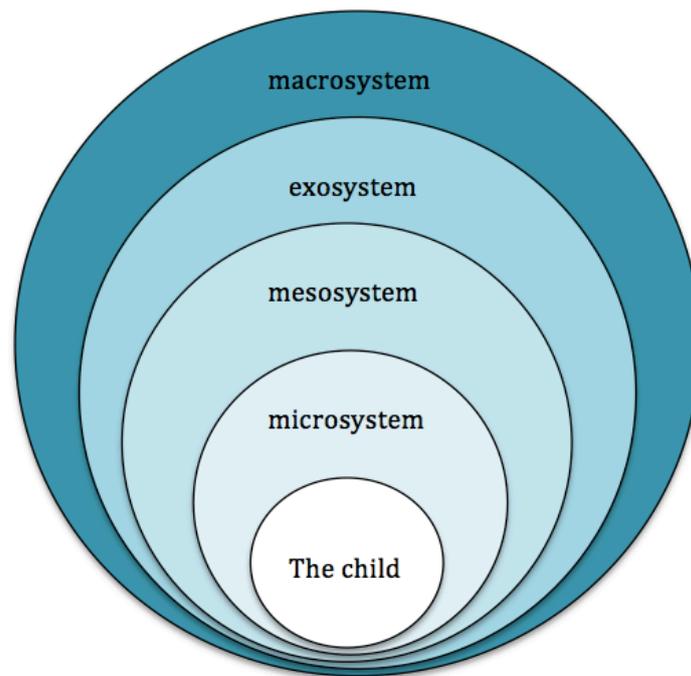


Figure 1: Bronfenbrenner's bio-ecological model of child development (Based on Bronfenbrenner, 1989)

Overall, the bio-ecological model emphasizes childhood development within a context by grouping and incorporating all the factors that may influence the child into different systems. The bio-ecological model is excellent in its inclusion and recognition of internal and external influencing factors on childhood development, however the model does not specifically differentiate risks and protective factors within such systems, and although the model represents influences 'closer' and 'further' in contact to the child, it does not clearly differentiate between larger or smaller influences or influences with a greater impact (Christensen, 2016).

2.2.2. The Transactional Model

The transactional model was originally proposed in 1975 by Sameroff and Chandler. The model represents the culmination of the effects of both 'nature' and 'nurture' on childhood development and emphasizes the reciprocity of these influences. Within the transactional model, the reciprocal mother-infant (or caregiver-child) relationship is emphasised as an important influential factor on the respective child's development. The model looks at the relationship between the child's own characteristics and behaviours, and the parent's child-rearing behaviours and beliefs (Sameroff, 2009). A mother, or primary caregiver, is the closest and most consistent influence on the child's development, and one that often has the opportunity to influence or mediate negative factors that

may affect the infant or child's development. It is however highly important to acknowledge the reciprocity within the mother-child relationship. Using maternal sensitivity to illustrate this, the mother may influence a child's response through the nature of her interaction, whilst the mothers' interaction patterns may also be influenced by the child themselves. An example of such reciprocal influences may be illustrated in children with language delays or emotional difficulties, such difficulties could discourage mothers' attempts at interaction or lead to maternal stress (Leigh, Nievar & Nathans, 2011).

In addition to the mother-child relationship, the transactional model also emphasizes the influence of context, where the child's surrounding contexts and experiences are essential in influencing their development. This is similar to that of the bio-ecological model and is where the two models overlap. The transactional model also includes influences at a larger level amongst school context, ethnic and cultural background, and socioeconomic environments (Sameroff, 2009). Although similar to the bio-ecological model, this level of the transactional model does not go into the same depth of categorisation of these external factors. Pascoe, Bissessur and Meyers (2016) designed an intuitively simple figure representing the transactional model applied to childhood development, presented in Figure 2 below (please find the figure on the following page):

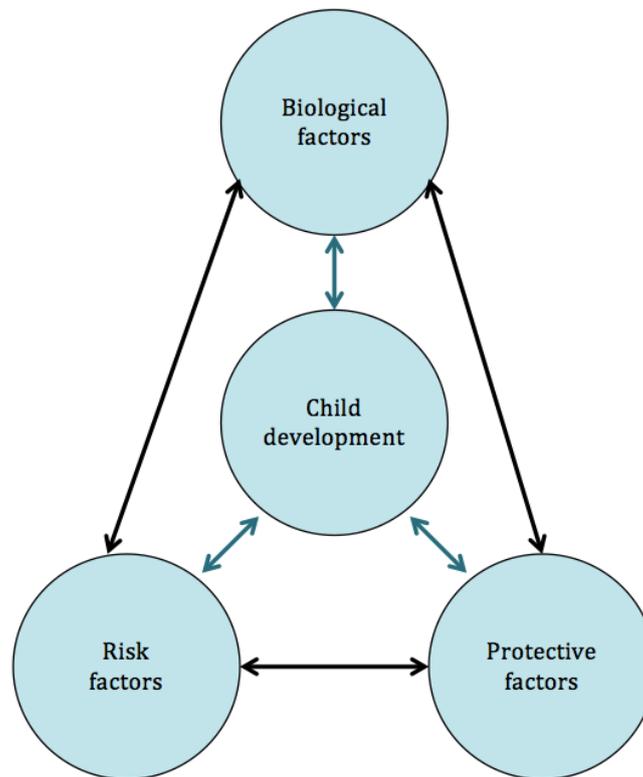


Figure 2: The transactional model applied to childhood development (as illustrated by Pascoe, Bissessur & Meyers, 2016).

Within the above representation, there are three main components or categories that may affect a child's development: biological factors, risk factors, and protective factors. The first category, 'biological factors', would include biological and congenital factors within the children themselves that may affect their development, such as prematurity. Pascoe et al.'s (2016) representation of the transactional model also assists in drawing attention to the bi-directionality of the model. As mentioned before, the mother's nature and actions may affect the child, but the child may also affect the nature of the mother's interactions towards the child.

Pascoe et al.'s (2016) representation of the transactional model is particular in the identification of 'protective factors' as a separate group of influencing factors. Protective factors in the context of development in preterm children refer to those factors that nurture childhood development (for example a secure attachment bond and language stimulation). The inclusion of the 'protective factors' category makes the transactional model particularly useful in research and intervention in the domain of childhood development. External efforts from healthcare professionals, educators

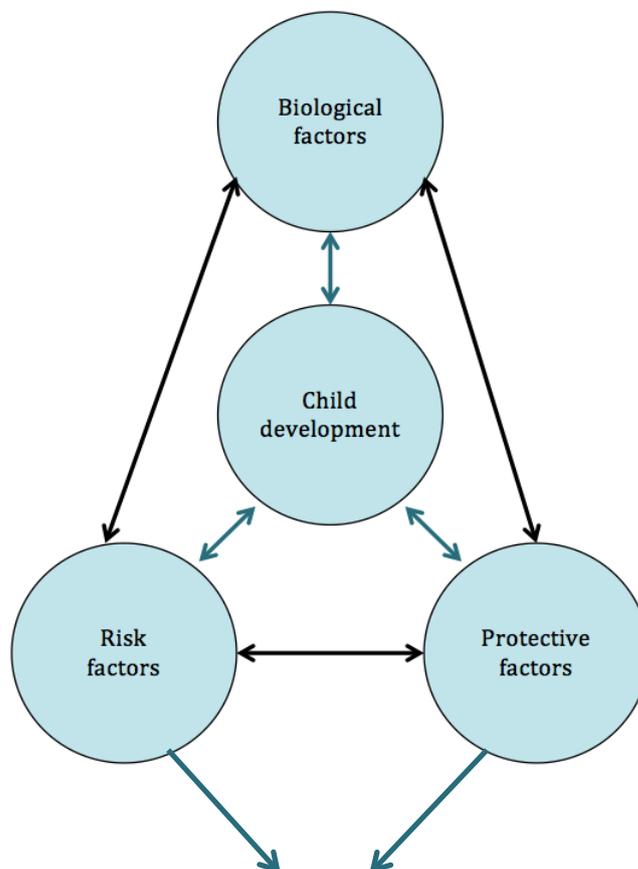
and the mothers' own efforts to improve the child's or infants' wellbeing and development can be conceptualised and represented in this way.

2.2.3. Conceptual framework for the current study

Both the bio-ecological model and the transactional model prove useful for research in the area of studying the influences acting upon childhood development. The current study investigates mothers' perceptions and experiences. The caregiver's perceptions and experiences are well highlighted within the transactional model; however, one cannot ignore the influence of the external factors that are well represented within the bio-ecological model. Thus, for the purpose of the current research, an integration of the models was used to guide data collection, analysis, interpretation, and discussion.

The transactional model was used as the base framework. The systems from the bio-ecological model were then used to categorise and represent influencing factors within the different 'risk factors' and 'protective factors' categories.

A visual representation of the integration of the models is represented in Figure 3. The figure will be then be further explained below.



<p><u>1. Microsystem:</u> <i>Mother</i></p> <ul style="list-style-type: none"> • Overall maternal experience of having a preterm infant • Attachment/bond (poor or safe) • Expectations, difficulties, achievements • Knowledge
<p><u>2. Mesosystem:</u> <i>Context of mother and child</i></p> <ul style="list-style-type: none"> • Other caregivers • Relationships (familial or other influencing relationships) • Experience at the hospital and with the hospital staff • Home environment • Early childhood intervention (ECI) or education • Support system
<p><u>3. Exosystem:</u> <i>Community</i></p> <ul style="list-style-type: none"> • Employment status, environment and experience • SES (Socio Economic Status) • External barriers to mother-infant interaction and intervention • Culture and community <ul style="list-style-type: none"> ○ Beliefs and practices
<p><u>4. Macrosystem:</u> <i>Economic context and governmental policies</i></p> <ul style="list-style-type: none"> • Policies that may influence the mothers' experience of childcare

Figure 3: The integration of the bio-ecological and transactional models of development

This integrated model illustrates that child development may be influenced by three different factors, namely biological factors, risk factors and protective factors. The two categories of risk and protective factors are further broken down into influencing factors at each systemic level. Influencing factors within these systems are, for the most part, inversed in the protective and risk

factors. However, there are certain elements that will fall under only one category – protective or risk.

2.3. Theoretical perspectives applied: Mothers within the South African context

The following section will apply the integrated bio-ecological and transactional models, as seen previously in Figure 3, to mothers of preterm infants within the South African context. The South African context itself will be discussed in more detail in Chapter 3.

The biological component of the combined models consists of biological and congenital risk factors that are associated with premature birth. Biological factors in the instance of the current study are also accompanied by particular disease exposure. In South Africa, the Human Immunodeficiency Virus (HIV), Tuberculosis (TB) and Necrotising Enterocolitis (NEC) are amongst the biggest health threats to the preterm (and general) population. HIV has been reported to affect almost 19% of the South African population (UNAIDS, 2017; Popich, Louw & Eloff, 2006). Furthermore, South Africa's HIV population is said to form 17% of the global HIV burden (Mayosi & Benatar, 2014). As described by Linda Richter (2004), HIV may affect child development in many different ways, for example HIV may increase vulnerability to illness and infection, possibly affecting physical and neurological development. Although figures are improving due to the implementation of the ART (anti-retroviral treatment) program, HIV is still responsible for many maternal deaths (Nabukalu, Klipstein-Grobusch, Herbst & Newell, 2013). In addition, HIV may have a large effect on psychosocial development of children through the influence of family dynamic (i.e. illness and family mortality).

In South Africa, HIV infections often go hand-in-hand with Tuberculosis (TB). Despite improved treatment outcomes, the burden of TB, largely driven by HIV, remains enormous. Approximately 322,000 cases of active TB were reported in the year 2017 (Global Tuberculosis Control 2018, WHO, 2017). TB during pregnancy affects maternal health and is known to impact perinatal and neonatal health, often leading to infants born prematurely with low birth weights (Bekker, Schaaf, Draper, Kriel & Hasseling, 2016). If precautions are not taken, preterm infants are highly susceptible to any forms of illness to which they are exposed. Neonatal TB has an unfortunately high mortality rate of up to 60% (Mittal, Das & Faridi, 2014). Additionally, TB may lay dormant

for some time and go undetected. One of the common complications of TB experienced by the paediatric population is that of TB Meningitis (TBM). TBM is a common cause of meningitis in the South African population (Marais & Wilkinson, 2014). Although research on the effects of TBM on neurodevelopment is sparse, studies have found that most patients have neurological deficits after contracting TBM, including cognitive, behavioural, visual, auditory and developmental difficulties (Rohlwink et al., 2016).

As previously mentioned, preterm infants are particularly vulnerable to infection. NEC is a health-risk common to newborn infants in South Africa, and is said to be a significant complication for preterm infants, currently one of the leading causes of morbidity and mortality within this population. NEC is a disease of the gastrointestinal tract of preterm neonates resulting in bacterial infection and inflammation of the bowel wall (Thompson & Bizzarro, 2008). Although the neurodevelopmental outcomes for NEC have not been widely reported, some studies have shown that preterm NEC survivors show significant neurodevelopmental delays at the ages of 12 and 20 months corrected age (Hintz et al., 2005).

When an infant is born prematurely, (s)he is already vulnerable to various risk factors that may accompany premature birth, such as the known risk of developmental delay (Han, Bang, Lim, Yoon & Kim, 2002). Thus, the combination of established risk factors (developmental delays) and additional biological risk factors (disease exposure) may be detrimental to the child's development. The risk factors and the possible effects of prematurity on child development have been discussed in the first segment of the literature review. Therefore, the following sub-sections will outline possible risk and protective factors within a premature child's life that may affect their development, focussing on the primary caregiver or maternal role.

2.3.1. The 'microsystem'

It must first be acknowledged that the majority of the research regarding caregiver-child relations, relevant to the microsystem, stems from research findings from the 'global north', which may not be accurately representative of- or suitable for- the South African population. This issue is further discussed at a later stage. Additionally, for ease of writing, the term 'mother' will be used throughout the text, although it is acknowledged that other family- or non-family members may also fill the role of primary caregiver. Similarly, there may be more than one

primary caregiver within the caregiver-child dynamic. Thus, for the purpose of this literature review 'mother' refers to any primary caregiver(s).

Within the microsystem are those influencing factors with which the infant has direct contact. The mother is often the individual who has the opportunity for the most contact with the child. Thus, the mother often has a large influence on child's wellbeing, and reciprocally, so does the child have a large influence on the mother. The mother's wellbeing, knowledge and beliefs have a large influence on the nature of her interactions with the child, or how the child is 'parented'. It is therefore easy to understand why research has identified caregiver traits (or 'parenting') and the home environment as the two most important influencing factors regarding child development and abilities (Donnalley, 2013). There are different parenting styles that have been studied and classified, none of which can be said to be the 'correct' or 'incorrect' style. However, there are certain parental behaviours or traits that may prove as either more-positive or more-negative as they influence aspects within childhood development. Positive mother-child interactions are those that nurture emotional development and create the environment for optimal growth and development, for example maternal interest in the child's engagements encourages both safe mother-child bonding and provides learning opportunities for the child. Those children who have positive caregiver interactions more frequently exhibit increased cognitive, social and linguistic development (Pridham, Baker & Brown, 2000; Young, 2013). It has been suggested that positive interactions may also prove to be a protective factor against developmental delays (Nicolaou, Rosewell, Marlow & Glazebrook, 2007). Many factors may however jeopardise the nature and frequency of these influential interactions, including that of lack of support for the mother and high-risk pregnancies (Young, 2013). Because of the importance of these positive interactions and safe mother-infant attachment, the impact of poor attachment and interactions can be seen across many areas of physical, socio-emotional and other developmental domains (Feldman, Gordon, & Zagoory-Sharon, 2011). Preterm infants are at high risk of experiencing the negative impact of poor interaction and attachment due to maternal stressors (Fegran, Helseth & Fagermoen, 2008).

As mentioned previously, premature birth may be traumatic for parents and may result in feelings of grief, guilt and unpreparedness (Leonard & Mayers, 2008; Klaus & Farenoff, in Rosetti, 2001). The aforementioned negative feelings as well as poor confidence, if unresolved, may negatively affect the nature of infant-parent interaction and the important process of attachment (Feldman,

Gordon, & Zagoory-Sharon, 2011; Glazebrook et al., 2007). Studies have found that preterm infants can be described as ‘sleepy’, ‘passive’ and less responsive during their interactions in comparison to full-term infants. The perception of a less-responsive infant may lead to parents or caregivers providing less interaction and stimulation, potentially compounding the effects of prematurity on delayed communication- and neurodevelopment (Davis, Edwards & Mohay, 2003; Nicolaou et al., 2007). It is of importance to acknowledge that the mother herself would have likely gone through the traumatic process of early delivery, often an emergency caesarean-section, which in itself may lead to feelings of stress and anxiety, in turn possibly affecting her interactions with her infant. All these factors combine to affect the mother-infant bond, interactions and relationship. The wellbeing and experiences of the mother or primary caregiver are therefore highly important components surrounding the infant’s development, and thus maternal support in this respect is crucial (Young, 2013).

In addition to maternal emotional factors, maternal/caregiver knowledge can be particularly influential on the child’s development. At the microsystem level ‘maternal knowledge’ within the context of the current study refers to the direct education and knowledge that the mother (or the primary caregiver) has received regarding the following: general caregiving for a preterm infant, recognising developmental milestones, recognising and responding to communication attempts, strategies to encourage development (specifically neurocognitive and thus communicative development), as well as knowledge of and about feeding norms and signs of hazardous feeding or swallowing (e.g. coughing or gagging when eating). Maternal knowledge and beliefs are closely correlated with maternal involvement or efforts. Both maternal knowledge and efforts are mutually constructed by various life influences and may either present as a risk factor or a protective factor (Bond & Burns, 2006). A lack of maternal knowledge surrounding the aforementioned areas of development may lead to poor recognition of difficulties, for example feeding difficulties, which may result in high-risk mealtimes (e.g. risk of aspiration). Poor maternal knowledge regarding developmental milestones (communication, socio-emotional and feeding) could lead to the mother or caregiver not identifying difficulties at an early stage before the difficulties affect other aspects of life, such as school performance or making friends. Additionally, such early intervention services might not be available to the children, possibly due to geographic, financial or transport difficulties. Such intervention is crucial in minimizing the effect of the developmental difficulties on the child’s holistic wellbeing. Research has shown that caregivers often misjudge the timing of their child’s developmental abilities, expecting developmental milestones inappropriately late, which may affect the child negatively (Tamis-

Lamonda, Shannon & Spellmann, 2002). If parents are unaware of delayed development, the child would likely not receive early intervention, exacerbating the developmental effects of prematurity. Lack of important developmental knowledge may therefore be a potential ‘risk factor’ to an infant or child’s developmental potential. Similarly, studies have shown that parents who have a good knowledge of developmental milestones often provide more constructive learning environments and engage in interactions that are developmentally appropriate. Such interactions have shown to contain increased responsiveness and sensitivity (Walker, Pearce & Devine, 2014). Therefore, maternal or caregiver knowledge may be a protective factor by leading to the promotion and support of child development. Mother or caregiver knowledge is therefore a powerful protective tool in the intervention of those infants at risk for developmental delays, such as premature infants (WHO, 2004).

2.3.2. The ‘mesosystem’

Within the context of the mesosystem are those factors that form part of a relationship or connection between the elements within the microsystem. For the purpose of the current study, included within the mesosystem are factors that may influence both the mother’s caregiving experience and the child’s development. Such factors will include the physical and emotional environments affected by relational dynamics. As one of the most significant influences and influence-mediator in the life of the infant, it is evident that the mother is an important relational component, and one for whom the birthing and caring for a preterm infant is likely a stressful experience. For preterm infants, the first weeks of their lives are often spent in a hospital where they are mostly kept in incubators with an array of monitors, drips and tubes inserted for medical reasons. Mothers lack a large portion of parental opportunity in the NICU as they are often not able hold their infants during this stage of medical instability (Craig et al, 2015). Mothers are therefore denied the opportunity to perform so-called ‘primary maternal preoccupations’, such as holding and grooming their own infants. Scholars acknowledged the importance of this bonding many years ago. Psychologist and paediatrician Donald Winnicott (1956) described that if mothers are denied this stage of ‘primary maternal preoccupations’ it may affect their attachment to the infant, which, as mentioned previously, may adversely affect a child’s development. This alone presents as a risk factor for compromising both maternal wellbeing and infant development (Winnicott, 1956). Furthermore, literature suggests that mothers who are unable to experience parenting at this early stage likely hold misconceptions about their infants’ behavioural cues and

may find caring for their infant ‘difficult’ (Craig et al, 2015). There is thus an opportunity for protective factors to arise during this time in the form of maternal support. As suggested by Young (2013), the hospital staff hold a responsibility in supporting mother-infant bonding through their knowledge, experience and position.

Hospital staff may play an important protective role in carefully adjusting the manner of care for the infant to include and encourage the mother, or primary caregiver, to be as involved as possible, thereby possibly reducing the risk of the mother and infant forming unhealthy attachment patterns (Young, 2013). Within the hospital in this early stage, the SLP also plays an important educational role. The role of the SLP lies not only with the assessment and management of communication, feeding, and swallowing delays/difficulties, but also in health promotion, prevention and advocacy, as well as education and training (Republic of South Africa, Department of Health, 2017). Health care interventions that form part of ‘prevention’ at crucial stages of infant development constitute as ‘protective factors’. These factors are those such as caregiver (mother and hospital staff) education and training that assist in the prevention and early identification of communication and feeding difficulties or delays, and to help encourage and stimulate development where possible.

External support systems, such as familial support, are also protective factors within this system. Craig, et al (2015) suggest that “family involvement is a key to realize the potential for long-lasting positive effects on physical, cognitive and psychosocial development of all babies, including those in the neonatal intensive care unit”. Within the hospital context mothers and family members may be exposed to other protective factors that could positively influence child development, such as advice from professionals or educational programmes. A large portion of these educational sessions presented by doctors, nurses and other staff members such as SLP’s take place within the KMC ward. In these encounters and programmes mothers might receive information regarding developmental milestones, identifying signs of developmental delays and developmental stimulation advice for their infant, which is vital information for mothers of preterm infants known to be at risk for developmental delays. This developmental knowledge may assist in early identification of difficulties, which may lead to early intervention. Early intervention is fundamental in reducing the effect that the developmental delay might have on the child and should not only focus on the infant, but also on improving contextual and environmental factors that may affect child’s development (Black & Hurley, 2016; Richter et al., 2017; Popich et al., 2006).

In addition to relations and support systems, the physical and social home environment are important contexts within the mesosystem and can hold within them both protective and risk factors. Research has established that early childhood environments that are stimulating assist in establishing neural connections within the brain that supports the child to thrive at a later developmental stage (Shonkoff et al., 2003). A home environment is said to play an important role in addressing the needs and providing developmental opportunities for children, for example providing opportunities for children to explore and learn about the world as well as develop interpersonal and social skills (Nadeem, Rafique, Khowaja, & Yameen, 2014). Thus, within the home, familial organization and child stimulation may prove to form strong protective factors in the minimization of the effects of prematurity and developmental delays. However, the home environment may also be a negative risk factor. A home environment where an infant or child remains in solitude or receives limited stimulation with little interpersonal and object interaction may be detrimental to the child's cognitive development. Similarly, within the social context of a household, familial dynamics and relationships play a large role in childhood development, specifically socio-emotional development. Negative household relationships are not conducive to positive interpersonal interactions, from which an infant learns and models their own behaviour. Additionally, traumatic emotional experiences (such as instances of domestic violence, or parental separation) may negatively affect a child's emotional growth, thus also affecting other developmental progressions.

The home environment itself may, in some circumstances, not be entirely safe for a vulnerable infant; bearing in mind that, preterm infants are particularly vulnerable to respiratory infections and other health problems. Thus, those preterm infants living in poor housing conditions without access to adequate sanitation and protection from the elements are more vulnerable to illness compared to those residing in sanitary, warm and safe environments (Emond, Howat, Evans & Hunt, 1997). Broadly, within the South African population the burden of illness lies largely with the poor communities. Health risk factors are likely to be more prevalent within homes in lower socio-economic circumstances (SES), as lower SES communities often do not have adequate access to resources needed for optimal health and safety, including proper sanitation, clean and sterile water sources, electricity and financial funds for protection against cold weather such as household insulation (Ataguba, Akazili & McIntyre, 2011). The household is the context in which a child spends a large amount of time and learns a large amount of valuable information. It is therefore a potentially rich source of developmental stimulation. In addition to providing a

nurturing environment, the house may also be built to act as a structure of protection against those elements that may compromise child and familial health. The household and relationships within are therefore important contexts affecting health and developmental potential.

2.3.3. The ‘exosystem’

Influences at the exosystem level include those of external factors that the child does not have a connection or contact with directly and can usually not be manipulated. One of the largest factors within this system is often that of the caregiver’s employment status, affecting household financial income. It has been discussed the developmental, medical and health risks imposed on a preterm infant, for which they often need medical treatment and follow-up appointments, require financial resources (if not the cost of the appointment itself, then at the very least the cost of transportation). According to the Basic Conditions of Employment Amendment Act, No. 11 of 2002, in South Africa mothers have the right to four months of maternity leave, however employers are not obliged to pay the mother during the four months, often leaving mothers with no income whilst caring for an infant or long waiting periods for payment from the Unemployment Insurance Fund. Furthermore, the employment status and stipulations of mothers who do not apply for maternity leave might form a barrier to mother-infant-interaction as the mother might work for many hours daily away from the newborn infant, thus limiting interaction and attachment opportunities during early infancy. It is acknowledged that many working mothers have secure and strong attachment bonds with their infant/child, however it is emphasized that time bonding in early infancy (i.e. with a newborn) is supportive of maternal and infant health and wellbeing. In some household situations where the mother is able to afford extended work leave without pay, or even to not work for a period of time, the mother has the opportunity to provide daily developmental stimulation and interaction with the infant, as well as having the time to attend follow-up appointments. Poor socioeconomic factors (e.g. little financial income, many financial dependents, little or no financial reserve/savings) may exacerbate the mother’s need to work and to be away from the infant early on due to the financial needs of the family. The current unemployment rate in South Africa stands at 27.6% in 2019 with the majority of those unemployed falling within low SES circumstances (Statistics South Africa, 2019). Steady financial income linked to employment is often not assured within these communities.

Caring for a premature infant may include many costly medical and other appointments (for example, hearing tests, doctor's and therapy appointments, and inoculations), more so than that of full-term infants as premature infants have more health care needs. For those with little financial resources, this follow-up infant care may be difficult to access. For those working mothers, unpaid leave must often be taken in order to attend such appointments. Unfortunately, time is not the only expense when attending important appointments for the child, transport is often a significant expense and not always easily accessible. Again, the circumstances are exacerbated by financial constraints and low SES. Therefore, it is not difficult to infer that important appointments aimed at identifying, minimising and mitigating developmental difficulties for those infants might be more difficult to access within low SES communities.

Other influences at the exosystem level include those of the surrounding community and culture. Aspects within the community may prove to form protective factors, for example a strong interdependence between community members may assist with childcare and infant developmental stimulation opportunities. Receiving such support from community members may also reduce maternal stress, which may improve the quality and nature of mother-infant interactions. Support is not the only manner in which a community may exert an influence, as within a community exists a unique matrix of beliefs and values. Many studies have shown that surrounding community values and beliefs in combination with cultural practices, belief systems, and values, interact to influence a mother's personal belief systems, thus the manner in which she understands information and interacts with her infant and with others (Al-Madaadi & Ikhlef, 2015; Ball & Lewis, 2014; Verdon, Blake, Hopf, Pham & McLeod, 2016). Literature stresses that maternal cognitions (such as beliefs, knowledge and attitudes) strongly influence the nature of a mother's interactions with her infant/child and how she or the caregivers construct the learning environment surrounding the infant/child (Huang, O'Brien Caughy, Genevro, & Miller, 2005). Such influences may either act as risk factors or be protective in nature. For example, studies have shown that in some communities infancy and early childhood are considered to be 'passive periods' for learning, during which the infant is cared for with less communicative interaction compared to infants born to those whom do not share this belief. There is evidence that links lack of early interaction and stimulation as a key element in developmental delays, even more so with preterm or 'at-risk'⁶ infants (Ertem et al., 2007). Thus, this belief may pose as a potential risk

⁶ 'At risk' infants refer to those infants who are known to be at risk of developmental delays or medical complications, such as those preterm infants or infants with neurological diagnoses.

factor to communication delays, especially for infants who are already at-risk for such delays. In a similar manner, culture may also affect the mother or caregiver's knowledge and beliefs regarding all aspects of communication (such as the importance of oral communication) and the cause, meaning and importance of developmental delays or disorders, as well as the importance placed on different communicative aspects. A good example of cultural communicative differences is that of eye contact and amount of speech. In most western cultures eye contact is valued during interaction and there is usually a large amount of speech between adults and children, whereas within the Japanese culture the avoidance of eye contact is seen as respectful and interaction patterns are shown to reflect less exchanged speech between adults and children (Akechi, Senju, Uibo, Kikuchi, Hasegawa & Hietanen, 2013). South Africa's population is particularly diverse. Belief and practice are not identical throughout language groups but may have many cultural variations, depending on many variables (such as community location and educational exposure). Although information regarding differential communication patterns amongst South Africa's population is difficult to source, it has been found that interaction patterns and beliefs differ greatly across the country. It has been found that in many cases, biological parents are not always primary caregivers, but rather older siblings fulfil this role (Updegraff et al., 2011; van Kleek, 1992). Additionally, communicative interactions in some African cultures, such as the Basotho culture, are not dyadic but multiparty in nature. The Basotho people have also been reported to 'highly regard' interactions with children, thus fostering communicative development (Demuth, 1986). It is thus evident that communication patterns and practices differ across cultures and communities. This emphasis on childhood communication differs across different cultures and communities, for example other international studies found that adults in some American communities did not prompt conversational continuity with children (such as through asking questions) (Heath, 1982).

This information is not included to compare different communication patterns within different cultures, but rather highlight the diversity thereof. The impact of certain communicative values and practices on the manner of appropriate communication within those differing communities and cultures cannot be ignored. As SLP's working with domains of communication, it is the SLP's professional duty towards cultural competence to be aware of- and respect such differing communicative patterns. Insight into such patterns, beliefs and communicative values is thus crucial to the provision of intervention congruent to such beliefs and practices. Overall, the influences at the exosystem level act together to create and influence the environment in which

the infant or child develops, whether it be the social circumstances, surroundings and surrounding persons, as well as the knowledge, beliefs and values that shape the infants' world of interactions.

2.3.4. The 'macrosystem'

The macrosystem in the context of the current study refers to larger customs, laws and cultural values that may have a cascading influence on the other systems and thus the child (Berk, 2000). Contextual influencing factors at the macrosystem level include that of governmental policies and grants. In paediatric health care in South Africa, the child-support grant, disability child support grant and service delivery in Public Health Care are of particular importance. In South Africa parents or primary-caregivers of a child who fall within specific lower-income brackets are entitled to social child-support grants. Child-support grants are a monthly sum of money provided to the caregiver intended to assist in supporting the child. Additionally, if a child has a disability, the caregiver may receive an additional grant (South African Social Security Association, 2018). Social grants may therefore be an example of a positive influence on the child's development or wellbeing as the allowance may enable the caregiver to cover transportation costs to attend important medical and developmental appointments. Another influencing policy is that of maternity leave which is currently 4 months in duration. As discussed before, preterm infants spend a large amount of their early life in the hospital, thus this time might encompass most of the mothers' maternity leave, robbing her of time spent at home with the infant. This may therefore contribute to maternal stress.

Health care, including the quality of health service as well as accessibility, is a very important factor for premature infants within the macrosystem, as preterm infants and children are at high risk for a multitude of medical and developmental complications. In South Africa there currently exists a subsidised public healthcare system where eligible individuals receive subsidised healthcare according to their income bracket and may receive some services free of charge or at a substantially reduced fee (Western Cape Government, 2018). As an example, South African law states that pregnant women, and children under the age of 6 years receive free healthcare from the public healthcare system if they do not belong to a medical aid scheme (Moodley, 2011). As a general principle, healthcare facilities with specialised care, such as secondary and tertiary level hospitals, are often located in or close to urban areas. In order to service rural areas located far from urban facilities, smaller clinics are distributed amongst communities. These local clinics have trained nurses and visiting doctors but no specialised staff such as paediatricians.

Additionally, the clinics are equipped with basic neonatal equipment such as a few incubators and monitors, but they do not have specialised care facilities, such as those found in an NICU. Thus, for those mothers in more rural settings, geographic access to emergency specialised care, as in the case of preterm birth, forms as a barrier to appropriate healthcare. Delayed specialised care (such as specialised life support and respiratory machines located at large hospitals) may prove an additional risk affecting a preterm infant's developmental potential. The accessibility of the health care system (physically, geographically and financially) is therefore an important influence on a premature infant's developmental potential, and one to be taken into consideration in intervention planning.

Chapter 3:

THE SOUTH AFRICAN CONTEXT

Due to the interrelated nature of development, influential factors and context, a degree of unavoidable repetition of information occurs within this chapter. Factors previously mentioned are discussed again with similar supporting literature within this chapter, specifically pertaining to that of the South African context.

3.1. The South African context and cultural sensitivity

3.1.1. Healthcare in South Africa

South Africa is home to a unique population with a diverse range of languages, cultures and contexts. The distribution of resources in the country - such as economic, educational and health resources – remains problematic as more-advantaged and less-advantaged groups remain a reality. This disparity is affected by South Africa's complex past, specifically with regards to the discriminative distribution of resources and restrictive access to education and healthcare that led to the neglect of a large portion of the South African population based on race. Despite industrial and healthcare advances and the change to a democratic government, the effect of the misdistribution of resources is still evident in today's population. Reportedly 71% of the population is reliant on public healthcare services, which are largely understaffed, specifically in more rural areas (Statistics South Africa General Household Survey, 2016). Furthermore, only around 30% of the country's doctors are working in the public sector (Mayosi & Benetar, 2014). Difficulties within the state healthcare system are further exacerbated by 'disempowered patients', inequality, inadequate household resources and high rates of unemployment and poverty (Penn & Watermeyer, 2018, p.28).

Preterm birth is prevalent in both rural and urban areas. Those preterm infants and respective mothers without the financial resources for private healthcare rely on the services of the public healthcare system for both survival and mitigating possible medical and developmental consequences of preterm birth. Prematurity, as well as many other health conditions such as HIV and TB, often require lengthy health care interventions. Therefore, accessibility and appropriate healthcare should be a priority for vulnerable populations. As previously mentioned, difficulties with healthcare distribution could negatively affect emergency care needed by newborn preterm infants, as well as the follow-up intervention often necessary to ensure optimal developmental outcomes.

3.1.2. Prematurity and poor socioeconomic circumstances in South Africa:

The World Health Organization (WHO) (2017) reports a stark difference in survival rates of preterm infants within Africa and Asia compared to that of higher-income countries, likely due to differing standards of healthcare and the increased number of risk factors that accompany preterm

births in the global south. In South Africa the majority of preterm infants are exposed to a myriad of risk factors accompanying the aforementioned biological risks of preterm birth. Dawes, Biersteker and Irvine (2008) named key threats to childhood outcomes in South Africa as follows: maternal factors influencing birth weight (linked to poor nutrition and substance abuse), the impact of HIV and AIDS, inadequate access to healthcare, and poor childhood stimulation. Low socioeconomic status (SES) can be related to most of these factors. Krieger and Higgins (2002) suggest that the quality of housing, as well as housing accessibility⁷, are important determinants in an individual's health. Those living in poorer socioeconomic circumstances are likely to reside in poor housing conditions, in which lack of safe drinking water and overcrowding have been associated with higher health risks such as pneumonia, diarrhoea, injuries, poor nutrition, chronic illness and mental disorders (Mathee, 2011). Additionally, housing factors often have a reciprocal relationship to work factors, which may also affect an individual's health. Stress in general stemming from many reasons has been found to increase an individual's risk of disease (Ncho & Wright, 2013).

According to Statistics South Africa (2017), over 30.4 of 55.91 million South Africans are living in poverty or poor socioeconomic conditions, for example in unstable housing with poor sanitation and limited access to water and electricity. Unfortunately, this is a rising figure. Statistics South Africa (2017) also states that "growing up in poverty is one of the greatest threats to healthy childhood development", but it is the reality that most have to face in South Africa. It is the population with a low socio-economic status that is most vulnerable to the risk factors incurred in the global south.

In addition to housing status, parenting practices and infant development have also shown to differ across different economic settings (Bornstein et al., 2012). Research suggests that the language development of those in lower SES households often "lags behind that of their middle-class peers", and that cognitive stimulation and verbal input in the homes of low SES families are typically less than that of middle-class homes (Brockmeyer-Cates et al., 2012, p. 578). There are many studies that illustrate the importance of early childhood stimulation (cognitive, linguistic and developmental stimulation) in the development of language and cognitive skills. It is clear that household factors have an important influence on the child's development, however caregiver interactions, as previously mentioned, have also been strongly related to childhood developmental outcomes (Korja, Latva & Lehtonen, 2012). Thus, an important group of risk

⁷ Housing accessibility: referring to the financial, physical and geographic accessibility to living in a house.

factors to consider are those of maternal or primary caregiver factors within a low socioeconomic environment. This includes maternal/caregiver education, health, perceptions and knowledge. An article by Goldenberg, Culhane, Iams and Romero (2008) discusses the causes of preterm birth, which include various maternal history, biological and social factors that those mothers from a low SES are more frequently exposed to. Factors common to those from low SES backgrounds include poor nutritional status of the mother, younger maternal age, hard physical labour and a stressful work environment/routine or unemployment, substance abuse and/or exposure, as well as psychological factors such as stress and depression linked to housing instability, stressful conditions and material hardship⁸ (Goldenberg et al., 2008). Although these factors mentioned might contribute to a preterm birth itself, they would continue to affect the mother's health (psychological and physical) after the birth, and thus the infant's health and developmental potential will be threatened by maternal stress and the same physical environmental risk factors faced by the mother, e.g. access to water, sanitation, food security etc. Literature suggests that mothers raising children in low socioeconomic circumstances often have reduced opportunity and time to focus on caregiving and acquiring developmental knowledge as the mothers are usually occupied with long working hours and other responsibilities, more so than mothers with a higher socioeconomic status (Korja, Latva & Lehtonen, 2012).

Regarding maternal knowledge, earlier literature such as Bornstein et al. (1996) suggests that maternal knowledge and beliefs about child development and developmental stimulation differs amongst cultural, race and ethnic groups. Maternal knowledge is said to be influenced by socioeconomic status, education and culture (Bornstein et al., 2012). Research has linked low socioeconomic circumstances to that of poor maternal knowledge regarding childhood development, particularly underestimating the timing of milestones and holding a 'compact view' of development (Tamis-LeMonda, Shannon & Spellman, 2002). Studies performed in Western countries suggest that mothers'/caregivers' knowledge of their infants' development has important implications for recognizing developmental delays and seeking intervention (Bornstein et al., 2012). Awareness of developmental milestones may also allow structuring of the home environment so to promote development and provide learning experiences. According to Haung et al. (2005, p. 150) "mothers who are knowledgeable about child development are more likely to create an environment that is appropriate to their children's development and/or more likely to

⁸ Material hardship: "an inadequate consumption of goods or services that the public deems minimally necessary for decent human functioning" (Nelson, 2012, p. 1).

interact with their children in more sensitive ways, which in turn will support their children's social and cognitive development". Additionally, clinicians also rely on the mothers'/caregivers' knowledge and reports of their child's development and health status for making important decisions regarding interventions (Ertem et al., 2007). There are, however, contrasting studies that have shown no correlation between maternal knowledge and the parenting manner (environment created, and support and interaction provided to the child), however these studies were conducted within the westernized, well-educated, middle-class homes and may thus not be relevant to the majority of the South African population (Conrad et al., 1992).

It is evident that maternal knowledge is an important protective factor when it comes to stimulating childhood development, and a possible risk factor if caregivers are unaware of expected and delayed milestones. Furthermore, poorer maternal knowledge has been linked to lower SES, in which more than half of South Africa resides. Thus, for the South African healthcare providers working with preterm infants and children maternal education is a highly relevant factor in research and intervention.

3.1.3. Culture

What is culture?

Before exploring culture as an influence, the term 'culture' itself should be explored. Spencer-Oatley (2008) suggests "Culture is a notoriously difficult term to define". "Culture" within the context of healthcare may either refer to the institutional culture of the clinic or hospital, or that of the patient or the healthcare provider (Penn & Watermeyer, 2018), however within the context of the current study "culture" refers to that of the patient's culture. Schwartz (1992, as cited in Avruch, 1998, p17) defined culture as consisting "of the derivatives of experience, more or less organized, learned or created by the individuals of a population, including those images or encodements and their interpretations (meanings) transmitted from past generations, from contemporaries, or formed by individuals themselves". Culture is thus not definitive, but rather dynamic. Culture is constructed by experience and acknowledges that we are exposed to several different influences throughout our lives – our family, traditions, community, education, religion, hobbies and interests and many more. Therefore, an individual's culture is not a single identity, but a culmination of experiences and influences such as "ethnicity, race, age, income, education, sexual orientation, class, abilities, faith and more" (Yeager & Bauer-Wu, 2013, p. 12).

Within the bounds of the current study, the aspects of culture that will be explored refer to the caregiving and child-rearing beliefs and traditions shared by individuals with certain common characteristics. The chosen population speaks isiXhosa as their home language (their first acquired language and that which is spoken with family in the home) and lives within urban low socioeconomic circumstances within the Western Cape Province of South Africa.

Culture as an influence:

It is well known that infant-caregiver emotional attachments result from interactions with the attachment figure and are key elements in childhood development (Biringen & Robinson, 1991). Culture provides and equips parents and caregivers with a specific repertoire of experiences, parenting cognitions and practices, which ultimately lead the parents to interact with their infants in this culturally mediated manner. In a reciprocal fashion, infants react to these parental interactions and communicate in a number of different manners, for example through sounds, facial expressions and movements. Thus parent-infant attachment occurs bi-directionally through nurturing interaction and communication (Sullivan et al., 2011). Although it is fairly common in most cultures to engage in such caregiver-infant interactions, the margins of such interactions vary with both ecological and cultural context. Although the ability to acquire language may be biologically inherent, the manner in which meaning is created, shared and understood are culturally embedded (Farran, Lee, Yoo & Oller, 2016), and passed from parent to infant through interactions and the creation of a specific “niche” or learning environment (as termed and described by West, King and Arberg (1988) and more recently explored by Lupyan and Dale (2010)). Interactions that are appropriate in such cultural contexts are crucial in the development of social competence in those specific contexts or communities. The development of communicative skills thus occurs in a culturally guided manner (Bornstein, 2012). Ertem et al. (2007) report for instance, that some communities in rural Turkey believe that infancy and young childhood are ‘passive periods’, during which a child is cared for without much communication or play stimulation. This belief shapes the way that the parents in this community interact with their children, thus also influencing their communication development. All parents’ and caregivers’ communications are embedded within the cultural context they experienced, which they then pass on to their children. Cultural beliefs provide people with a sense of what is considered their norm (Donnalley, 2013). Culture shapes interactions, attitudes, beliefs, experiences and caregiving.

Rural and Urban culture

It is acknowledged that “culture” is defined by many influential concepts, but for the purposes of the current study it is considered those groups of individuals with shared beliefs, traditions, caregiving practices, and language be grouped as a larger or broader form of ‘culture’, such as the extent to which first language isiXhosa speakers living within a widespread community can be observed as a broad ‘culture’. Caregiving and parenting practices, beliefs and experiences have shown to differ even within broader ‘cultures’, for example certain culturally-grouped practices and beliefs are not necessarily uniform across different geographic and economic settings, such as rural and metropolitan communities. Studies have shown that individuals from different contexts (rural or metropolitan) may share similar cultural information but have quite different experiences, structures and dynamics (Bornstein et al., 2012). Research suggests that rural environments often consist of smaller and closer communities that are mutually dependent and cohesive, as well as more traditional or firm in following cultural norms (Greenfield et al., 2006). These rural communities have also found to be slower at cultural change and tend to prefer conformity to a set of practices. Additionally, rural communities often have limited access to social resources such as higher quality education and health care (Lichter & Jenson, 2002). In contrast to rural families, those who live in metropolitan areas are usually exposed to a wider range of ideas, actions and perspectives from a range of different cultures. Parents from metropolitan areas have been found to believe that they are more influential within their child’s development. Individuals from metropolitan areas are also often more independent, often have access to a better quality of education and are likely to be more literate than those living within rural areas (Greenfield et al., 2006). Living in metropolitan areas also allows for one to be exposed to a larger amount of educational and informative information, such as that on the topic of health care and development. Therefore, the perspectives and practices of individuals may also be influenced by the geographic context of the individual.

Culture and Health Care:

As previously discussed, cultures influence an individual’s perspective of health and illness, influencing how symptoms are recognised, the perceived cause, the interpretation of the illness and how the illness is addressed (Anderson et al., 2003). Many initial studies that looked into health and culture found variations in beliefs between different cultures, for example a study by

Suchman (1965) related the delays in seeking healthcare to patients' beliefs and perspectives about modern and professional medical care. These, and other studies, also found scepticism about health care professionals and settings, and that delays in seeking medical care was attributed to negative experiences of attitudes towards health care professionals. An Institute of Medicine report (2001) addresses negative health care experiences and inequalities noting that the "disparities are complex, are rooted in historic and contemporary inequalities and involve many participants at several levels, including health systems, their administrative and bureaucratic processes, utilization managers, healthcare professionals and clients". Thus, cultural knowledge, -competence and -sensitivity is an important skill for the modern health care professional. In recent research there has been a growing awareness of the importance of cultural knowledge, -differences and -sensitivity toward different cultures and their respective norms and practices. A recent study by Farran, Lee, Yoo and Oller (2016) for example looked at the cross-cultural differences in infant-directed speech within the Lebanese and American-English cultures. A study by Bornstein et al. (2012) also looked at cultural characteristics in mother-infant dyads across cultures in Argentina, Italy and the United States with the goal of evaluating culturally- and community-specific emotional processes within mother-infant dyads. The rationale for both studies involved the gap in cross-cultural research regarding parent-infant interactions.

In South Africa, there have been studies looking at communication patterns within different language groups, however not a large amount of research into cross-cultural healthcare could be sourced. It is known that in South Africa there exists 'traditional' healthcare practices involving traditional healers and traditional medicines, however information about these traditional domains remains scarce. Further information and research is needed about this topic in order to assist healthcare providers in understanding the views, experiences and values of the communities they serve. This point has been the central focus of a recently published Lancet Commission on Culture and Health (Napier et al., 2014). This Lancet Commission provides a comprehensive perspective of culture and health, highlighting the significance of culture in health and health promotion whilst drawing attention to its apparent neglect. Furthermore, the commission makes widespread suggestions that are critical to achieving worldwide health, advocating that professionals "constitute an agenda for the reversal of a systematic neglect of culture in health, the single biggest barrier to advancement of the highest attainable standard of health worldwide" (Napier et al., 2014, p 1608). South Africa houses a culturally and linguistically diverse population facing unique and large health challenges as well as persistent

inequities, thus making the country an ideal place for the realization of such suggestions (Penn & Watermeyer, 2018).

3.2. The South African Speech-Language Therapist

The mother and infant in the healthcare setting

As previously discussed, the role of the SLP lies not only in assessment and intervention of feeding and communication disorders, but also in the prevention (including education and counselling) thereof (Health Professions Act, 1974 (Act No. 56 of 1974)). Direct intervention with young preterm infants often has to do with feeding. This role encompasses the assessment and intervention of feeding and swallowing difficulties, outlined at the beginning of the chapter, in order to ensure that the infant is able to safely and efficiently ingest nutrients. Involving the mother at this stage is crucial in the long-term feeding safety and development of the infant as the mother (or primary caregiver) will be the individual responsible for feeding at home, outside of medical or SLP guidance. Caregiver education, and thus prevention, is therefore an important indirect intervention strategy. Typically, the preventative intervention that would take place consists of educating the mother or caregiver about preterm communication development, including information about providing the infant with a stimulating environment (cognitively, linguistically, socially, emotionally and physically) in order to foster development, as well as arming the mother with information that would help identify developmental delays. The intervention and educational process is guided by the SLP's knowledge and experience. Unfortunately, the SLP does not always have a chance to interact with every preterm mother in a hospital or follow-up setting, and not all health care facilities have SLP's on staff or in the NICU. Thus, in order to provide services at this level, the SLP should involve and educate other healthcare professionals that work with this population, such as the nursing staff. The SLP should equip other healthcare providers with information regarding early communication development, feeding and swallowing, stimulation and the information needed to identify potential delays or disorders as well as when and to whom to refer.

Cultural knowledge, competence and humility

The foundation of speech-language therapists' interventions is evidence-based practice (EBP), which described by the American Speech-Language-Hearing Association (ASHA) (2005) is the

acquisition and maintenance of “knowledge and skills that are necessary to provide high quality professional services”. This includes knowledge of the population in which intervention is taking place. ASHA (2005) also states that the professional SLP practicing EBP is required to “recognize the needs, abilities, values, preferences, and interests of individuals and families to whom they provide clinical services, and integrate those factors along with the best current research evidence and their clinical expertise in making clinical decisions”. In order to implement this appropriately, a sound understanding of the population and individual clients and families is needed.

South Africa is a largely diverse nation and home to 11 official languages, with many additional unofficial languages, such as Siphuthi and Sindebele. Although English is the predominant language in the context of educational, political and vocational settings, it is estimated that only 10% of South Africans speak English as their home language (Statistics South Africa, 2016). Thus, most South African homes house indigenous languages. Unfortunately, most of the standardised assessment tools and protocols available to SLP’s in South Africa are those standardised and developed in English speaking contexts within the global north, and thus are largely irrelevant in the South African context (Pascoe & Norman, 2011). South Africa’s constitution emphasises the value of culture and language (Constitution of the Republic of South Africa, 1996), however many SLP’s are still facing challenges linked to poor knowledge and understanding of patient linguistic and cultural properties, essential for quality intervention (Southwood & Van Dulm, 2015).

Furthermore, South Africa houses an array of different cultures and ethnic groups that hold their own unique attitudes, beliefs and values (Mesthrie, 2002). The South African scope of practice for SLP’s states that services be provided to all individuals and groups from “diverse linguistic and cultural backgrounds” (Health Professions Act, 1974 (Act No. 56 of 1974)). In order to provide culturally congruent, effective and appropriate intervention in such an exceptionally diverse population one needs to understand the beliefs, knowledge and practices of the clients. Such understanding would allow SLP’s to optimize intervention outcomes, patient compliance, -satisfaction and minimize misunderstandings (Anderson et al., 2003). Unfortunately, in South Africa, such knowledge and understanding is often not shared or available amongst healthcare professionals and SLPs in particular. Pascoe, Klop, Mdlalo & Ndhambi (2018) have effectively summarised this difficulty in their statement that “SLPs comprise a small group poorly equipped to serve the needs of the population due to a homogenous composition (largely female, white,

English or Afrikaans speaking) and a lack of data about local people and their languages and cultures, together with few resources appropriate for use with the population”(p 68). Therefore, when providing services, the SLP is likely to use their own worldview, as well as the profession’s western worldview as a basis for the intervention process (Verdon, Blake, Hopf, Phm & Mcleod, 2016). Without the knowledge and background of the client/patient’s culture and language, this intervention may likely not be culturally or linguistically congruent (Mdlalo, Flack & Joubert, 2016). In high-risk and vulnerable populations, such as preterm infants, intervention efforts through maternal education are likely to be futile if insensitive to and incongruent with the mother’s own beliefs and traditions, often guided by her culture.

In light of this, the HPCSA board for Speech, Language and Hearing professionals released a document in late 2019 entitled “Guidelines for Practice in a Culturally and Linguistically Diverse South Africa”. This document responds to the recognition of the difficulties faced by South African SLP’s in providing appropriate services within such a diverse nation, thus providing a set of guidelines to support professionals in providing “ a just, ethical, effective and relevant service” (p. 6). The guidelines further stipulate that the SLP’s should take into consideration the influences of culture and cultural diversity as well as value local knowledge. As communication is transpired within a culturally structured niche, these are integral to the provision of culturally congruent and patient-centred service provision within such a diverse population. The guidelines thus indirectly highlight the importance of cross-cultural research and the knowledge generation thereof.

3.3. Research performed in South Africa

3.3.1. Current research

Recently there has been a growing awareness around the importance of cultural and linguistic knowledge and sensitivity in speech-language therapy (SLT), which has been reflected in the research that is taking place in South Africa. Examples of such studies include Bornman et al.’s (2018) research regarding adapting an early learning assessment tool used in speech-language therapy for the South African context, a case study by Pascoe and Russouw (2018) that investigated an intervention for a bilingual speech disorder in an isiXhosa-English speaking child, and Tayob and Moonsamy’s (2018) research exploring perceptions and experiences of reading and promoting literacy in a South African children’s home. It is clear that there is a trend

illustrating the importance of contextual South African research. The majority of the research within the SLT domain focuses on children and adults with communication and hearing disorders. Although there have been some SLT-focussed studies regarding preterm infants in the South African context (for example Kritzinger and McInroy's (2005) case study of the communication development of a preterm infant from birth to NICU discharge), little cross-cultural research thereof could be sourced. Furthermore, limited studies could be found exploring maternal experiences of prematurity within a cross-cultural South African context. Research within the domain of prematurity predominantly focuses on infant-related morbidity and mortality, and mother-infant attachment. However, there has been a recent increase in recognition of the importance of maternal experience in caregiving, as there have been more studies related to maternal perceptions and experiences, for example the study by Pascoe, Bissessur and Meyers (2016) that described mothers' perceptions of premature infants' communication, as well as Steyn, Poggenpoel & Myburgh's (2017) study that investigated the experiences of parents of premature babies in the intensive care unit of a private hospital in South Africa.

No research exploring the experiences of isiXhosa-speaking mothers of preterm infants could be sourced.

3.3.2. Methodologies used in similar studies to the current study

Qualitative methodologies are common in studies investigating the experiences of specific populations with regard to health and health care. A number of such studies have been performed in the local context. A study that investigated parental experiences in the NICU within a private South African hospital used a qualitative, cross-sectional, exploratory research design with in-depth phenomenological interviews (Steyn et al., 2017). Similarly, a study looking at caregiver perceptions of the use of reading to promote literacy in South Africa by Taylob and Moonsamy (2018) used qualitative, exploratory, semi-structured interviews. Additionally, Penn, Watermeyer, MacDonald, and Moabelo (2010) investigated the experiences and beliefs of South African grandmothers regarding genetic childhood disorders using focus groups led by trained interviewers who were familiar with and part of the same culture as the participants, and with whom their home language was shared. Furthermore, Barratt and Penn (2009) studied the experiences of South African caregivers of children with cerebral palsy, and made use of qualitative narratives with the help of a cultural broker. Where linguistic and cultural differences exist between researchers and participants, using interpreters and cultural brokers appears to be necessary for fuller understanding of the participants' experiences. Cross-cultural research promotes studies that occur over a longer period of time to allow researchers to experience the

culture and become familiar what they intend to study, as well as developing a trustworthy relationship with the participants (Goulding, 2007). An example of such longitudinal cross-cultural research is a study by Legg and Penn (2013), which explored the quality of life of persons with aphasia living in a township setting in South Africa and took place over 3 years using both observation and interviews. As the aforementioned study progressed it became clear that the original study framework was no longer appropriate as the participants did not separate ‘everyday’ struggles from those of aphasia, but rather the participant narratives included the communication difficulties within the domains of gender and social struggles. These findings highlight not only the importance of such cultural research in reframing the South African speech-language therapist’s role, but also the value of narratives or patient’s stories in research.

3.3.3. Cross-cultural research

Claire Penn and Jenifer Watermeyer’s (well-recognised South African speech-language pathologists) research expanded into the broad domain of health communication. Their research used primarily qualitative methodology to explore cross-cultural and cross-linguistic healthcare interactions, the cultural beliefs regarding illness and causality, as well as the impact of health systems on rural communities. In a recent book written by Penn and Watermeyer (2018), titled “*Communicating Across Cultures and Languages in the Health Care Setting*”, the authors discussed the need for- and implications of cross-cultural research, as well as the best practice thereof. The book addressed research with vulnerable populations; specifically those who are more often sick, less educated and come from low socioeconomic circumstances. The authors suggested that this population has been “marginalised by society and their voice is often misrepresented and silenced” (p.9-10), thus leading the authors to represent these people through qualitative research, known to be more expressive in nature than quantitative methods. According to the authors, cultural competence, -awareness, -safety and -security are becoming increasingly popular as important discussion topics amongst health care professionals who deal with diverse caseloads as it is evident that patients’ culture and beliefs can impact treatment-seeking behaviour and adherence to treatment regimens (Martin & DiMatteo, 2013). Within the domain of SLT, cultural competency also assists in establishing positive and cooperative therapist-client relationships through dialogue and interventions supportive of individual perspectives and values (Brown, 2017). However, unique difficulties may be encountered with cross-cultural research, which could affect the nature and quality of the research. Some of these difficulties are illustrated below as discussed by Penn and Watermeyer (2018).

Interpreters and cultural brokerage

It has become apparent that the traditional use of interpreters in research methodologies, whereby the interpreters (attempt to) remain completely neutral and translate information verbatim, is ineffective when cultural and linguistic differences exist between the participant and the researcher. Additionally it has been shown that the interpreter has profound effects on the quality and effectiveness of the communication, and that the quality of interpreting depend on many factors such as interpreter-training, opening and closing of the interactions, role (mis)conceptions, and research-interpreter power relationships (Penn & Watermeyer, 2018). Establishing a favourable and comfortable relationship between an interpreter, interviewer and interviewee, as well as training the interpreter regarding his/her role in the interaction and what is expected of him/her, is highly important in achieving an effective research interview or interaction.

The research on interpreting suggests that the use of interpreters where they are expected to remain 'neutral' is unrealistic in the multicultural South African setting, and that cultural brokerage is a more useful research tool in transmitting meaning in intercultural contexts and interactions (Penn & Watermeyer, 2018). A cultural broker in the context of a health or research setting would act as a mediator between the two individuals. He/she offers a framework of understanding in which the actual message, not just the semantic properties but also underlying meaning of the message, can be appropriately transferred. The cultural broker would navigate the cultural and linguistic differences between the interviewer and interviewee in order to facilitate understanding and to achieve the communicative goal, rather than pure direct translation of the message. Examples of such situations in which a cultural broker is needed is when the participant uses phrases, idioms or sayings which convey specific meanings (more than merely the semantic content), or when the participant speaks of a culturally-specific tradition or belief with which the researcher is unfamiliar. The cultural broker will then both translate the message directly, but also explain to the researcher the intended meaning of a phrase or idiom, as well as provide the necessary insight into certain beliefs, traditions or practices that the researcher is unfamiliar with. Penn and Watermeyer (2018) suggest that comfortable communication between the researcher/interviewer and the cultural broker is important in allowing for the clearing of misunderstandings or revision of information, and that 'asides' (often used for either 'small talk' or culture-specific uncomfortable information) must be approached and discussed clearly to determine their meaning and contribution. It should be noted that the inclusion of an interpreter

or cultural broker is implemented in a manner respectful of the participants' ethical entitlements. Sylvia Kalina (2015, p. 69) suggests "there is agreement that general ethical principles such as discretion, professional secrecy, careful handling of documents received, and, with a view to interpreting quality, accuracy, apply to virtually all interpreting situations and settings...", thus the interpreter was subject to the same ethical principles respected by the researcher. More information concerning research ethics can be found in Chapter 4 (Methodology).

Context: place, time, and space

Broadly, context is a factor that has noticeable effects on the nature of communication. Examples of contexts where differing manners of communication is likely to take place include rural versus urban settings; the patient's own home compared to a school environment or a healthcare facility; and in a public environment versus a private space. Contextual factors (including the physical-, social- and emotional environments) influence individuals' behaviour and communication, and as stated by Penn and Watermeyer (2018, p. 16) "illness and its experience are located in spatial and temporal dimensions". Thus, if research is conducted in a healthcare facility context, the context may lead to participants 'reliving' or being reminded of experiences that previously occurred within a healthcare context. Acknowledgement of contextual factors, including environmental-, temporal- and spatial factors, is therefore very important in the planning of the collection, analysis and interpretation of data as the context itself may affect the nature of the data collected (for example an interview that takes place in a health care setting is likely to yield results that are more medically inclined). Additionally, quiet and private spaces are more likely to provide a sense of comfort and openness, which is ideal for sensitive topics and depth-investigations. Furthermore, the influence of time should be acknowledged as it may affect the amount and quality of information gained in a research setting, for example if a participant or researcher feels rushed, interactions are more likely to be short and reserved. Because of the pragmatically compelling context, research conducted in healthcare facilities should therefore show sensitivity to temporal, environmental, spatial and cultural features.

Methodological difficulties

When working across culture and language in a sensitive setting, such as health care, there are often methodological difficulties that are unique to this cross-cultural or intercultural research. Methodological difficulties and barriers are discussed at length in Penn and Watermeyer's (2018) book, and those relevant to the current study are mentioned shortly below.

Interviews:

The authors suggest that interviews exploring participants' subjective experiences and interpretations require a full understanding of linguistic and cultural barriers, thus important decisions are to be made regarding the interviewer, and the language, terminology and phrasing used in the interview. Open and semi-structured interviews are suggested in order to elicit narrative-like responses, which appear to have become increasingly popular in 'sociological medicine' (p.74). A narrative approach to enquiry often elicits a lengthy response and, by placing the participant in control of the response, also allows for participant comfort (thus allowing often for salient points to emerge), which is usually not permitted by overly structured interviews. Caution must be exercised when interviews are of a sensitive nature, as it cannot be assumed that these responses or narratives are always of a restorative nature, but may also evoke powerful emotions and may be stigmatising for an individual when in the presence of others, for example a cultural broker or member of the same community.

Managing language diversity and language shifting:

In intercultural and linguistically diverse interactions there lie communication challenges, of which effective management proves crucial. These challenges occur across the translation of the research material as well as the interviews themselves. Therefore, research assistance is needed in the form of a skilled translator for formal research documents, as well as an interpreter or cultural broker during the interview process, as previously discussed. Interpreters or cultural brokers have to be carefully selected, as facilitating the research process is more than simply translating. It is ideal to include an interpreter or broker who is experienced and who is closely linked to the culture and setting of the interviewee. The interpreter/cultural broker should also be sensitive to participant distress in the event such distress should occur, reiterating the importance of interpreter/broker training mentioned beforehand. There is also an existing danger of letting the research assistant (interpreter or cultural broker) conduct the interviews with regards to answering the aims of the study as well as avoiding biases.

Interactions that occur across languages often exhibit 'shifting' between the two languages in order to accommodate understanding and terminology. According to Haberland (2007) and Wei (2005), language shifts are determined by "social rules, -attitudes, power, and hierarchies" (p. 208). Studies exploring language and communication within the South African healthcare context have revealed that amongst indigenous languages, English words are commonly used in medical circumstances where medical terminology is used (e.g. to refer to concepts such as medical

assessments, diagnoses and medications). However, these switches are not only made during intercultural and cross-linguistic interactions, but also during same-language discussions. Penn & Watermeyer's (2018) review of such studies looking at healthcare communications found that the language shifts were also linked to perceived education levels, literacy, medical knowledge as well as a language-gap (i.e. there are some English terms that do not as of yet have direct translations in other languages such as isiXhosa). It is mentioned in Penn and Watermeyer's (2018) book that the use of English terminology could be viewed as prejudicial, as "English may be considered a language of prestige in some contexts and there is a perceived erosion of literacy levels in vernacular languages" (p.95). Thus, acknowledgement of the effect of using the English language and terminology in relation to a power-dynamic must be taken into consideration when conducting interviews.

Transcription and translation:

Translation of the research documents is an important consideration, for example the provision of critical information and consent forms should be made available in the participant's home language so to ensure truly informed consent to participate in research. However, translation of documents is a complex process as language use (terminology, phrasing and semantic meaning) is not consistent throughout a language-speaking population. The words chosen to convey messages are often influenced by the geographical location, dialect preferences and educational factors. Thus, the language use of the translator might differ from that of the participant. Dialectal differences thus need to be taken into consideration when translating documents aimed for use by participants. In formal document translations there are often differences between the written and spoken language, including use of terms, language shifts, tone and sometimes structure, often giving an 'unnatural' linguistic property to the formal translated documents.

The transcription and translation of interviews are important processes in qualitative data analysis as it allows opportunities for accuracy checking at a later stage. Many decisions need to be made at this point, including the amount of detail recorded, inclusion of non-verbal cues and interruptions, as well as the inclusion of both languages (original and translation). Penn and Watermeyer (2018) comment on the importance of the addition of non-verbal communication within transcriptions, and the meaning that it gives to text, highlighting non-verbal communication as an important inclusion in the transcription process. The authors suggest that the detail needed in the transcriptions vary in accordance with the goals of the study and the text and is thus a flexible component in transcriptions. Additionally, Penn and Watermeyer (2018)

recommend that, in culturally and linguistically diverse populations affected by socio-political factors, rigorous control of language-related issues is needed. Examples of such issues include language-use history taking, appropriate training and monitoring of research assistants, and the careful consideration and awareness of the potential communication barriers affected by terminology, linguistic proficiency and literacy levels (Penn & Watermeyer, 2018).

In summary, Penn and Watermeyer (2018) propose that cross-cultural interviews and oral narratives exploring subjective experiences require a good understanding of both cultural and linguistic barriers, and bring with them complex decisions about terminology, phrasings and language. In the South African context however, oral narratives are said to be a “particularly fruitful” research tool and one that many different cultures are familiar with (p.225). In such complex contexts it is important that linguistic factors are carefully considered throughout all aspects of the study. The use of interpreters and cultural-brokers may involve additional complications that influence temporal and spatial factors as well as the perceptions of confidentiality. However well chosen and trained cultural brokers are particularly useful in reaching effective communication in linguistically and culturally diverse populations, specifically when the researcher is not a part of the same cultural and language groups as the participants.

3.4. Conclusion

Preterm birth is one of the largest contributors to infant mortality and morbidity, making this phenomenon a primary health concern worldwide. In summary, the literature review has outlined how vulnerable the preterm population is to both health and developmental complications, with an emphasis on those sequelae falling within the SLT domain – feeding and communication. Furthermore, external (or non-biological) factors that may further influence infant and child health and development, both risk and protective factors, have been discussed. Such risk factors include those that are faced by majority of the South African population, such as the burden of disease, South African public healthcare challenges, political/policy-related factors and poverty or low socioeconomic status, as well as those SES-related factors. It has been acknowledged that the mother, or primary caregiver – although affected and challenged by the same set of risk factors - can play a large role in mitigating the impact of such risk factors and implementing protective factors with regard to the development of the infant and child. Therefore, in early infancy, the mother plays a large role within the life of the infant and thus SLT intervention

process. Additionally, it is important to note here the possible impact of maternal experiences, stressors, beliefs and values on mother-infant interaction, health practices and development. In South Africa however, SLP's are poorly equipped with the knowledge and understanding of the patient's background, including their culture, encompassing unique values, beliefs and healthcare practices. This lack of knowledge could present as a strong barrier to effective, efficient, culturally competent intervention. A research gap has thus been identified within the aforementioned areas.

Additionally, a short section reflected research concerns in studies similar to the current study within the South African context. Methodological and research design challenges faced within intercultural studies were explored, illuminating cautionary steps and considerations to be taken in such studies. Such information was used to guide the methodological aspects of the current study that will be discussed in the following chapter.

In light of the issues and contexts discussed in this chapter, the following methodological elements emerged:

3.4.1. Research problem

Within the context of SLT intervention with prematurity, a leading contributor to the disease burden in South Africa, it is necessary for the SLP to have an understanding of the stressors and perceptions of their patient population in order to identify risk and protective factors affecting the patient (directly or indirectly). Such knowledge should assist in enabling clinicians to provide effective, culturally competent intervention. The research problem, as it stands, is that SLP's working with preterm infants and their mothers or primary caregivers are not adequately equipped with knowledge and understanding of the perceptions and experiences of the majority of the South African population, specifically more vulnerable populations – that is, those living in poor socioeconomic circumstances with various different cultural and linguistic backgrounds.

3.4.2. Research question

What are those experiences of mothers from a vulnerable population (isiXhosa-speaking individuals residing in urban low socioeconomic circumstances) regarding caregiving, feeding and communication with their preterm infants?

3.4.3. Aims and sub-aims

1. To describe and explain the perceptions of a group of mothers regarding prematurity;
2. To describe and explain the mothers' experiences of giving birth to and caring for a preterm infant;
3. To describe and explain the interactions between preterm birth, the mothers' maternal beliefs and traditional practices;
4. To describe and explain the mothers' perceptions and experiences of feeding their preterm infant;
5. To describe and explain the mothers' perceptions and experiences of communication with their infant;
6. To describe and explain the mothers' perceptions of their role in their child's caregiving and early communication development;
7. To describe and explain the mothers' perceptions of other important role-players in their child's caregiving and early communication development; and
8. To describe and explain the information that the mothers of preterm infants feel they need after hospital discharge.

Chapter 4:

METHODOLOGY

4.1. Introduction to methodology

When performing research within the domain of others' experiences, a reflection into ontology and other philosophical concepts is a necessary first step. Bracken (2010) suggests: "investigating ontological distinctions is a critical facet of the research process because it enables the researcher to uncover how their perceptions of human nature impact on the approach, they consciously adopt to reveal social truths" (p. 2). Therefore, reflections on ontology may assist researchers in thinking about the true nature and existence of the phenomenon under study. Through ontological reflection, interpretive frameworks or perspectives can be investigated and chosen as best suited to the aims of a particular study. Such interpretive frameworks or positions are said to "...provide a pervasive lens or perspective on all aspects of a qualitative research project" (Cresswell, 2007, p 24).

4.1.1. Ontology

Strauss and Corbin (1998) have defined methodology as "a way of thinking about and studying social reality" (p. 3). As a researcher, one's decisions regarding methodological strategies within a study are influenced by one's own knowledge and experiences of both research and the topic. Ontology refers to the claim that the researcher makes regarding the nature of reality, with epistemology being how individuals view the nature of knowledge about reality, and methodology as the process of research to gain knowledge (Cresswell, 2003). As the researcher, my own philosophical stance has been reflected in the statement by Crotty (1998) where he states "all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context" (p. 42), as I the researcher believe experiences are subjective and constructed by one's own unique combination of influences, perceptions and past experiences. This aligns with the views of Guba and Lincoln (1994), namely that individuals respond to their social environment in a manner that is based on their own perceptions and experiences, and that these perceptions and experiences contribute significantly to their future actions and interactions. This view aligned with the goals of the current study, which aimed to study the subjective experience and knowledge of a group of individuals, and thus further guided the epistemology of the study.

4.1.2. Epistemology

Fundamental to the methodology and interpretation of the data collected through a research study is the philosophical viewpoint of the nature of knowledge, or how people construct their understanding and knowledge of the world. As supported by the above-mentioned ontological stance, the study took a constructivist approach in epistemology. The more renowned contributors to the constructivist paradigm are Jean Piaget, John Dewey and Lev Vygotsky. A constructivist epistemology allows for an open-minded approach to research and discovery, and declares that holding knowledge is a process, and that understanding is constructed through each individual's own unique experiences and background knowledge. Constructivism maintains the view that individuals construct their own understanding or knowledge through the complex interaction of their own beliefs, views, ideas and experiences and that with which they come into contact (Ultanir, 2012; Ciot, 2009). Thus, the application of this view was relevant to the current research in that different people may experience a similar phenomenon, however the manner in which the phenomenon is received, interpreted and explained is a result of a construction of past and present experiences, beliefs and values. Similarly, the manner of response to the experience is constructed by such personal interpretations affected by past and present experiences, beliefs and values. Although each individual interprets a phenomenon (e.g. giving birth to and caring for a preterm infant) uniquely, a community with similar beliefs and values, facing similar conditions are likely to experience similar factors that influence this experience in a similar manner. Those living in similar socio-economic situations are likely to experience similar effects of this circumstance. In an urban low-income community it is likely that members might feel similar effects of financial stress with regards to a particular phenomenon, for example difficulties with financially caring for a preterm infant when this includes frequent travel to and from a medical centre, or when it is necessary to buy expensive milk-formula to feed the infant. Similarly, as mentioned previously, the experience of a phenomenon is also affected by personal beliefs and values, which may relate to one's own unique culture and likely the larger culture surrounding the individual. Ultanir (2012) states that "the knowledge that people have is related to their social and cultural content, as well as the media's recommended stage of life and life situations... moreover, cognitive knowledge cannot be learned receptively but is a mixture of personal experience, emotions and intuition. Learning requirements are born of a complex life and the rate of technical and social change" (p. 208). Individuals that are part of a broader culture that share certain traditions, beliefs and values are therefore also likely to experience similar effects of these

influences with regards to a phenomenon. For example, if there exists certain traditional health practices and beliefs within a culture/community, it is likely that these beliefs will affect the healthcare behaviour of those individuals within the culture in a similar manner. These behaviours, influenced by beliefs, traditions and values, are also affected by knowledge to which the individual has been exposed. Thus, in order to understand someone's perspective or experience, it is necessary to understand the key elements in the construction of their view, a fundamental rationale for current research.

It must be acknowledged that due to the nature of a constructivist epistemology, the relationship between the researcher and participant (as well as the dynamic of the interpreter) is subjective and complex, and thus interpretation thereafter is also influenced by the values and experiences of the researcher. Thus, Locke (2001) suggests that the best approach to interviews involves the constructivist acknowledgement that experiences are subjective and engaging with the participant in sharing similar and different experiences is encouraged.

4.1.3. Qualitative approach

A qualitative approach to research aligns easily with a constructivist epistemology (Creswell, 2003). A prerequisite for qualitative enquiry is a belief of the "multiple realities and commitment to the participant's viewpoint" (Penn & Watermeyer, 2018, p. 63). The qualitative approach leads the researcher to focus more on emotional responses, perceptions and perspectives of participants, as opposed to quantified variables or yes/no or other forced-choice answers. Thus, in-depth interviewing best fits the approach in allowing the participants time to revisit and describe their experience, as well as reflect and interpret these experiences to create meaning. Open-ended questions afford the participants the freedom of their own interpretation and construction of their experience without the provision of a framework suggesting what factors were most influential.

The goal of the qualitative exploration is to describe in all its complexity a social phenomenon through the defining patterns of the emerging data (Marshall & Rossman, 2006). As the primary data collection tool, the flexibility of the qualitative approach allows the researcher to direct the interview to explore experiences in greater depth and re-direct energy into those areas in need of better explanation (Creswell, 2003). Unlike the quantitative approach, which aims to support

statistical outcomes, generalizability and study replication, this qualitative study aims to provide insight and understanding into a complex phenomenon through in-depth exploration.

4.1.4. Phenomenology

A background to phenomenology

The origin of phenomenology is credited to a German philosopher and mathematician, Edmund Husserl, developed during the period of the late 1800's and early 1900's. Many philosophers followed on from Husserl's work, which has led to different philosophical arguments for the use of phenomenology today. However, across all differing philosophies, it is evident that all are based on common grounds, which explore persons' lived experiences. In summary, phenomenological enquiry aims at "attaining a profound understanding of the nature or meaning of our daily experiences" (Crotty, 1998, p. 25), broadly encompassing four philosophical perspectives as outlined by Stewart and Mickunas (1990, as cited in Creswell, 2003). Firstly, the perspective that takes a traditional root in philosophy as the search for wisdom, as opposed to a more scientific and empirical philosophy of research or exploration. Secondly, the phenomenological approach is one in which all prior judgements about the natural attitude, or what is real, are suspended through an 'epoche' (as termed by Husserl) until founded on increased certainty. Thirdly, as discussed by Husserl, the idea that consciousness is always intentionally directed toward an object, thus acknowledging that the reality of an object is related to the consciousness of that object. Fourthly is the view that reality of objects is perceived only within the meaning of the individual's experience. As phenomenological enquiry has been studied and adapted by philosophers and scientists alike there exist different approaches, or types, of phenomenology, mainly 'hermeneutic phenomenology' (van Manen, 1990) and empirical, transcendental, or psychological phenomenology (Moustakas, 1994). For the purpose of the current study the approach is based on that of a transcendental phenomenology, which Moustakas (1994, p. 34) defines as an approach "in which everything is perceived freshly, as if for the first time", although he admits that such perspective is seldom well achieved. Within the transcendental approach, the research is focussed largely on describing the experiences of the participants rather than the interpretation of the researcher. A transcendental phenomenological approach is widely used in research within the domains of sociology, health sciences, education, and psychology.

Phenomenology applied to methodology

Giorgi (2012) suggests that the researcher who wants to “employ the descriptive phenomenological psychological method has to begin by assuming the correct attitude” (p. 6), by assuming phenomenological reduction and resisting “positing” or theorizing that which is present to him/her. The researcher thus concentrates on the phenomenon under examination, and analysis of that phenomenon based only on what is given or found. The researcher is first to establish his/her psychological viewpoint, as illustrated above in the relevant ontological and epidemiological viewpoints (Cresswell, 2003).

In an overview of the methodological approach guided by transcendental phenomenology, one of the researcher’s first task is to ‘bracket’ or set aside his/her own experience in the form of an epoche in order to allow a fresh perspective to be taken in analyzing the phenomenon under investigation. This task was completed for the purpose of this study and evidence thereof can be found in Appendix A. The subsequent major procedural steps within a phenomenological study described by Moustakas (1994) are as follows:

- A topic of interest relevant to the field of study is identified. The researcher then determines whether a phenomenological approach is best suited to the chosen research topic.
- The researcher must then recognize and specify the broad philosophical assumptions of phenomenology.
- Data are collected from participants who have experienced this phenomenon. Phenomenology suggests that 2-25 in-depth interviews, consisting of open-ended questions, be collected from different participants (Polkinghorne, 1989)
- Data analysis typically occurs through highlighting significant statements in the interview transcripts and collecting ‘clusters of meaning’ that work to provide understanding as to how the participants have experienced this phenomenon. Giorgi (2012) suggests the following steps to data analysis:
 1. First, the researcher reads over all the data in order to gain a holistic understanding of the phenomenon.
 2. The researcher then reads over the data a second time from the beginning, during which the researcher codes the data into “meaning units”.
 3. The data are then “transformed” into expressions relevant to the importance of what the individual has said. In other words, this step is where the data set is

transformed into a set of codes and grouped together within themes.

4. The direct and more sensitive expressions are reviewed and an essential structure of the phenomenon or experience is written.
 5. The essential structure is then used as a framework to interpret the raw data (Giorgi, 2012, p. 5-6).
- The statements and themes are then described both texturally and structurally. A textural description is broadly a description of what the participants' experience, and a structural description refers to a description of factors that influence this said experience. From these descriptions the researcher constructs a composite description that depicts the overall 'essence' of the phenomenon (Creswell, 2003, p. 60-62)

4.1.5. Conclusion

Therefore, after a brief overview of epistemological frameworks, the methodology for the current study is proposed below. The study followed a constructivist approach to a qualitative enquiry, guided by the phenomenology.

4.2. Aim of the study

The broad aim of the study was to describe and explain the perceptions and experiences of a group of isiXhosa-speaking mothers, living in low socio-economic circumstances, of having and caring for-, feeding and communicating with their preterm infant.

In order to reach this aim, the following sub-aims were developed:

1. To describe and explain the perceptions of a group of mothers regarding prematurity;
2. To describe and explain the mothers' experiences of giving birth to and caring for a preterm infant;
3. To describe and explain the interactions between preterm birth, the mothers' maternal beliefs and traditional practices;
4. To describe and explain the mothers' perceptions and experiences of feeding their preterm infant;
5. To describe and explain the mothers' perceptions and experiences of communication with their infant;

6. To describe and explain the mothers' perceptions of their role in their child's caregiving and early communication development;
7. To describe and explain the mothers' perceptions of other important role-players in their child's caregiving and early communication development; and
8. To describe and explain the information that the mothers of preterm infants feel they need after hospital discharge.

4.3. Research Design

A cross-sectional, qualitative research design was chosen, which was explorative, descriptive, and contextual in nature. The research design was employed within the context of phenomenological methodology/tradition which is appropriate for studies aimed at describing the "meaning for several individuals of their lived experiences of a concept or phenomenon" (Creswell, 2007, p. 57). The study made use of in-depth personal interviews guided by a semi-structured discussion schedule consisting largely of open-ended questions.

In a cross-sectional study, all data are collected at a single point in time (for example, though only one interview with each participant), although recruitment may occur over a longer period such as several days or weeks. A longitudinal approach is used to study a subject or phenomenon over time and observe changes, in comparison to a cross-sectional study where the aim is to capture unchanged data. Thus the cross-sectional design is suited to the aims of the study where the data needed is related to the experience of participants up to the point of an interview, as opposed to the longitudinal change in experience over time. Cross-sectional studies have also been said to be intuitively clear, allowing for the examination of a large number of factors, such as the numerous sub-aims of the current study. Such clarity also allows for standardisation of the methods and clear definitions to be applied (Thelle & Laake, 2015). In addition cross-sectional studies are usually more affordable with regards to money, time and skill, making the design attractive to smaller-scale studies such as this one (Sedgwick, 2014). Interviews fit well with the cross-sectional design as a single-point interaction that usually yield large amounts of information. The use of some open-ended questions in the interviews are used in attempts to elicit narratives, which are a particularly fruitful research tool in complex intercultural contexts (Penn & Watermeyer, 2018).

4.4. Research Personnel

4.4.1. The researcher:

The researcher was a qualified Speech-Language Therapist and master's student in Speech-Language Therapy at Stellenbosch University. The researcher's first language was English and she was competent in Afrikaans, but had a very basic and limited understanding and speaking ability of isiXhosa (despite training in the language over a period of four years as an undergraduate student). Thus, for those interviews where the participant was proficient in English, the researcher was competent in conducting the interviews alone, however assistance was necessary in those interviews where the participants could not speak English proficiently.

4.4.2. Research assistants:

A research assistant was employed to assist with the isiXhosa interviews through the means of interpreting (and cultural brokerage), transcription, and translation of the interview transcripts. The research assistant was a 38 year-old first-language isiXhosa speaking female and mother (also proficient in English), who resides in the Western Cape. The research assistant fell within the target cultural and linguistic group but did not reside in the same areas as the participants. The research assistant held experience in interpreting for qualitative research purposes, ten years of experience of providing clinical interpretive assistance for medical students, as well as eight years of experience in the field of transcription and translation of data for research purposes. Thus, the research assistant was competent in the roles and requirements for the purpose of this qualitative study, namely interpreting, translation and transcription of isiXhosa interviews into English as well as providing the researcher with insight and additional explanations of some of the culturally specific phenomena. Prior to the commencement of data collection, the research assistant was enlightened with regards to the aims of the study, purpose and nature of the data collection process. Equipped with insight into the study, the research assistant was also trained regarding the expected interview dynamics and her role and related expectations thereof (i.e. facilitating communication and understanding rather than directing the interviews). Within this training period ethical parameters, such as participant confidentiality, were discussed and measures were placed in order to respect such ethical rights. This research assistant is referred to as the 'interpreter', however her role also encompassed that of cultural brokerage.

Furthermore, an additional research assistant was employed in order to evaluate the accuracy of the translated interview transcripts. This second research assistant is also an isiXhosa-speaking female and mother living in the Western Cape. This second research assistant has many years' experience working with health professionals in providing language-based assistance. The second assistant, who was blind to the design and purpose of the study, transcribed and translated a portion of one randomly selected interview in order to check the quality of the translated English interview transcripts prepared by the first research assistant. This second assistant was requested to directly translate and transcribe (where possible) the isiXhosa speech provided in an audio file. The results of this quality assessment will be discussed in the "Data analysis" section below.

4.5. Participants

IsiXhosa-speaking mothers who fitted the selection criteria, and who have had preterm infants that receive care at a chosen tertiary hospital in the Western Cape, were invited to participate in the interview.

4.5.1. Selection criteria:

Those participants who fit the following criteria were invited to partake in the interviews:

- The participant was to be over the age of 18.
 - A decision was made to exclude those under the age of 18 years as it was thought that school-aged women/girls would likely face a whole additional group of influencing factors, such as school- and age-related factors. Additionally, guardian consent would have been necessary for those under the age of 18 and it has been previously observed that teenage individuals are not always accompanied by a guardian when attending various medically related visits in the catchment area for the study.
- The participant was to be an isiXhosa first-language speaker.
- Participants must be of 'low socioeconomic status', determined by the following:
 - Socioeconomic status is determined by more than income alone, other factors such as educational attainment, financial security and perceived social status also determine an individual's socioeconomic status (American Psychological Association, 2017).

- Therefore, participants qualified to participate in the study if they did not hold a post-matriculation degree or diploma in combination with Tygerberg Hospital's income classification bracket of H0-H1. Tygerberg Hospital's patient-classification bracket of H0 – H1 was the lowest income bracket, representing a patients' household annual income (the patient and spousal joined income figure) of R0- R100 000. This was used to identify those patients who fall within a 'low socioeconomic' financial circumstance.
- The participant was to be the mother and primary caregiver to an infant fitting the criteria defined below:
 - The infant was premature, defined as being born before 37 weeks of gestation (Rossetti, 2001).
 - The infant was to be 3-6 months of (chronological) age, with a corrected age of term to 3 months. Corrected age refers to the age from the expected date of birth (Rose et al., 2002).
 - The infant had a low birth weight ranging from 800g to 2500g (encompassing those infants with ELBW, VLBW and LBW), as this is a criterion placing infants at risk for developmental delays.
 - The infant was to be medically stable at the time of the interview.
 - The infant was to be absent of any known biological, physical, sensory, congenital or neurological disorders at the time of the interview.
 - It was decided that mothers with preterm infants with additional medical needs would be excluded from the study as these mothers would likely face an additional and different group of factors influencing their caregiving experience, particularly related to the special needs of different diagnoses (e.g. specific surgical interventions or long-term care for different diagnoses).
- The participant was to be living with said infant.
- The participant was to have had a time period of one week or more where the infant has been at home with her, and not only at the hospital.

4.5.2. Sample size

A total of 16 participants took part in the study. However, one interview was discarded as after the interview took place the infant attended a doctor's appointment where the infant was

diagnosed with a neurological disorder (thus disqualifying the mother from the inclusion criteria), leaving a total of 15 participants that were included in the study.

There are no set limits, minimum or maximum, on the number of participants that need to be included in qualitative studies, however Polkinghorne (1989) recommends between 2 and 25 participants are included in phenomenological studies making use of in-depth interviews. For the purpose of the current study, the aim was to recruit between 15-20 participants, but to ultimately focus on data saturation. Data ‘saturation’ is a concept that originated in 1999 through the works of Glaser and Strauss as an element of Grounded Theory (GT). The term data “saturation” is a common find in qualitative research methodologies, inferring that the addition of more data will not change the results, however not many authors specify what is assessed to reach this conclusion, nor to its approach or methodology in non-GT frameworks such as phenomenology (Malterud, Siersma & Guassora, 2016). Thus the following criteria have been used in order to justify, describe and monitor data saturation as described in Malterud et al. (2016):

Data saturation:

- Sample specificity:
 - Specificity concerns arise when participants are specifically chosen because they belong to a certain target group whilst also exhibiting some variations within the experiences explored. Therefore in order to allow for variation, the researcher ensured through purposive sampling that the participants showed diversity in the following areas:
 - Range in the ages of participants.
 - Whether this infant was their first child, or the participant has had children before.
 - Whether or not this child was the mother’s first preterm child.
 - Range in the gestational ages at which the infants were born.
 - Range within the set infants’ age of 0-3months corrected age.
 - Varying residential areas that the participants come from.
 - As the research site provides services to a large surrounding area, the residential areas were monitored to ensure that participants were included from a range of different surrounding residential areas, instead of one homogenous group from a single area. This

would have assisted in achieving insight into the phenomenon from a broader perspective and allow for the possibility of exploring differing influencing factors from different areas.

- The mothers hold varying occupations, thus varying job-related influences.
- The mothers included are single, married or had a partner and thus have varying support systems.
- Variety in household environments, including the structure, resources and number of people living in the house together.
- When variety in the above-named areas is achieved, ‘sample specificity’ has reached saturation.
- Applied theory:
 - Studies supported by little theoretical background usually require a larger amount of data that offers sufficient information. The phenomenological framework outlines a methodology through a description of an experience, as opposed to the interpretation of data in formulating and linking theories. Thus, a large amount of data is not needed as theories do not need to be formed. However, the study makes use of two strong and thoroughly researched theories, namely Bronfenbrenner’s bio-ecological model of childhood development and the transactional model applied to childhood development. These theories provide a framework in which to understand and report findings of influential factors both within the mother’s and infant’s life. Thus, reinforcing that large amounts of data are not relevant to the purpose of the current study.
- Quality of dialogue:
 - Quality of dialogue between the researcher and the participant is affected by many factors, mainly the inexperience of the researcher. Due to the fact that the researcher (and interviewer) was a young individual with relatively little qualitative research and interviewing experience, the quality of the interviews could be of concern. In order to address this, the researcher attended a qualitative methodology course prior to the data collection procedures where interviewing skills and procedures were priority topics. The course offered theoretical background to interviewing, as well as practice and feedback in preparation for the data collection process from a very well experienced qualitative researcher. Additionally, the researcher attended another course, offered by the African

Doctoral Academy, which involved training in qualitative data analysis and methodology. These courses offered insight into interviewing skills, which should have assisted in acquiring interviews of good quality. Good quality interviews could decrease the need for a larger volume of participants and interviews to reach data saturation, as good quality interviews should often be rich with information.

- Analysis strategy: case or cross-case
 - Malterud et al., (2016) suggest that studies that are exploratory in nature usually require more participants, however in-depth analysis of qualitative data, particularly narrative data, requires less participants due to the rich nature of the data. Those studies using cross-case analysis also require more participants and data to offer sufficient information, however the current study does not apply cross-case analysis. The current study employed in-depth analysis of the interviews, and thus did not require large amounts of data in order for sufficient ‘information power’ or saturation to occur.
- Conclusion:
 - Therefore, measures were taken to ensure data saturation has occurred in fulfilment of the measurements suggested by Malterud et al, 2016). Due to the in-depth nature and other characteristics of the current study, as described above, a large amount of data was not necessary, and 15 interviews were sufficient for data saturation and study requirements.

4.5.3. Sampling method

The method of purposive sampling was used to recruit participants. Purposive sampling refers to the “deliberate choice of a participant due to the qualities the participant possesses” (Etikan, Musa & Alkassim, 2016, p. 2). Purposive sampling is a non-probability sampling method where randomisation is not of importance and not every member of the target population has an equal chance of being recruited. A disadvantage of non-probability sampling is the lack of ability to generalise results to the rest of the population. However, this method was chosen because of the relevance to the study aims and design where an in-depth description and explanation of the findings is more important than the generalizability of the findings. Due to the small scale of the study and the specificity of the population in question, complete randomisation using a probability sampling method was not feasible.

Purposive sampling does not require pre-set underlying theory or a set number of participants. Put simply, the researcher decides what needs to be investigated and chooses individuals who are available and willing to provide information, are well-informed regarding a phenomenon, and who hold rich information about this phenomenon. A more specific description of the purposive sampling method would be ‘maximum variation sampling’ as the researcher identified and included participants that have experienced the same phenomenon, but whose backgrounds and biological information is different so to represent the experience of the phenomenon within a range of the specified population. This sampling method is said to be useful when random sampling is not used and when the sample pool is small (Etikan et al., 2016). This strategy was employed when two or three candidates arrived simultaneously on two occasions and logistics could not allow time for all three to be invited to participate in the study as the third candidate would have likely had to wait for approximately three hours before her interview. An authorised file review was then used to reveal which candidate presented with a different background to those participants already included in the study (e.g. a candidate who resided in a different urban low SES area from other participants). The participant with differing background factors, in comparison to the other participants at that time, was chosen.

4.5.4. Setting and participant recruitment

The study took place in Tygerberg Hospital in the Western Cape. Tygerberg is a large public hospital with a total of 1400 beds servicing a population not belonging to medical aid schemes. The hospital is a tertiary level facility, one of three on the Western Cape, with wide drainage areas, thus the patients at the hospital are likely from a variety of different areas within the Western Cape. Subsequently, the nature of health care received at Tygerberg are those of a more serious nature, including premature birth and low birth weight. The study recruited those mothers who had come to the hospital for a medical follow-up appointment for their preterm infant, a situation which was both favourable to the researcher and the participants as participation in the study thus posed no cost other than that of time (i.e. no additional money was needed for transport for either researcher nor participant). The hospital thus formed a suitable site for the purposes of the study.

The interviews took place between three similar private consultation rooms, depending on the room availability on the day of collection, located in an out-patient wing of the hospital. Each room housed a desk and 3 chairs, and one room had a bed. The interview space was set up so that

the three chairs were grouped together in a 'circle' formation facing inward to one-another indirectly, whilst the desk was used to set up refreshments and paperwork. The rooms used for the interviews were located in the same wing as the paediatrician's out-patient consulting room where the participants had their follow-up appointments.

The recruitment process can be described as follows:

- The researcher consulted with a paediatrician at Tygerberg Hospital who runs a follow-up clinic for those infants who were born prematurely. The paediatrician assisted in the identification of possible candidates for the study fitting the selection criteria.
- Potential participants arrived for the follow-up medical appointment for their preterm infant and were asked by the paediatrician, in the absence of the researcher, whether or not the researcher may sit-in on the medical appointment. Once verbal consent was provided, the initial planned process of proceedings was for the researcher to attend the follow-up appointment for the infant, prior to the commencement of the interview.
 - The researcher saw it important to attend this appointment as it assists in establishing trust, comfort and rapport between the researcher (interviewer) and the participant. This also provides the researcher with an opportunity to access the content of the appointment, providing insight into the content of the interview, i.e. allowing the researcher to note the information that the participant has received from the paediatrician, which may be mentioned or discussed again during the research interview.
 - Unfortunately, due to logistical difficulties, such as when two potential participants arrived at the same time, it was not possible for medical appointments to be attended with all participants. In cases when this occurred, in order for the researcher to be able to attend the medical appointments of the potential participants and interview them afterwards, it would have required the subsequent potential participants' medical appointments to be postponed for a minimum of 50 minutes whilst the researcher finished the interview with the previous participant. This would be unfair to ask of the potential participants. In the six cases where the researcher could not attend the participants' medical appointment, the researcher held a discussion with the paediatrician prior to the interview in order to gather relevant information, such as whether or not the mother had asked questions or received information about developmental milestones. Additionally, prior to the

commencement of the interview, the researcher engaged in casual conversation with the participant in order to establish rapport and sense of comfort between the participant and the researcher.

- When the medical appointment had concluded, the researcher informed the potential participant's privately about the study and invited them to participate. If the potential participant agreed to the interview, the researcher and participant proceeded to the interview space, and if the potential participant declined the researcher thanked them for her inclusion in the appointment and any notes made thereof were discarded in a proper and discreet manner.
- The participants were led to an available consultation room, in the same corridor as the medical appointment, where the participants were offered tea and coffee in an effort to provide comfort and gratitude for participation. It is here where the interpreter was introduced if necessary. Those present at the time of the interviews included only the researcher, participant, the participant's infant and if necessary, the interpreter. The interpreter assisted with 11 of the 16 interviews, including the interview later discarded from the data set.
- The participants were read the information and consent form in English or isiXhosa and given the opportunity to ask questions pertaining to the study or questions of clarification. This was done in order to ensure that those participants who were illiterate could also participate in the study. Formal written consent was then obtained through the signing of the official forms.
- The semi-structured interview was then conducted, in most circumstances with the assistance of the interpreter.
- After the interview was complete, the participants were offered a small gift of clothing for the infant in order to thank them for their time.

4.5.5. Participant demographics

A total of eighteen candidates were invited to participate in the study. Two candidates declined the invitation to participate in the interview as both reported they did not have the time to stay after their medical appointment. Therefore, sixteen candidates participated in the interview process. Unfortunately, as previously mentioned, one interview was discarded as the infant of the participant was diagnosed with a neurological disorder shortly after the interviews had taken place. The medical diagnosis of the infant resulted in the participant no longer fitting the

inclusion criteria. Fifteen interviews therefore constituted the data set. The fifteen participants were similar in that all were isiXhosa first-language speaking, mothers of a medically stable preterm infant (that was chronologically 0-3months old), living in low socio-economic circumstances within the catchment area of the chosen medical establishment. The fifteen participants were diverse in characteristics as their ages ranged from 22 – 36 years old. Additionally, the participants resided in 9 different communities within the surrounding areas of the hospital. Seven of the fifteen mothers were first-time mothers, whereas the other eight participants had either one, two, or three other children ranging from 1 to 14 years in age. Eight of the participants were unemployed at the time of the interview, with the other seven participants either on maternity leave or having returned to their place of employment. Only one participant was married, with the remaining fourteen participants unmarried and living in a variety of different social household dynamics. Six participants lived with their partners and fathers of the preterm infant. Nine of the participants resided with a variety of different family members, including parents, cousins and siblings. Furthermore, the participants had been living with their preterm infant at home from a range of one week to two and a half months. The biographical information of each participant was translated into spread-sheet format in order to describe participant demographics and variation. This spread-sheet may be found as Appendix B.

4.6. Materials

4.6.1. Semi-structured interview:

A semi-structured or discussion schedule was used to collect information around the topics of the study aims. Within semi-structured interviews there exists the structure that allows the interviewer to touch on pre-determined topics, as well as the freedom to change between topics and spend varied amounts of time on different topics depending on the value of the topic to the participant. In following what is most important to the participant, the researcher may gain a better understanding of the research topic, as well as a gaining a better ‘answer’ to the research question. The flexibility of a semi-structured interview allows for clarifications between the participant, researcher and interpreter or cultural broker, which is often necessary during intercultural and cross-linguistic interviews. Such flexibility also provides a more appropriate format for the discussion and exploration of sensitive topics (Fylan, as cited in Miles & Gilbert, 2005), and is further suggested when exploring subjective experiences and perceptions through a

qualitative methodology (Penn & Watermeyer, 2018). Thus, a semi-structured approach was appropriate to both the design and nature of the research.

The interview consisted of two sections. The first section was questionnaire-like and aims at collecting important biographical information pertaining to the mother (participant) and the infant. Here information is collected about mother herself, including her age, her other children (preterm and non-preterm); information pertaining to housing including the location, type and number of people living in the household; socio-economic information such as education and employment status; and brief section of important information pertaining to the infant for which the medical appointment was for, such as gestational age at birth, current age, and complications. This information was used to monitor participant diversity and gather information about the mothers' background that might be important in data interpretation.

The second section contains the discussion or interview schedule designed to investigate the aims of the study. There are six main topics in the discussion schedule that cover the topics of the aims, namely (a) perceptions of prematurity, (b) experiences of giving birth to and caring for a preterm infant, (c) communication and interaction, (d) roles, (e) feeding and (f) other. Within each topic there falls 1-4 main questions aimed at sparking discussion around the topic, with additional optional prompts that could be used to elicit elaboration of the topic. Because of the flexibility of the semi-structured interview design not all questions on the interview schedule were asked in each interview and the order of the topics and questions was not rigid but aimed to follow a natural conversational flow.

A copy of the discussion schedule can be found as Appendix C.

4.6.2. Voice recorder:

A digital voice recorder was used to record the interviews for later transcription. This was performed with the participants' verbal and written consent to do so. The specific device used was the Philips Digital Voice Recorder DVT2510.

4.7. Research procedures

4.7.1. Approval and additional permissions

Prior to the initiation of data collection, approval to conduct the research was gained through the Health Research Ethics Committee 2 (HREC) of Stellenbosch University (Appendix D HREC reference: S18/04/068, project ID: 6707). 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 (Appendix E) Furthermore, permissions to conduct the study within the follow-up clinic, where participants were recruited, was gained from the medical doctor in-charge of the clinic.

4.7.2. Preparation

The researcher was not well experienced in the area of interviewing for research purposes. In order to account for this the researcher attended a qualitative methodology course in which interviews were one of the core focal points. The researcher learned the foundational theory of research interviewing as well as receiving the opportunity to trial interviews and receive feedback thereof. Additionally the researcher attended a five-day qualitative data analysis course on the software ATLAS.ti, through the African Doctoral Academy of Stellenbosch University in preparation for data analysis.

4.7.3. Pilot study and interviews

It was originally planned that a pilot study would be conducted with two participants in the exact conditions of the research interviews in order to assess the recruitment and interview process, and the discussion schedule. It was planned that after the pilot study interviews were conducted that the researcher will use feedback from the consulting paediatrician, interpreter, participant and the researcher's own reflections to adjust and make improvements to the process or discussion schedule itself. However, after the pilot interviews were conducted and reviewed, it was decided that there were no major changes to be made. Therefore, the interviews initially intended as pilot interviews were included in the final study data.

In total 16 interviews were conducted over the course of four weeks in August and September 2018. The researcher and research assistant were present at the research site on the days where the preterm follow-up clinic was active within the four weeks of data collection. Depending on

clinic attendance, a range from 1 to 3 participants were recruited in a single day. Each interview took roughly 1 hour to complete. The researcher and research assistant first established rapport with the participant, read the participant the information and consent form in the participants' language of choice and obtained formal participation consent, and then gathered relevant biographical information. The voice-recording device was then switched on and the semi-structured interview/ discussion was conducted. Each recording (of the discussion directed at fulfilling the study aims) ranged between 35 to 55 minutes in duration, with the average time being 48 minutes. The researcher decided to exclude the collection of biographical information in the voice recordings in order to reduce the presence of identifying information in the recordings when a randomly chosen interview was to be studied by an external research assistant (for purposes of quality evaluation).

Field notes were written during the infant's medical consultation with the paediatrician as well as during the interview itself. Additionally, the researcher wrote a reflection after each interview.

4.7.4. Data management

Throughout the research process all research data was handled in a discrete manner so to protect the identity of the participants. Hard copies of information, field notes, reflections, and signed consent forms were kept in a locked cabinet to which only the researcher and her supervisor had access. All electronic information was kept within a password-protected file to which only the researcher and her supervisor had access. The research assistant had temporary access to the voice-recordings in order to transcribe the information. The audio-recordings of the interviews were temporarily handed to the research assistant for transcription purposes on a USB drive. The research assistant kept the only copy of the electronic transcriptions on the same USB drive, which was handed back to the researcher upon completion of the transcripts. The audio recordings of the interviews and the related transcripts were then transferred onto the researcher's computer under a password-protected file and deleted off the USB.

4.8. Data analysis

The approach to data analysis was largely guided by the phenomenological tradition previously described. As there are many different ways in which the phenomenological framework can be

implemented, specific methodologies were investigated and implemented. As an overall approach, the phenomenological framework for data analysis was used with the implementation of the guidelines of the ‘framework method’ of analysis, as described by Gale, Heath, Cameron, Rashid and Redwood (2013). Furthermore, within the framework method the process of thematic analysis took place. The stages of thematic analysis that was followed in the data analysis process is that which has been described by Braun and Clarke (2006).

Additionally, the computer-assisted qualitative data analysis software (CAQDAS) programme ATLAS.ti was used to assist with overall data management and analysis phases.

The framework method and thematic analysis process:

Originally developed by Jane Ritchie and Liz Spencer, the framework method has been widely used for managing and analysing data since the early 1980’s (Ritchie & Lewis, 2003). Although the framework method was originally used more in the social science domain it has become increasingly popular in medical and health research. Due to the flexibility of the method, it may be used in either deductive or inductive data analysis approaches and is most commonly used in studies where the data set consists of semi-structured interviews. The framework method was chosen due to its fit with the research aim and design as this method is a flexible tool that is well suited in supporting thematic content analysis of textual data, as well as shedding light on important phenomena through in-depth analysis (thus fitting with the broader framework of the phenomenological tradition). The framework method is said to be particularly useful when managing large qualitative data sets, as in the case of 15 relatively long interviews, where obtaining a “holistic, descriptive overview of the entire data set is desirable” (Gale et al., 2013, p. 2). Additionally, the framework method allows for the use of CAQDAS such as ATLAS.ti.

Within the framework method lies the process of ‘thematic analysis’. The steps followed regarding thematic analysis are those as described by Braun and Clarke (2006), which will be described in further detail below. Whilst the framework method provides a more general outline of the steps of the overall data handling and analysis process, the thematic analysis method provides more in-depth detail regarding coding and theme organisation.

4.8.1. Data preparation

The transcripts in their raw form, as received by the research assistant, included the direct transcript of the discussions between the interviewer and the participant (and when involved, the

interpreter). For holistic insight into the transcripts the researcher added an introductory summary page to each transcript that contained additional relevant information not available in the transcripts, such as background information (gathered before initiation of recording), information gathered in the medical appointment, and field notes. The addition of such information created a valuable context in which the data could be analysed and interpreted meaningfully.

4.8.2. Transcript analysis

The transcript analysis process, guided by the framework method and thematic analysis process as suggested by Braun and Clark (2006), is as follows:

1. Transcription of the audio-verbal data

- Oral data needs to be transcribed into written data in order to conduct thematic analysis. The transcription process is a good opportunity to become familiar with the data. Due to the interviews having been conducted in both English and isiXhosa and for data uniformity, all transcriptions were completed, and translated into English where necessary, by the isiXhosa-speaking research assistant, as the researcher does not have a sound understanding of the isiXhosa language.
- As suggested by Gale et al. (2013) and Braun and Clarke (2006), ideal transcriptions are verbatim, although for the purpose of thematic analysis do not need to contain the conventions of the dialogue unless they are of great importance in contributing to meaning (for example, indicating crying). The interviews were transcribed verbatim in isiXhosa, and thereafter translated into English. The English dialogue spoken during the interviews were transcribed verbatim in English.
- In order to review the quality of the translations, one section of a randomly chosen interview transcription was translated and transcribed by a second first-language isiXhosa-speaking individual. This individual was blind to the aims of the study. It was felt that the individual being blind to the aims of the study would assist in eliciting a direct translation without interpretation within context. The results of the review revealed that there were no notable discrepancies between the two transcripts. Upon discussion of a small vocabulary difference between the transcripts, this individual explained to the researcher that there are some words in

the isiXhosa language that do not hold English counterparts or exact translations, but in one such case that the reviewer had observed, the translator had chosen the appropriate English words depicting a similar meaning.

2. *Familiarisation/ Immersion in the data*

- Gale et al. (2013) suggest that familiarisation with the data is a vital stage within the data analysis process. The researcher immersed herself in the data through the process of data preparation (as described above in 4.8.1.) where every interview-recording was listened to whilst simultaneously reading the transcriptions (additionally checking for accuracy regarding English transcriptions and communicative aspects). After this, the field notes and other relevant information pertaining to the participant were incorporated into a short introduction and summary for each interview/participant. An anonymised version of a participant introduction/summary can be found as Appendix F.
- It is at this stage where the researcher marks initial thoughts or impressions within the page margins of the transcribed data.

3. *Coding*

- Coding aims to classify the data in order to allow it to be analysed or compared systematically with other data. The coding process was completed using the CAQDAS system ATLAS.ti (version 8).
- The approach to data analysis was inductive and data-driven, thus the information is not coded based on pre-set themes but rather in terms of meaning. Thus ‘open coding’ initially took place at a semantic level⁹, with notes or ‘memos’ made pertaining to latent level¹⁰ meanings of the code.
- Each segment of text that held information pertaining to the phenomenon of interest was coded. All relevant text was coded for as many potential themes/patterns as possible. Where necessary, additional notes were attached to codes so as to incorporate the context of the quotation/unit of text.
- ‘In-vivo’ codes were also identified at this level. In-vivo codes refer to those segments of text or quotations that are highly important and stand out as a meaningful quotation to be noted individually. (refer to Appendix G).

⁹ Semantic level code: referring to coding the words themselves as they are, for example when a participant described that having a preterm child “... is difficult” – this would be coded under ‘General experience: difficult’ (Braun & Clarke, 2006)

¹⁰ Inferring meanings from the participants words, for example when a participant explained that having a preterm infant is - ‘...it is difficult. I have no one to help me’, a note would be made linking the lack of support to the experience of caring for a preterm infant.

- Coding line-by-line is said to be meaningful in that the thorough process may alert the researcher to that information that may otherwise remain ‘invisible’ because it may not be expressed clearly or may not ‘fit’ with the majority of the data. The recognition and reconciliation of anomalies in the data may make the analysis process stronger (Gale et al., 2013).
- The code list is then refined so to eliminate redundant or dubious code collations, as well as rename and define the codes if needed.

4. *Developing and applying a working analytical framework*

- Searching for themes: at this stage the analysis is re-focussed to the broader level of themes. The codes are reviewed and clustered, collating the coded data into ‘code families’ and allowing for themes to emerge (Braun & Clarke, 2006).
- Reviewing the themes: Once possible themes have been identified they are reviewed and refined at this stage. Refining occurs through the reconciliation of similar themes, identification of main themes, sub-themes and miscellaneous themes. Additionally, grouping of the codes and related themes occurs within the context of the sub-aim to which the text is directed. The themes are then defined and named.

5. *Charting the data into the framework matrix*

- Charting data: Gale et al. (2013) suggest that charting the data involves summarising the data by category for each transcript. This ‘chart’ or summary includes main themes that emerged in the transcript as well as interesting quotations or ‘in-vivo’ codes. This ensures that the researcher is able to describe the data using the participants’ own subjective expressions before moving to the interpretation of the data. This stage involves the creation of a relationship ‘tree’ (as illustrated in Appendix H) which illustrates the relationships between different codes and themes.

6. *Interpreting the data*

- The data were first interpreted in terms of the themes that occurred naturally throughout the data set. Each theme was then analysed within context of the phenomenon, in other words, a theme was then related to its’ influence on the participant’s experience. This forms part of a so-called ‘textural’ description of the data.

- The data were then analysed in terms of the themes pertaining to each aim. A structural description of each experience pertaining to that particular aim was then created.
 - A structural description, termed by Moustakas (1994), refers to ‘*how*’ an individual experienced a phenomenon, as opposed to a description of ‘*what*’ the individual experienced, known as a textural description (Creswell, 2007, p. 60).
- Finally, an interpretation of the raw data and the structural descriptions were combined to create an overall composite description of the phenomenon. Creswell (2003) refers to this description as “the essence of experience and [the description] represents the culminating aspect of a phenomenological study” (p. 159).

7. *Reporting and discussion of findings*

- The findings of the data analysis and interpretation, and thus the study, will be presented in threefold. A submission-ready journal article discussing a summary of the findings will be presented first. Secondly follows a description of the findings in relation to the aims and sub-aims. Thereafter the interpretation of the findings will be presented graphically within the bounds of the combined bio-ecological and transactional models discussed in the literature review.
- The final chapter will then discuss all of the findings in relation to the outcome of the study and context of current research.

4.9. Scientific rigour:

Reliability and validity are evaluative techniques that evaluate scientific rigour in quantitative research. Due to the flexible nature and subjectivity of qualitative research the techniques of validity and reliability cannot satisfactorily be applied to qualitative research. In order to substitute ‘validity and reliability’ in qualitative research, Guba and Lincoln (1994) introduced the concept of ‘trustworthiness’. The evaluation criteria of ‘trustworthiness’ includes four aspects, namely that of credibility, confirmability, transferability and dependability. Within these aspects are methodological strategies for demonstrating qualitative rigour (Morse, Barrett, Mayan, Olson & Spiers, 2002). After completion of the study, the researcher evaluated trustworthiness as follows:

4.9.1. Credibility

Credibility can be equivocated to the qualitative version of ‘internal validity’ in quantitative research, and thus it may be defined as the “confidence that can be placed in the truth of the research findings” (Anney, 2014, p. 276). Various strategies were employed to build research credibility, including that of peer-debriefing, triangulation, negative case reporting and member checking.

Peer debriefing “provides inquirers with the opportunity to test their growing insights and to expose themselves to searching questions” (Guba, 1981, p. 85). ‘Peer debriefing’, or scholarly guidance, was sought throughout the research process. The various sources of peer guidance included the research supervisor, two members of the isiXhosa community (who provided assistance in interpreting culturally unique information), other qualitative researchers and lecturers within the University of Stellenbosch and the African Doctoral Academy.

Member checking was implemented throughout data collection. Prior to the interviews, rapport between the researcher and each participant was established through casual conversation in order to allow and encourage open and honest communications without hesitance. After each interview (and often after the closing of a topic of conversation during the interviews) the researcher reviewed and summarised the main points and themes back to the participant in order to ensure that the researcher correctly understood and interpreted the information conveyed by the participant. The participants could then either affirm that the summaries reflected their views, experiences and reflections, or the participants may assist in correcting or clarifying such points. Additionally, other measures were taken in order to improve the quality of the data and interpretation thereof. After each interview, the main points/findings and possible themes were discussed with the research assistant (cultural broker and interpreter). Furthermore, the quality of the isiXhosa-to-English transcript translations was checked through the translation of a randomly chosen interview by a qualified individual blind to the specific aims of the interview. The mention of culture-specific terminology and traditions by participants were discussed at length with the isiXhosa research assistant so to gain proper insight and understanding for appropriate analysis. Negative case reporting was also used as a method of increasing the credibility of the study. This involves reporting findings that were not congruent with the researcher’s initial expectations. The negative case reporting process is said to improve credibility of the study, as

the researcher must account for these cases in order to investigate plausible alternative explanations (Anney, 2014).

Triangulation is another strategy employed to enhance credibility, and “involves the use of multiple methods, investigators, sources and theories to obtain corroborating evidence” (Onweugbuzie & Leech, 2007, p. 239). Triangulation thus assists in reducing bias. Unfortunately, only one source of evidence regarding the phenomenon was sought, that of the mothers’ perspective. Other role players within the phenomenon, such as hospital staff and other family members were not interviewed. However, triangulation was used in other respects. The researcher employed triangulation in the form of combining different methods throughout data analysis, namely the combination of the framework method and thematic analysis used within the domain of phenomenology.

4.9.2. Confirmability

Confirmability refers to “the degree to which the results of an inquiry could be confirmed or corroborated by other researchers” (Anney, 2014, p.279). Thus, in order to improve the confirmability of a study, the researcher needs to address the possibility of bias. The researcher employed the technique of reflexivity throughout the research process in order to reduce the risk of bias. Reflexivity has been described as a continuous reflective process employed by researchers that aim to recognise, examine and understand how their “social background, location and assumptions affect their research practice” (Hesse-Biber, 2007, p. 17). At the beginning of the research process the researcher, as guided by the phenomenological methodology, constructed an epoche in an attempt to ‘bracket’ her own experience relating to the topic and allow a fresh view of the experience as found in the research. During the interviews the technique of summarizing or ‘active listening’ was used to reflect back the researcher’s understanding of what was said by the participant, allowing the researcher’s understanding to be confirmed as well as allowing opportunities for misunderstandings or misinterpretations to be cleared (Given, 2008).

In addition to the above measures, the researcher kept a reflexive journal that contains reflections of each interview, as well as tentative interpretations and emerging points of interest. These points were recorded in order to record the initial impressions and interpretations of the information within the immediate interview context (i.e. whilst the influence of contextual information remains apparent, such as non-verbal communications such as instances of upsetting

topics, reactions to questions, or apprehension in discussing certain topics), as well as creating transparency. Within the same journal the researcher kept detailed notes documenting the research process, thus creating an audit trail (Holloway, 2008).

4.9.3. Transferability

Transferability refers to “the degree to which the results of qualitative research can be transferred to other context with other respondents” (Anney, 2014, p.277), which relates to the ‘generalizability’ of quantitative research. According to Bitsch (2005), the researcher “facilitates the transferability judgement by a potential user by thick description and purposeful sampling” (p.85). The provision of a ‘thick description’ refers to a rich, extensive description of the methodology and context, and the elucidation of all the research processes. A thick description of the research process allows understanding of the context in judging whether or not the data fits with, or may be ‘transferred’ to, other contexts. Additionally, thick descriptions allow for the replication of the study. Due to the nature of this study and the specificity of the population in context, the results may not be easily transferable, however due to the thick description of the research process, similar studies may be performed in the future, and results could be compared. Similarly, purposive sampling was used to ensure individuals from a variety of backgrounds within the selection criteria were chosen, however the population and context remains unique and thus the data is difficult to ‘transfer’ to other contexts. However, the implications and recommendations from the current study may be useful to the study site, which services a large portion of the population in the Western Cape.

4.9.4. Dependability

Dependability involves the evaluation of the findings, interpretations and recommendations in order to ensure that they are supported by the data collected from the study participants (Cohen, Manion & Morrison, 2011). Dependability was established through the use of an audit trail, peer examination and code-recode strategy. As mentioned previously an audit trail has been created, including that for the inquiry process (process and interview notes, reflections and all raw data) as well as the analysis process, as all code and thematic groups created are reviewable within the ATLAS.ti project file. The emergent themes and important points of discussion were summarised, reviewed and agreed on by both the participant themselves as well as the research assistant present during the interviews. Furthermore, the code-recode strategy was employed to

warrant dependability at the level of data analysis. The code-recode strategy involves one set of data being coded twice, with a period of one to two weeks between each coding. Seven of the fifteen transcripts were coded twice. The results of each coding were then compared. The codes were largely similar with small adjustments due to learned experience. This similarity or code-agreement is said to improve the dependability.

4.10. Ethical considerations

Ethical clearance for the study was granted by the HREC from Stellenbosch University as well as the NHRC at a national level. This study was conducted according to the ethical guidelines and principles within the Declaration of Helsinki (World Medical Association, 2013). The four basic ethical principles as described by Moodley (2011) were followed, namely that of autonomy, beneficence, non-maleficence and justice.

4.10.1. Autonomy

Autonomy refers to the dutiful respect of every individual's right to make decisions for themselves (Moodley, 2011). In order to respect this, the researcher or isiXhosa-speaking research assistant read out the information and informed consent form to the candidates in order to accommodate participants regardless of literacy levels. This was completed in a language of the participant's choice, either English or isiXhosa, in order to facilitate true informed consent (please refer to a copy of the information and consent form in Appendix I). Candidates were informed of the purpose, nature and expected duration of the interviews and study as well as the implications of their participation. Candidates were informed that participation in the study was entirely voluntary and that they were able to withdraw at any stage without consequence. Permission to voice-record the interviews was obtained with the informed consent form that was read aloud. Written formal consent was then obtained if the candidates agreed to partake in the study.

Throughout the research process data was handled so to respect the identity of the participant. Anonymity could not be guaranteed in this study as the researcher and research assistant had access to the participants' biographical information, thus the process of de-identification was employed. Identifying personal information was kept separately from the interviews, and the

interviews were assigned corresponding codes throughout data handling. Written data were kept in a locked cabinet, whilst electronic data were kept in password-protected files, both to which only the researcher and supervisor had access. Audio-recordings of the interviews and the related transcripts were additionally available to the research assistant for the purpose of transcription and translation. The intention of this study is for findings to be available to clinicians and other scholars and the broader public through publication and presentations at conferences, however, participants will not be identified in any of these reports. If quotations are used in a research report or article stemming from the results of this study, no identifying information will be present in the quotation and participants will be referred to by code so as to respect their identity.

4.10.2. Beneficence and Non-maleficence

Within the context of research, beneficence refers to the researcher's obligation to maximise possible benefits for the participant. Non-maleficence is the counterpart, referring to the researcher's responsibility to minimize any possible risk posed to the participant (Owonikoko, 2013). There were no immediate benefits offered to the participants in the study, however on completion of the interviews each participant was offered a small gift (clothing for the infant) in order to express gratitude for their time. Participants were also offered refreshments prior to and throughout the interview process in order to ensure comfort and assist in familiarisation and rapport. Additionally, participants were offered an information brochure in either English or isiXhosa after the interview. These brochures held information about infant language and feeding milestones as well as information about language stimulation. The gift and brochure were not advertised prior to participant recruitment so to avoid 'enticed' participation. There were no foreseen risks to participating in the study and there was no known harm caused to any of the participants or research personnel. There were referral measures in place should concerning information or actions arise (for example, if the mother expressed or showed signs of emotional distress, mishandling/abuse by others etc.), including referrals to psychologists and social workers. No referrals were deemed necessary in this study.

4.10.3. Justice

Justice within the context of research refers to the ethical obligation that all participants (and all those involved in the study) be treated equally and fairly throughout the research process (Owonikoko, 2013). This principle was respected throughout the research process. During

participant recruitment all those individuals that were present at the out-patient preterm clinic over the data collection period, who met the inclusion criteria, were invited to participate in the study. Participant recruitment continued until data saturation was attained. Participant recruitment, informed consent requesting, as well as data collection were completed in a manner that accommodated and included those isiXhosa-speaking participants that were not proficient in English as well as those who are illiterate though the gathering of oral informed consent (concreted through signed consent). An interpreter was available to all participants in order to accommodate those individuals not proficient in English. All participants received a similar gift that included an outfit for the participant's infant. For those participants with twins, the mother received one outfit for each baby.

Chapter 5:

FINDINGS

The findings are presented in two different formats, the first being an article manuscript intended for later publication followed by a more detailed report of the findings. As the findings of the study encompass a vast amount of information, the manuscript focuses on the more significant findings, whilst the subsequent section presents all the related findings. Due to this format there exists a degree of unavoidable overlap within the findings as presented in the article and the subsequent section.

5.1. Article

The format followed current for the thesis is that of ‘Masters by publication’, which requires that an article be prepared for submission. The following article was prepared for submission to the journal titled “Health SA Gesondheid”, thus the article follows the required guidelines as set out by the journal (no more than 5000 words excluding those within tables, with compulsory sections). The article will be submitted after feedback, examination and changes to the thesis are complete.

Maternal experiences of preterm birth, caring for, and feeding their preterm infants within a vulnerable population in South Africa

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Abstract:

Background: Within diverse South Africa, SLP's are often poorly equipped with knowledge and understanding of their patient populations. In order to design effective interventions for any population, healthcare professionals require insight into factors that may affect the process. The chosen vulnerable population, isiXhosa-speaking mothers of preterm infants living within low socioeconomic circumstances, are 'vulnerable' in their "state of susceptibility to harm, powerlessness and marginality" (Adger, 2006). It is well documented that preterm infants are at high risk for developmental delays and that early intervention programs should be aimed at the mother or primary caregiver, however healthcare professionals are not always aware of personal factors influencing maternal decision-making (such as maternal experiences, cultural beliefs and traditions, and financial circumstances).

Aim: To explore a group of isiXhosa-speaking mothers' experiences of having-, caring for, and feeding their preterm infants within low socio-economic circumstances in South Africa within the first 6 months of the infant's life.

Setting: The study was performed at a public tertiary hospital in an urban part of the Western Cape, South Africa.

Methodology: The study employed a qualitative, cross-sectional design that was explorative in nature. A discussion schedule was used to guide 15 in-depth interviews that were later thematically analysed.

Results: Support positively influenced maternal coping, whilst socio-economic related factors were not highlighted. Medical stability is the peak concern for mothers early in their preterm infant's life and concerns regarding development did not arise. Furthermore, prematurity influenced mothers' decisions to use traditional medicines and affected traditional practices.

Introduction

Preterm births account for a growing 5-18% of all births worldwide, with more preterm infants surviving at younger gestational ages. It is well established that preterm infants are at increased risk for developmental difficulties and medical sequelae, reportedly two to three times that of full-term infants (Soleimani, Zaheri, and Abdi, (2014). Such developmental difficulties range across physical and motor development, sensory development, attachment, social and behavioural development, cognition, communication and feeding (Bhutta et al., 2002; Forcada-Guex et al., 2006). Furthermore, studies have linked higher incidences of preterm birth with lower socioeconomic status (SES) as 60% of preterm births occur within the global south (WHO, 2018; Blencowe et al, 2012). In South Africa majority of the population live within low SES with the poverty striking 55% of the population. This population experiences unique additional risk factors pertaining to their health (such as the disease burden of HIV/AIDS and TB, poor housing circumstances, and poor sanitation). It is easy to foresee that such factors may negatively influence a vulnerable preterm infants health and development, not only directly but also through the wellbeing of the mother or primary caregiver.

Early childhood intervention (ECI) is crucial in reducing the effects of such delays on other aspects of the preterm child's life, such as schooling. A large focal point of early intervention surrounds the mother herself (or primary caregiver). Following Pascoe, Bissessur and Meyers' (2016) application of the transactional model on childhood development (Figure 1), influential factors are grouped as either 'risk' or 'protective' in nature toward development. It can be interpreted that a mother is crucial in the engagement of such protective factors and mediation of risk factors through maternal action, such as the provision of effective language stimulation in preventing or mediating a communication delay. Additionally, it is well known that positive mother-infant interactions foster optimal developmental environments. Caring for a preterm infant has understandably been found to be quite a stressful experience (Steyn, Poggenpoel & Myburgh, 2017). Furthermore, mothers with preterm infants are at a higher risk for maternal anxiety and depression (Allen et al., 2004). Maternal wellbeing may very well affect the nature and frequency of mother-infant interactions and thus an important focal point during early intervention, one that is often neglected.

Current literature suggests that there is a growing awareness of the importance of early intervention within child development. Although there is increased recognition for the importance of ECI, there still exist multisectoral constraints within the improvement and implementation of such programmes (Pelletier & Neuman, 2014). Within ECI, maternal beliefs and values are important considerations when designing appropriate and culturally congruent interventions. If interventions are incongruent with maternal values, such interventions aren't likely to carry over to the home environment and are thus less likely to be effective. Krummer, Lopez-Reyna and Hughes (2007, p. 271) emphasize this in their statement: "cultural values and parental beliefs are of primary importance due to the developmental focus on the young child with a disability and the critical role of family members in the service provision process". In recognition of this, a recent document was circulated by the Health Professions Council of South Africa (HPCSA) outlining the speech-language pathologists' (SLP) duty to "- ensure that their practice is consistently responsive to the cultural and linguistic backgrounds of their clients...", in order to provide appropriate services (Guidelines for practice in linguistically and culturally diverse South Africa, 2019, p. 6-7). However, SLP's, as well as other healthcare professionals in the South African context, are not equipped with the cultural and linguistic knowledge necessary to fulfil this duty (Southwood & Van Dulm, 2015). This is closely linked to an apparent lack of data about local peoples, cultures and languages (Pascoe, Klop, Mdlalo & Ndhambi, 2018).

The current study therefore focussed on investigating maternal experiences of a vulnerable group of people about which very little is known. The study investigated the phenomenon from the perspective of those belonging to the isiXhosa-speaking culture, living within low socioeconomic circumstances in the Western Cape province of South Africa. The study investigates such experiences of the preterm birth itself, caring for a young preterm infant (3-6 months chronological age) and feeding said infant. Influential areas, such as cultural beliefs and traditions and socio-economic related factors were found to occur naturally within such experiences. The current study adopted a theoretical approach that identified 'protective' and 'risk' factors affecting the mother and childhood development of the described population. Such factors are further sorted into the different systems of Bronfenbrenners bio-ecological systems model (Figure 2).

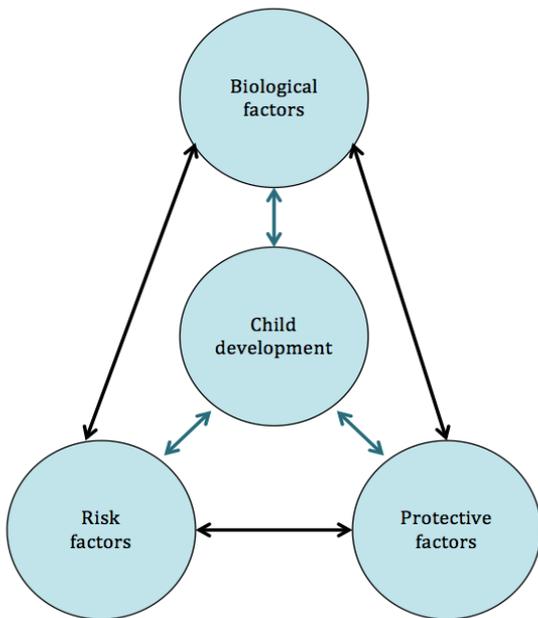


Figure A - 1: The transactional model applied to childhood development (Pascoe et al., 2016)

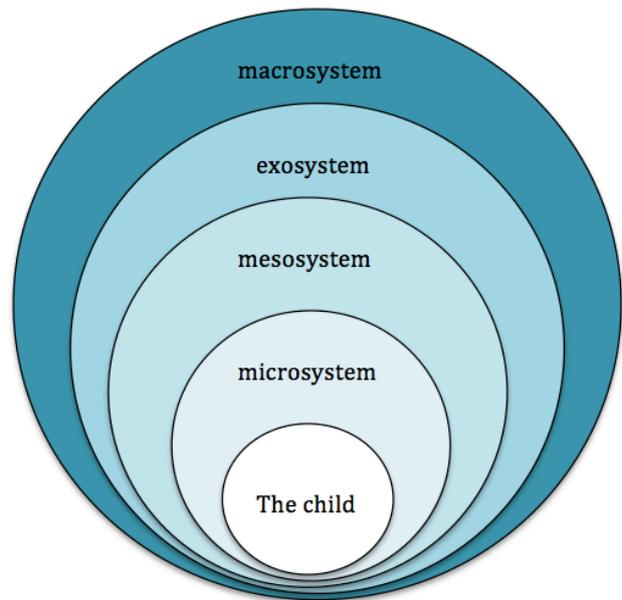


Figure A - 2: The bio-ecological systems model applied to child development (Based on Bronfenbrenner, 1989)

Methodology

Aim:

To explore and describe a group of isiXhosa-speaking mothers' experiences of having-, caring for, and feeding their preterm infants within low socio-economic circumstances in South Africa within the first 6 months of the infant's life.

Study design

The study employed a qualitative, cross-sectional design that was explorative, descriptive and contextual in nature. The phenomenological tradition was followed, which is appropriate for studies aimed at describing the “meaning for several individuals of their lived experiences of a concept or phenomenon” (Creswell, 2007, pp. 57). The study made use of in-depth personal interviews guided by a semi-structured questionnaire consisting largely of open-ended questions.

Setting

The interviews were conducted in a private office at a paediatrics out-patient clinic a public, tertiary-level hospital in the Western Cape province of South Africa.

Participant recruitment and Sampling Strategy

Purposive sampling, with maximum variation sampling, was used to recruit participants who fitted the inclusion criteria. Polkinghorne (1989) recommends between 2 and 25 participants be included in phenomenological studies making use of in-depth interviews. The data were monitored and analysed throughout collection and data saturation was reached after 15 interviews (as determined by the measurements described in Malterud, et al. (2016)).

The participants were first-language isiXhosa- speaking mothers of preterm infants who were living in low-socio-economic circumstances. Participants were recruited if they were 18-years or older and they were mothers (and the primary caregivers) of infants who fitted the following criteria:

- The infants were born before 37 weeks gestation and presented with a low birth weight of 800 – 2500 grams;
- The infants were 3-6 months chronological age (thus 0-3 months corrected age);
- The infant was to be medically stable without any known biological, physical, sensory, congenital or neurological disorders at the time of the interview.

Participants were to be living in ‘low-socioeconomic circumstances’, as determined by educational attainment (participants did not have post-secondary-school education) and financial status (participants had to earn less than a combined household income of R100 000 per annum).

In total, 18 candidates were invited to participate in the study. Two candidates declined the invitation due to insufficient time available on their part. Thus, sixteen recruits participated in the in-depth interviews. Shortly after one of the interviews, participant 3’s preterm infant was diagnosed with a neurological condition, thereby negatively impacting her eligibility to partake in the study. The interview with this participant was thus discarded. Fifteen interviews therefore constituted the data set. The table below illustrates the participant demographics. Information regarding household composition was excluded for confidentiality purposes, however six participants lived with their partners and fathers of the preterm infant, and in some cases their other children. Nine of the participants resided with different family members, including parents, cousins and siblings.

Table A - 1: Participant demographics

Participant number.:	Participant's age:	Ages of participants' other children (years):	Preterm infants' age (chronological) (months):	Preterm infants' age (corrected):	Preterm infants' gestational age (weeks):	Area in which the participant resides:	Employment Status of participant:	Marital Status of participant
1	22	NA	4	3 weeks	26	Brackenfell	Unemployed	Single
2	34	NA	3.5	1.5 months	29	Khayelitsha	Employed	Single
4	26	9	5	3 months	28-29	Mfuleni	Employed	Single
5	24	NA	5	3 months	33	Delft	Unemployed	Single
6	26	10	5	3 months	31	Bloekombos	Unemployed	Single
7	29	NA	2	Term	29	Goodwood	Unemployed	Single
8	35	NA	6	2 months	22*	Khayelitsha	Unemployed	Single
9	36	4	2	Term	28	Khayelitsha	Unemployed	Single
10	24	NA	3	Term	27-28	Strand	Employed	Single
11	36	14; 10	3	Term	29	Kraaifontein	Unemployed	Single
12	26	NA	5.5	3 months	28-31	Strand	Unemployed	Single
13	24	NA	5	3 months	32	Khayelitsha	Unemployed	Single
14	26	5	6	3 months	27	Strand	Unemployed	Single
15	35	14; 9	4	2 months	32	Stellenbosch	Employed	Married
16	30	7; 4	3	1 month	31	Khayelitsha	Unemployed	Single

*This participant (no. 8) reported that she was not certain about her length of gestation but that she thought she was around 5 months pregnant when she went into preterm labour. Her medical file did not hold this information.

Data collection

The first author collected the data. Potential participants arrived for their infant's medical follow-up appointment at a clinic of the hospital where the infant was born prematurely. Upon conclusion of the medical consultation, the researcher was introduced to the potential participant by the consulting paediatrician. The researcher then conversed with the candidate to establish rapport, inform the candidate about the study and invited her to participate. Once the candidate accepted the invitation, the researcher led her to a private consultation room where the participants were read the approved information- and consent form in either English by the author or isiXhosa by the interpreter, and given the opportunity to ask questions pertaining to the study or questions of clarification. Formal written consent was then obtained and the interview commenced. A total of 16 interviews were conducted over a period of 4 weeks. Each interview

was semi-structured in nature and guided by a discussion schedule compiled by the researchers in accordance with the aims of the study.

The discussion schedule was piloted during one interview, and no changes were deemed as necessary. A trained and experienced interpreter was contracted to assist with those isiXhosa interviews as well as provide assistance with cultural brokerage (i.e. explanation and provision of insight into the reasoning or significance behind certain beliefs or traditions mentioned by the participants). Member-checking and reflexivity were strategies employed to improve the credibility and confirmability of results throughout data collection. Upon conclusion of the interview, participants were offered a gift for their infant in order to thank them for volunteering their time towards the study. No mention of this gift was made during the participant recruitment phase, in order to ensure voluntary participation.

A voice-recorder was used to record each interview, which were later transcribed (and translated from isiXhosa to English when necessary). One randomly chosen interview-recording was reviewed against the English transcription and translation by a second isiXhosa first-language speaking research assistant, in order to check for discrepancies in the translation. No major discrepancies were found.

Materials

The self-compiled semi-structured questionnaire/discussion schedule was set up after careful review of relevant literature and questionnaires used in similar studies. The questionnaire consisted of largely open-ended questions covering the main topical areas of the study.

Data analysis

Data analysis of the translated interview transcripts was performed upon completion of data preparation (transcript translation). The data analysis process was guided by the phenomenological framework in combination with the framework method of analysis as described by Gale, et al. (2013) and thematic analysis as described by Braun & Clarke (2016). The computer software programme ATLAS.ti was used to assist in data management and analysis. Peer debriefing, reflexivity and the creation of an audit trail were methods employed to improve the trustworthiness of the findings.

Ethical considerations

Ethical clearance for the study was granted by the Health Research Ethics Committee (HREC) of Stellenbosch University (reference: S18/04/068, project ID: 6707). The National Health Research Committee (NHRC) at a national level. All participants provided informed consent to participate. Participation was voluntary and the identity of the participants has been protected throughout the research process.

Findings and Discussion

There were several themes that emerged from the data along with sub-themes in some cases. Each theme will be now be described and discussed.

1. The experience of having a preterm infant was described as ‘difficult’ by all participants:

Every mother in the study described the experience of having and caring for a preterm infant as “difficult”, often using the words “scared”, “overwhelmed” and “stressful”. These initial feelings were often followed by descriptions of shock and disbelief over the sight of their small infants and concerns over their infants’ health. A review of similar studies revealed similar descriptions of difficult experiences and feelings of disbelief, suggesting that these are universally shared experiences (Aagard & Hall, 2008; Russell et al., 2014; Steyn et al., 2017). Such findings emphasize the psychological impact of preterm birth on the mother, highlighting the need for trained hospital staff to support these mothers during this time. When this topic was further explored, it was found that there were two major contributing factors to the overall participants’ experiences, support (caregiving, emotional and household support) and size of infant. Many mothers explained that they were less stressed and coping better once the infant was larger (as determined by weight and physical size).

2. The size of the infant and general maternal support were the two largest influences of the mothers’ overall experiences.

All mothers remarked feelings of shock or disbelief at their infants’ small size at birth. This small size appeared to be a cause of stress amongst the mothers. Participant 9 explained: “*It’s not really nice to have a small baby, you always think about what could go wrong...*”. Many participants

made similar statements suggesting high perceptions of child (infant) vulnerability (PCV). Furthermore, another mother suggested the perception of a negative stigma attached to smaller infant size in relation to poor maternal wellbeing as she expressed: “*it was embarrassing because if you compare [the infant] to other children then it’s like you don’t feed her...*” (Participant 11). Additionally, participants appeared to relate the small size of the infant to the caregiving difficulty within different areas (e.g. washing, feeding or general caring difficulties). The small size of the infant, and the subsequent perception of vulnerability, also appeared to affect other caregivers’ willingness to assist the mother with caregiving. Furthermore, high rates of PCV was found to affect caregiving routines as one mother was afraid to leave the house with her infant and another didn’t want to leave her child in the care of others. Such findings echo those found by Allen et al. (2004)

In addition to infant size, support (with caregiving, informational- and emotional support) played a large role in the mothers’ experiences. Those participants who received greater support underwent a perceived ‘change’ or ‘shift’ from an initial negative experience, to a more positive overall experience. Sources of support at hospital level varied from staff (nurses and SLP’s) to other mothers of preterm infants. Many participants mentioned KMC groups and educational groups (from nurses and other staff) to be positive influences in their experiences. Additionally, religion played a large supportive role in both finding reason for- and receiving emotional support in coping with the experience of having and caring for a preterm infant. Major positive elements of these mothers’ hospital stays were thus the access to religious groups and facilities. Religious aspects of maternal reasoning were also found in a similar study by Arzani et al., (2015) which explored maternal coping strategies in handling preterm infants. Although all mothers acknowledged numerous sources of support while the baby was still in the hospital, it was the support in the home environment that had the largest influence on the ‘change’ in the mothers’ overall experiences. Such valued support often came from the infants’ grandmother in the form of caregiving, advice and assistance with household chores, however caregiving support from other community members was briefly mentioned. Participants with minimal support did not appear to undergo the ‘change’ from negative to positive in their experience as those with supportive networks had. These findings highlight the positive impact of the hospital staff, facilities and support networks on maternal experiences. Additionally, these findings further emphasize the psychological impact of caring for a preterm infant and the benefits of support networks.

3. Participants described their hospital stays and home stays in different lights: hospital stays were experienced as ‘stressful’, whereas most mothers experienced a change to a positive experience when going home.

As mentioned previously, mothers described the stressful hospital experiences. Many mothers went on to explain that seeing their babies in incubators surrounded by loud monitors and tubes caused them to feel stressed, associating the medical interventions with their infants’ medical vulnerability. Participant 16 described: *“It was a lot of stress when I saw her in the incubators but I really didn’t think she was going to make it...”*, whilst Participant 5 described that she was *“traumatized”* from her experience in the hospital. These results once again mirror those found by Steyn et al. (2017), whose study explored parental experiences of caring for a preterm infant in the NICU of a private hospital in Johannesburg. Amongst negative experiences, some mothers discussed feelings of comfort within the hospital setting due to the accessibility of medical assistance and nursing support, as well as the subsequent worries about their infant’s medical stability upon leaving the hospital. Participant 8 illustrated this when she explained: *“I was excited but afraid, because of, they said here that when you take your baby who is a premature home, it’s easy for her when she to get infected with illnesses out there and everything, infection and everything, I was so scared!”*. Furthermore, those mothers without caregiving assistance or support at home were afraid of coping, as Participant 15 illustrates: *“I was feeling happy but I was scared because now I would be at home without the nurses, then I don’t have someone who is going to help me at home”*. Additionally, the participants were concerned about their abilities to feed their infants in accordance with prescribed schedules and check their infants’ breathing status regularly. A study by Reyna, Pickler and Thompson (2006), exploring maternal feeding experiences of preterm infants after discharge, also found many reports of similar maternal concerns. Moreover, upon hospital discharge four mothers were concerned about the temperature of their homes, for example, Participant 9 explained: *“...and in the shacks we stay in it’s very cold and I’m worried it’s very cold and maybe he gets sick”*. Additionally, seven of the fifteen mothers expressed that they did not feel competent in washing and cleaning their infant at home, some worrying about possibly injuring their infant in the process. These findings suggest strong maternal PCV. Parental PCV (PPCV) with preterm infants is a common find in the literature (Esteroff et al., 1994; Perrin, West & Culley, 1989, Allen et al., 2004). The findings of Allen et al. (2004), who investigated parents of preterm infants’ perceptions of vulnerability, found that maternal PCV affected maternal perceptions of child development, for example mothers who held perceptions of their preterm infant being vulnerable felt that their infants were developing

slowly. Furthermore, PPCV was also related to higher rates of maternal anxiety. Thus, mothers of preterm infants were found to be at high risk for maternal anxiety. It is therefore important that healthcare professionals working with mothers within this population are made aware of and trained to recognise PPCV and maternal anxiety, as well as how best to address such experiences.

4. Prematurity in interaction with traditional beliefs and practices:

Beliefs about the ‘cause’ of preterm birth often included both a medically influenced reason as well as a traditional and/or religious belief. All but one participant provided a medical reason behind the preterm birth of their infants as given to them by the medical doctor at the hospital (e.g. preeclampsia in eight cases), as well as their own personal belief. Participant 6 illustrates her integration of her religious and traditional beliefs as: *“I believe it’s someone bewitched me, I ask God why. If someone, maybe it’s the ancestors they punish me, maybe it’s the God, He is punishing me”*. Additionally, two participants described their belief in unfaithful partners leading to their children’s preterm births as a form of consequence. Another two participants also shared that within their communities it is believed that preterm children grow to be ‘smart children’ (referring to intellectual abilities). These findings illustrate the strong influences of both religion and culture or traditional views on both experiences and personal reasoning. Such diversity in the findings also highlight the uniqueness of each individual’s perspective. Thus, clinicians should be aware of the possibilities of different beliefs in order to provide culturally sensitive care and interventions.

Concerning traditional practices, it was found that prematurity had an effect on both ceremonial practices and practices in the domain of traditional healthcare. Two traditional practices were mentioned during the interviews, namely the tradition of ‘Imbeleko’, and grandparents’ assistance in raising the children. Imbeleko can be shortly described as a ceremony in which the umbilical cord is buried in a place of significance with the purpose of honouring ancestors for the safe arrival of the infant, as well as introducing the new infant to the clan/community. It is only after the ceremony has taken place that the mother and infant may be visited by the family and community. Due to a lengthily hospital stay after the preterm birth, the umbilical cord was often lost or thrown away by the nursing staff as medical waste. Therefore, many of the participants were not able to perform this traditional ceremony, as said by Participant 7, *“I didn’t have a choice”*, suggesting she felt deprived of the opportunity. This highlights the importance of cultural and traditional knowledge pertaining to such practices, and the consequences of the lack thereof. Furthermore, it was also found that in the participants’ culture, many maternal

grandparents assisted in raising the children as part of a community tradition. Most mothers who would take part in this tradition under ‘normal circumstances’ (i.e. with full term infants) expressed reluctance to do so in the case of their preterm infant, discussing either not sending their children to their grandparents at all or letting them go at an older age than usually expected. Reasons discussed behind these decisions involved preterm infants’ specified caregiving needs for which the mothers had received education during their stay in the hospital with the infant, and high levels of PPCV.

Furthermore, mothers also showed apprehension in the use of traditional medicines due to their infants’ preterm status. Fourteen of the fifteen participants discussed having previously participated in traditional health practices with other full-term children in their families. Those practices include ingesting traditional medicines as well as placing a pouch, containing a combination of different herbs, around the infant’s neck or stomach in order to ward off unwanted spirits. The mothers who believed in the protective properties of the herb pouch continued to make use of it with their preterm infants, however this was not the case with the traditional medicine. According to the participants, most full-term infants in the isiXhosa culture receive a traditional ‘bottle’ of medicine within a few weeks or a month after birth as a form of illness prevention, irrespective of signs or absence of illness. This mixture is reportedly used to prevent and treat stomach upsets (including gas, reflux, irregular stools and general infant unrest). Two mothers described their belief in the medicine assisting with preventing the milk in the infant’s stomach from turning sour, and another mother described that this traditional medicine is used to clean the stomach after the passing of the meconium. The fourteen participants shared different views on the use of the traditional medicines with their preterm infants. Four of the fourteen participants gave their preterm infants the traditional medicines under advisement of other family members, traditional healers and their respective church elders. One participant avoided the ingestible medicine due to her infants’ preterm status and instead used only topical traditional remedies (a mixture of oils and herbs given to her by a traditional healer to ward off unwanted spirits – used to rub on the infants’ skin), whilst the other nine participants were cautious to use all traditional medicines with their preterm infants. These nine mothers were told during their hospital stays that the infants were not to receive medicine (traditional or western) unless directed so by a medical doctor, up until the age of 6 months chronological age. Six of these nine participants reported that, as advised by health professionals, they will only introduce the traditional medicines after the age of 6 months or older, whilst three participants remained undecided on the use of traditional medicines with their preterm infants, even though they had

used these medicines with previous full-term children or family members. It appeared that the preterm status of their infant, as well as the advice from the medical professionals, had affected their use of these traditional medicines, as Participant 12 illustrated in her statement: *“If she was normal [full-term] I would go to traditional bottles”*. The four mothers that did use the traditional medicine whilst their infants were still under the age of 6 months did not recall being cautioned against the use of medicines during their hospital stay. These findings illustrate the impact and power of information provided by medical staff in a hospital setting. Furthermore, this information demonstrates that even those who make use of traditional forms of healthcare also placed importance on that provided by medical professionals.

5. Feeding was found to be a generally difficult process/experience.

Tube feeding was found to be a largely negative experience, whilst cup feeding elicited mixed perceptions. Of the fifteen participants, eight discussed tube feeding. Seven of the eight participants described tube feeding as a negative experience, largely due to the perception that a tube-fed infant is perceived to be an ‘ill’ infant. Participants described that it was difficult for them to see their infants struggle with the discomfort of the tube, as described by Participant 1: *“- he was really struggling on the tube because it was on his cheek and he would pull it out and they would have to put it back again and it really hurt him”*. Two other participants, described their concerns about the tube feeding affecting future feeding abilities, as Participant 5 illustrated: *“the cup was fine, I think the tube was something else, it was overwhelming and I thought she won’t be able to breastfeed and then obviously it would take a while for her to feed, like um with solid food...”*. One participant however, described that she found tube feeding ‘easy’ as all of the milk was ingested, in comparison to more laborious cup feeds as she explained: *“It was easy to feed them with the tube, and then I was struggling when they said I should feed them with the cup, with the tube they drink all the milk but with the cup they don’t get all the milk, if they say 30 ml, the rest they don’t get”* [Participant 15]. Thus, some mothers found cup feeding to be difficult as it did not come with the surety that the infants ingested enough milk. Contrarily, other mothers found that cup feeding showed positive progression, as Participant 6 expressed: *“I felt happy because he was eating, and he is eating the healthy milk”* and Participant 14 shared that *“It was lovely to see him swallowing on his own [when the infant progressed from tube to cup feeding]”*. Stressful feeding experiences and apprehensions with feeding preterm infants appear to be a universally shared parental experience (Stevens, Gazza & Pickler, 2014; Lutz, 2012). There is an important opportunity within the hospital setting to reduce maternal anxieties regarding tube feeding through education, a vital part of the role of a SLP.

6. All sources of information received and reported by mothers were interpersonal sources rather than paper-based.

The participants were asked about the sources of the information that they received regarding prematurity, infant caregiving, speech- and language development both during their hospital stay and afterwards at home. All resources discussed involved persons, as opposed to pamphlets, posters, books and other sources. Sources of helpful information for the mothers included the nursing staff, the SLP's (regarding feeding), staff running the KMC groups in the hospital, as well as the other mothers in the wards. Only one mother reported that she had used a book, as well as Internet sites, to learn more about prematurity and her infant.

Summary

A summary of the risk and protective factors influencing the participants' experiences have been formatted into tables below so to represent the findings within the structure of Bronfenbrenner's bio-ecological systems model.

Table A - 2: Summary of emergent protective factors to maternal wellbeing and thus infant development

1. Microsystem: <i>Mother herself</i>
<ul style="list-style-type: none"> • Majority of participants experienced a change from more negative to positive experiences after going home with their infants. • Religious beliefs and practices provided most mothers with a source of support in coping and rationalising their preterm birth experiences. • Witnessing their (the mothers') infants' progress and developments throughout and beyond their hospital stays showed to improve mothers' spirits, contributing to the aforementioned 'change' from a negative to positive experience.
2. Mesosystem: <i>Context of mother and child</i>
<p>Hospital context:</p> <ul style="list-style-type: none"> • KMC and educational groups provided caregiving information, experience and support to the mothers. • The nursing staff at the hospital proved to be a large source of emotional, caregiving and educational support for the mothers in the hospital, often easing maternal concerns. • Other mothers in the same hospital wards and groups were found to be a large source of emotional and informational support. <p>Home:</p> <ul style="list-style-type: none"> • Caregiving support (with the infant and household chores), largely provided by close family members such as mothers (often the infants' maternal grandmother)

<ul style="list-style-type: none"> • Emotional support from family, friends and community members proved a large influence in maternal coping in general. • Financial support from family members and partners assisted in easing some caregiving stresses. • Informational support from family, friends and community members assisted in easing caregiving concerns.
<p>3. Exosystem: <i>Community</i></p>
<ul style="list-style-type: none"> • Community members assisting with caregiving and caregiving advice.
<p>4. Macrosystem: <i>Economic context and governmental policies</i></p>
<ul style="list-style-type: none"> • Receiving child grants: Although only discussed by three participants, the grant was sought to provide financial assistance. • Maternity leave: All working mothers in the study received maternity leave that allowed them to be with their infants for their first four months of life. This allowed opportunity for all above-mentioned protective factors to impact maternal wellbeing, such as learning about childcare and receiving support from hospital staff and other mothers.

Table A - 3: Summary of emergent risk factors to maternal wellbeing and thus infant development

<p>1. Microsystem: <i>Internal maternal perceptions and experiences</i></p>
<ul style="list-style-type: none"> • Threats to maternal health during pregnancy and the preterm birth process are known to increase maternal stress. • Negative experiences in the hospital: <ul style="list-style-type: none"> ○ Machines surrounding the infants in the hospital were generally perceived as suggesting illness (unwell infants), contributing to maternal stress. ○ Tube feeding was perceived as suggesting illness (unwell infants) and described as a negative experience. • Concerns regarding maternal duties within the home environment: <ul style="list-style-type: none"> ○ Concerns regarding feeding their infants regularly within the prescribed schedules, specifically during the night. ○ Concerns about washing their infant safely and appropriately.
<p>2. Mesosystem: <i>Context of mother and child</i></p>
<ul style="list-style-type: none"> • Context (familial and physical) of their home: <ul style="list-style-type: none"> ○ Mothers showed concerns of having “cold” homes ○ Lack of caregiving and emotional support at home appeared to negatively affect maternal stress and caregiving experiences. • Hospital context: <ul style="list-style-type: none"> ○ It was apparent that not all mothers received the same information against traditional medicinal intake within the infants’ first six months of life. ○ Hospitals were associated with periods of high maternal stress.

3. Exosystem: <i>Community</i>
<ul style="list-style-type: none"> • Some mothers felt pressure from family and community members to carry out maternal duties in a certain way, for example in seeking traditional healthcare. • Maternal reluctance to leave their infants in the care of others, thus possibly limiting sources of caregiving support that was otherwise seen as assisting with maternal coping. • Affected participation in traditional practices: <ul style="list-style-type: none"> ○ Not participating in Imbekelo: Non-participation in a traditional ceremony could interfere with community interaction, again possibly affecting community support. ○ Reluctance to travel with the infant for other sources of support (e.g. grandparents in another province), as mentioned previously may be limiting caregiving support.
4. Macrosystem: <i>Economic context and governmental policies</i>
<ul style="list-style-type: none"> • Financial difficulty: <ul style="list-style-type: none"> ○ Although not highlighted, financial difficulties were mentioned in affecting the amount of times mothers or family members could visit at the hospital, in mentions of cold homes and in some mothers having to return to work with their infants only being around one month corrected age.

Clinical and Research Implications

The findings highlight that there are many factors affecting a mothers' experience of having, caring for and feeding a preterm infant, those that are universally shared and those that are culturally specific. Such factors may have a large impact on maternal coping, and thus infant wellbeing and development. It is important for healthcare practitioners working with these mothers to have access to such knowledge in order to provide appropriate and respectful education and understanding regarding traditional healthcare beliefs and practices. Continued in-service training opportunities with NICU staff working with the described population can be used to convey this pertinent information.

None of the mothers reported concerns over the risk of developmental delay associated with prematurity, although it is widely known to be common. Unawareness of such risk may result in late recognition of difficulties. This was identified as a knowledge gap that could be addressed by the SLP. It is evident that during the mothers' lengthy stays in hospital, informational support is sought and appreciated. SLP's thus have an opportunity to provide education about communication stimulation in order to mitigate possible communication delays. Additionally, because tube feeding appeared to be a large stressor in mothers' experiences, the SLP has an opportunity to educate the mother and other hospital staff in the NICU about tube feeding,

address any related concerns and involve the mother where appropriate (something that is strongly encouraged in NICU's worldwide (Craig, et al., 2015)). This may assist in reducing the stress/negativity of the tube feeding experience.

Furthermore, it is increasingly evident that healthcare providers are often unaware of their patients' cultural beliefs, practices and traditions that could be negatively impacted throughout the course of intervention (such as the importance of preserving an umbilical cord and the consideration of practices and beliefs surrounding traditional medicines). Thus, the findings of the current study and other similar research can help illuminate important patient perceptions, which can have a dramatic impact on the quality of services delivered. Such information can assist in providing healthcare providers with the information needed to improve the cultural competency of the healthcare system, as stressed in a large amount of recent literature (Martin & DiMatteo, 2013; Govender et al., 2017). Such information will be beneficial to both acute care settings as well as early childhood intervention programmes.

Limitations

Due to the relative small scope of the study, the results cannot be generalized to all isi-Xhosa-speaking mothers of preterm infants residing in urban areas and within low socio-economic conditions. However, due to the growing realization of the importance of research in the areas of mother- and infant health in different cultural and social settings, the findings of the study is felt to be important for healthcare professionals working in the South African context, especially to neonatal nurses, doctors and SLPs.

Conclusion

The findings of the current study provide valuable insight into a common phenomenon within a unique setting in South Africa. The findings highlight the importance of support for maternal coping, the need for maternal education regarding prematurity and development, as well as the interaction between preterm birth and cultural beliefs and traditions. The implications of the findings may be incorporated into healthcare professionals' education, maternal support infrastructures, SLP intervention in the NICU and maternal education.

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5.2. Findings by theme

The findings contain themes that emerged within the data. Each theme is described and explained below. Within the results are sections of text written between inverted commas and in italics, these sections indicate quotations of participants' speech (all are relayed in English, thus some phrases refer to the English translations of direct isiXhosa quotations). Between such quotations are additional sections of information that are between square brackets and not italicised. These additional sections of text add explanation or context within the quotation to allow the reader better understanding of, or insight into, the text.

Due to the semi-structured nature of the discussion schedule some themes, such as the participants' experience with feeding and communication with their infants, were prompted areas where purposeful investigation was led in order to address the aims of the study. Other themes, such as the role of support in maternal coping, occurred naturally within the data when exploring general maternal experiences of prematurity. Thus, the findings will be presented in two parts: Unprompted themes and Prompted Themes. In some cases, there exist sub-themes within the main theme. Table 4 below illustrates a summary of the themes discussed.

Table 4: A summary of the prompted and unprompted themes that occurred throughout the data

5.2.1. Unprompted themes:	
<i>Those themes relating to general maternal experiences of prematurity and preterm birth.</i>	
I.	The experience of having and caring for a preterm infant was described most commonly as “difficult”
II.	The size of the infant is a large factor impacting maternal experiences and decisions.
III.	Support played a great role in the mothers' overall experience.
IV.	Medical stability and health of the infant is the main concern at this early stage of life.
V.	Experiences in hospital and at home: <ol style="list-style-type: none"> a. Experiences at the hospital were generally described as ‘stressful’ b. Mothers reported mixed feelings about going home c. Concerns about being at home largely involved the medical status of the infants d. Prematurity affected caregiving routines and vocational plans
VI.	The influence of socio-economic related factors was not highlighted

<p>VII. Prematurity in interaction with cultural beliefs, traditional practice and religious beliefs</p> <p>e. Beliefs about the cause of prematurity ranged between medical, religious and cultural reasoning</p> <p>f. Prematurity notably impacted certain cultural traditions</p> <p>The use of traditional medicines was, in most cases, affected by the infants' preterm status</p>
<p>5.2.2. Prompted themes:</p> <p><i>Those themes where purposeful exploration was led in order to address the study aims</i></p>
<p><u>Communication and development:</u></p> <p>VIII. Poor maternal education regarding infant development and interactions with prematurity</p> <p><u>Feeding:</u></p> <p>IX. Tube feeding was described as a negative experience</p> <p>X. Participants described mixed experiences with cup feeding</p> <p>XI. The majority of participants' are using mixed feeding methods at home, most commonly breastfeeding with supplemented bottle-feeding (formula feeds).</p> <p><u>Findings related to participants' perceptions of prematurity</u></p> <p>XII. Participants' understanding of the term 'premature'</p> <p>XIII. Participants remarks regarding prematurity</p> <p><u>Information about prematurity:</u></p> <p>XIV. All sources of information reported were from persons, not paper based</p> <p>Information they did not feel confident about was washing the infant.</p>

5.2.1. Unprompted Themes:

- I. The experience of having and caring for a preterm infant was described most commonly as 'difficult'

Unsurprisingly, every mother in the study described the experience of caring for a preterm infant as “*difficult*”, often using the words “*scared*”, “*overwhelmed*” and “*stressful*” to describe their

emotions at the time. Participant 14 shared her experience as follows: *“I was scared and stressed, I was not fine at all”*, whilst Participant 1 described her initial experience as *“traumatic”* and Participant 12 reported that she was *“in shock”* and scared after the birth of her infant due to her small size. These initial feelings of stress were shared widely amongst participants and were often followed by remarks of concern over their infants’ health, as Participant 14 illustrates: *“I was stressed, I thought he was not going to be fine”*. There were however differing feelings expressed by a few participants. Participant 15 reported that she felt *“disappointed”* to have a preterm infant, explaining that she did not understand why her pregnancy with her preterm infant was difficult when she had successfully carried her previous pregnancies to term without complications. Additionally, one participant shared her feelings of embarrassment due to perceived perceptions regarding her infant’s small size, as she explained: *“She was small also, it was embarrassing because if you compare her to other children then it’s like you don’t feed her, or your baby is, you know mos how we are, so I decide not to tell.[not to tell others about her infant’s prematurity] I’m just going to keep quiet.”* (Participant 11).

Every participant shared unique combinations of factors affecting their personal experiences of having and caring for their preterm infant. However, it was found that there were two major contributing factors to the overall experience, that of support and size of infant. Those mothers who received caregiving support were found to report more pleasant experiences than those without support. Additionally, every participant related the small size of the infant to the caregiving difficulty within different areas, such as washing, feeding or general caring difficulties). The mothers’ caregiving concerns and focus were largely centred around that of their infant’s size, for example many mothers explained that they were not as stressed and coping better once the infant was larger (as determined by weight and clothing size).

II. Size of the infant is a large factor impacting maternal experiences and decisions

As mentioned previously, size appeared to be a recurring topic of discussion with every participant, and a factor that largely influenced maternal caregiving experiences. The preterm infant’s small size appeared to be a contributor to feelings of stress, for example one participant expressed: *“It’s not really nice to have a small baby, you always think about what could go wrong...”* (Participant 9). Participant 2 expressed that her experience was difficult and stressful due to her infant’s small size as she explained: *“It’s very difficult and stressing as well because they are very small.”*, furthermore Participant 10 conveyed: *“Sometimes I used to be worried*

about his health because he was so small...”. Participant 10, as well as most participants, thus associated small size with vulnerability or illness. As mentioned previously, another participant explained that she felt embarrassed regarding small size of her infant and felt that she needed to hide her preterm status due to perceived negative judgements associating small infant size with some form of maternal deficiency. Infant size also appeared to influence the perception of difficulty with other tasks such as washing and feeding, for example Participant 1 shared that she was “*scared*” to use formula feeds because of her infant’s small size. Additionally, the size of the infant also appeared to have an effect on other caregivers and family members’ caregiving assistance and interaction. A few participants explained that other family members in the home were reluctant to assist with caregiving and feeding because of the small size of the infant, for example Participant 11 shared: “*my youngest brother was scared to touch her, he could not touch her, she was too small*”. Furthermore, size of the infant was also found to have acted as a descriptive determiner regarding the participants’ employment plans, as the majority of the participants explained that they would seek employment only after the infant is ‘bigger’, as opposed to other deciding factors such as age of the infant (although these two factors are related).

III. Support played a great role in the mothers’ overall experience

As introduced previously, it was noticed that support (caregiving, informational and emotional) played a large role in the mothers’ experiences. It was found that greater caregiving support lead to a ‘change’ in the quality of the participant’s experience, i.e. participant reported negative initial experiences but positive subsequent experiences. Sources of support that were frequently mentioned included hospital staff (nurses, doctors and other healthcare professionals such as SLP’s), other mothers of preterm infants in the hospital, religious beliefs and family members. The source of support that had the most profound effect on positive caregiving experiences was found to be a maternal family member who stayed with the participant and provided assistance with daily chores, caring for the infant, caregiving advice and emotional support. Those participants that received a large amount of support described their caregiving experience as initially difficult, however at the time of the interviews, once the mothers had been at home (with support) for a period of time, the participants described their experience in a more positive light and suggested they were coping well both physically and emotionally. These participants experienced a shift or change in their experience of caring for a preterm infant. In contrast, those participants without such supportive networks appeared more emotional during the interviews

and described their experience at the time of the interviews in a negative light. Such participants were often alone in their responsibilities to care for the infant and maintain household responsibilities. Participants with minimal support did not appear to undergo the ‘change’ in their experience compared to those with supportive networks.

Examples of support received from nursing staff, other mothers and other professionals in the hospital environment can be illustrated in the following quotations:

- Informational/educational support: *“The nurses were a big support to us and told us that our children will grow and other mothers who have had premature babies before used to come as well and show us the children that are grown up and they lived and the nurses used to come and chat with us.”* (Participant 9);
“They [the nurses] taught us how to put the nappy on because the babies were very small, so I didn’t know what to do that, they taught us how to put a nappy and feed them because when you go to the KMC you do it yourself so they taught us all of those things so that you can do it ourselves” (Participant 12).
- Education from SLP’s: *“Yes and the other one [the SLP] they said they teach us when the premature baby makes the moves [stress cues, such as infants moving their hands in front of their face] they said stop, they said they don’t want”* (Participant 8); *“They [SLP’s] told us how to feed the baby”* (Participant 2);
“I had speech therapy there [at the hospital] then after a month and a half then we cup fed him then from cup feeding to breast” (Participant 4).
- KMC and informational support: *“I actually got a lot of information here as well [in the KMC ward], with the whole KMC thing, they schooled us on KMC, what the benefits of KMC, the benefits of breastfeeding and how important it is especially with the growth, and like with breast milk versus formula, not really on development though, not really much on development, but ya with the whole with nursing a baby, even when he gets sick I know what to do, they taught us CPR”* (Participant 1);
“You know for the first time I didn’t stress after I had the baby, I was just happy to have the baby and the kangaroo thing for me was like, I just enjoyed everything...” (Participant 11).
- Emotional support from other mothers in the hospital setting: *“It was nice, we were talking and telling each other why we gave birth early. So you really didn’t stress a lot about the child because it’s not really nice to have a very small baby and you always*

think about what could go wrong but when you are together as mothers and talk to each other that's very nice." (Participant 9).

It was thus found that support from nursing staff primarily involved support in the form of caregiving information whilst support from SLP's focussed on feeding (although not all mothers came into contact with a SLP). KMC was widely discussed as a positive form of both emotional and caregiving support. Additionally, shared experiences with other mothers in the hospital setting provided a large source of emotional support.

Examples of different forms of familial support can be illustrated in the following quotations:

- Financial and transportation support: *"...with transport her [the infant's] father helps with transport whenever we are in need and then there is not much that I struggle with as he helps with everything else. Financially he helps if she needs whatever, if she is sick he is there."* (Participant 5).
- Caregiving and emotional support: *"...maybe it's [the infant] crying a lot and you don't understand what is happening now but your mom is going to support you, you know"* (Participant 6)
- Daily task support: *"She [the participants' mother] is always feeding me, it's amazing."* (Participant 7)
- Social support: When asked if someone offered support and comfort, Participant 11 replied: *"My youngest brother. He came to visit me in the hospital."*; *"They are also supportive [the father of the infant and his family], even the time when I was here in hospital they used to come visit us and see her [the participants' preterm infant]"* (Participant 12)
- General caregiving support: *"A lot [of support], even when we were here in the hospital they [the participants' family] kept on asking when am I coming back with the baby? And when we got home, they took her from me, and she was very small but they didn't care."* (Participant 12); *"He [the participants' infant] used to get a lot of reflux at night, so my mother said she will sleep with him at night and look after him."* (Participant 13).

As previously discussed, it was found familial support in the form of caregiving support as well as financial and emotional support was a large contributor to participants reporting positive caregiving experiences at home.

An additional form of support that appeared throughout the findings was that of religious support. Five participants consistently mentioned their beliefs and use of prayer as a form of support and reasoning throughout their interviews. Participant 6 expressed her experience of support seeking in her sentiment: *“Then I started praying, I started asking for the bible in the hospital. I started asking when are the people coming that pray for you, I started asking for prayer”*. Participant 7 shared this sentiment as she reported prayer as her largest source of support, she explained: *“So the only thing that helped me was prayer, us mothers there we used to pray, I used to pray at one point there was a day that just got so bad and I was like ‘let’s go pray’ and the nurses got tired they would say you’ve been praying the whole day so I was like there is a prayer down stairs”*.

IV. Medical stability and health of the infant is the main concern at this early stage of life

Health and medical stability of the infants appeared to be the mothers’ main concern at this stage of the infant’s life as it appeared frequently in all interviews. Many mothers described the stress that they experienced seeing their infant with medical tubes and drips during their hospital stays. Furthermore, the mothers’ concerns of returning home revolved around their infants’ health and performing extra measures to prevent their infant from falling ill. One mother described her concerns of being at home as follows: *“Ja I was just so traumatized. There was just so much and I was so scared, I thought maybe when we get home the house is not even warm, she was in a glass here in intensive care and it was warm and at home it’s not warm. I was so scared that she would get cold, maybe that her sugar levels would go down. I was so scared seriously.”* (Participant 5). It is seen that the health vulnerability of preterm infants is a worrisome factor for mothers, one that they are highly concerned about when being at home away from immediate professional medical care. Eleven of the fifteen participants described feeling over-protective or very cautious with their preterm infants. Additionally, two of the participants that had previously had full-term infants prior to a preterm infant described that the preterm infants differed health-wise, and that the mothers were more concerned for their preterm infant’s health than that of their full-term infant. This can be illustrated in Participant 4’s sentiment: *“Caring for him I have to be like, I have to be like careful, aware of each and everything that is happening with him, each and every change, I must be curious about what is happening, like – why has that changed? – because he is totally different from the first one health-wise”*

V. Experiences in hospital and at home:

a. Experiences at the hospital were generally described as 'stressful':

All participants discussed mixed-feelings about their experiences of being at the hospital and being at home. The lengthily duration of the participants' hospital stays ranged between one to three months, largely due to the underdevelopment of the infants' physical and neurological systems. For majority of the mothers, their experience at the hospital was a generally frightening time as they described their experiences of unexpected early birth, often surrounded by their own health difficulties, and worries about the health of their child. All participants experienced complications threatening their own lives as well as that of their unborn infants, leading to the preterm birth. Participant 10 described: *"It was scary, when the doctors were running around I was so scared..."*. Participant 12 shared her birthing experience as traumatizing in the following statement: *"... first of all I started here in hospital because I thought that I would give natural birth but then everything was complicated and I did C-section and stuff so it started from there. Then uh seeing the small baby it's just traumatizing, she almost died 4 times I was there watching, so all of those things were scary. And I'm telling you that they make everything hard."*

Furthermore, mothers commonly shared descriptions of 'shock' or disbelief in seeing their infants for the first time, as can be seen in the following quotations:

- Participant 8: *"Then I gave birth and then they said '(participant name) this is your baby' and I said 'what, this is my baby?' I didn't believe it at first, no, this is not my baby can you please give me my baby. They said '(participant name) this is your baby you don't have another baby, this is the only one, this is your baby. It's okay it's okay' I said 'okay'. It was hard, hard time for me that time but I learned, I learned a lot."*
- Participant 7: *"When I first saw them I was like... Like in the operation room they said here is your first baby, and the baby was like ok but it was scary to see the small ones..."*

Additionally, many mothers described that seeing their babies in incubators surrounded by loud and beeping monitors and tubes caused them to feel stressed, as Participant 16 described: *"It was a lot of stress when I saw her in the incubators but I really didn't think she was going to make it..."*. Furthermore, two mothers discussed feelings of stress and anxiety after hearing of other infants passing away in the same ward as them and their own infants. However, majority of the mothers went on to discuss the feeling of comfort and support they received through various sources at the hospital. The most widely discussed source of support were those of other mothers in the same situation as they comforted and passed on knowledge to each other during their KMC ward stays. Other sources of support that helped the participants during this stressful time

included the nurses and other healthcare providers who both cared for the infants and provided education on caring for a premature infant to the mothers.

b. Mothers reported mixed feelings about going home:

Ten of the fifteen participants expressed that they felt the general mixed feelings of being both excited and 'scared' to leave the hospital and go home, whereas the remaining five participants remained mostly nervous. When investigated further it was found that the majority of the nervousness related to the fear of their baby falling ill as well as the fear of their baby not breathing. Participant 8 illustrated this when she explained: *"I was excited but afraid, because of, they said here that when you take your baby, who is a premature, home - it's easy for her when she to get infected with illnesses out there and everything, infection and everything, I was so scared!"* Those mothers without caregiving assistance or support at home were afraid of coping, as Participant 15 illustrated in saying: *"I was feeling happy but I was scared because now I would be at home without the nurses, then I don't have someone who is going to help me at home, like someone like a sister or mother."*

c. Concerns about being at home largely involved the medical status of the infants:

As discussed above there were certain topics mentioned that led the mothers to feel afraid to take their infant home. There were many specific mentions about waking up in the night to ensure that the infants receive their 2-hourly feeds for growth, as well as checking if they are still breathing. Additionally, some mothers were concerned about the temperature of their homes, for example Participant 9 explained: *"[responding to questions about why she felt afraid at home] It was sleeping with him in the night. I was asking myself 'how am I going to sleep with him' and in the shacks we stay in it's very cold and I'm worried it's very cold and maybe he gets sick".* Additionally, fifteen of the mothers expressed that they did not feel that they were competent in washing and cleaning their infant, some worrying about possibly injuring the child in the process (mentioned by Participant 5). Four mothers shared additional concerns regarding their homes being cold for their infants. Participant 5's story about going home illustrate all of the above-mentioned concerns, *"I was scared. I was. As much as I wanted to go home I was very scared. The thing is after, whilst we were supposed to go home the nurses said that some mothers they will take the babies home and since they are premature we have to feed them throughout the night, a 2-hourly period, so some mothers will get home and sleep and the baby's blood sugar would go down and then the baby would die, so I was SO traumatized. Ja I was just so traumatized. There was just so much and I was so scared, I thought maybe when we get home the*

house is not even warm, she was in a glass here in intensive care and it was warm and at home it's not warm. I was so scared that she would get cold, maybe that her sugar levels would go down. I was so scared seriously."

d. Prematurity affected caregiving routines and vocational plans

Mothers reported taking extra precautions with and being more thoughtful about their infants' care due to their preterm status. These precautions were linked to maternal perceptions of their infants' vulnerability. Mothers described being 'more careful' or 'scared' when it came to the use of traditional medicine with their preterm infants, performing daily caregiving tasks, checking their health status (checking if they are warm enough and breathing) and leaving their infants in the care of others. Such concerns also included increased awareness of germs and maternal hygiene. Participant utterances demonstrating these caregiving concerns were as follows:

- Participant 4: *"Caring for him I have to be like, I have to be like careful, aware of each and everything that is happening with him, each and every change, I must be curious about what is happening, like – 'why has that changed' because he is totally different from the first one health-wise"*
- Participant 8: *"I had to be careful; if I take her I must be careful and put her down here and now I have, it's better.... I was excited but afraid [to go home], because of, they said here that when you take your baby, who is a premature, home - it's easy for her when she to get infected with illnesses out there and everything, infection and everything, I was so scared. And every time I take her I wash my hands first and then everything like that. The things I was doing here [at the hospital], I'm doing them at home, before I feed my baby I wash my hands and after I change my baby I wash my hands then I can take her. I told them at my home - that you know what, when you want to take my baby, first you must wash your hands and then take my baby."*
- Participant 8: *"...now I have to look after her because some other people will, they will never know, they will act like she is a normal baby but she is not, but she is normal, but she is a premature and all that"*
- Participant 12: *"This one was different because, first of all it's like when I carried her I have to be careful as if I'm carrying an egg. A lot of things I have to look after her and see if she is breathing or what, because I don't know when this breath will stop or ja so..."*

For the working mothers, the majority of their maternity leave was used whilst in the hospital, meaning that they received only a short period of time at home with their child. Some of the mothers returned to work whilst others explained that they would stay at home with the child until they feel that the child is ‘bigger’, seeking employment after this time. Four mothers explained that they are afraid to leave their child with others (family members or a nanny or day-care facility), as they are afraid that the other caregivers will not know how to take care of their preterm infants appropriately. One mother (Participant 10) also expressed that she does not want to leave the house in order to procure a child-support grant as she was too afraid to leave her ‘small’ infant in the hands of other caregivers, even close family.

VI. The influence of socio-economic related factors was not highlighted:

The participants did not specifically mention socio-economic factors as factors affecting their experiences, however it was noted that in their responses within other areas of the interviews, that socio-economic factors did indeed play a role. Four participants mentioned concerns that their informal homes were not warm enough for the infants, as Participant 9 shared “...and in the shacks that we stay in it’s very cold and I’m worried its very cold and maybe he gets sick”, whilst Participant 11 illustrated how the cold home environment affected her caregiving routines and especially baby massaging as she reports “...I don’t have time to massage but at least I know when it’s hot, because I mustn’t use my paraffin heater, so the shack is not that warm so I just make quick but when it’s hot I will make time and massage her”. Additionally, one mother reported that she couldn’t afford a nanny to assist with caregiving, but that rather someone in her community was assisting her with caregiving whilst she worked. It was commonly found that family members, neighbours and other members of the community provided caregiving assistance to those who could not afford to send the child to a crèche. Additionally, Participant 4 explained financial difficulty in relation to transport costs to the hospital to visit her infant, as she explained: “Yes I did, I stayed with him at the hospital. I only went home once because there were no beds in Tygerberg then the following day I went to the matron and I told her I didn’t have money and wouldn’t have money to travel every day because I was the only one working, the father was not working. Because if I go up and down I won’t have money because it’s R50 to come here travelling. So I explained my situation to her and she understood and there was a bed available so I stayed that day”. Participant 4 further explains that she had loaned money in order to buy caregiving supplies: “So far I think since, I just recently went back to work I’m still struggling but I think as... then maybe next month and the month after that I will be fine, so for

this month I will get paid next week so I have so many debts because I've been borrowing from friends to buy nappies because at the end of the day I feel that it's not always right to ask from my mother. She never complains but when I look myself in the mirror I cannot ask from my parents because she also doesn't have, so I borrow from friends and tell them that I will pay you month end so this is my first month back at work and next week will be my first pay so I think along the way I will be fine". Participant 4 was one of three mothers to discuss childcare grants for which she had applied and was awaiting the outcome at the time of the interview. An additional one participant had received a childcare grant whilst another mother (Participant 10) intended to apply for one when she felt her infant was older and less vulnerable as the application requires her to leave the safety of her home with her infant.

VII. 7. Prematurity in interaction with cultural beliefs, traditional practice and religious beliefs:

a. Beliefs about the cause of prematurity ranged between medical, religious and cultural reasoning

Fourteen of the fifteen participants described medical reasons behind the cause of their infants' preterm birth with maternal hypertension being related to eight of the cases, the remaining one mother reported that she wasn't told why she had given birth early. Accompanying the medical reason for preterm birth, seven participants further described their personal beliefs surrounding their preterm birth, which included both cultural and religious beliefs as well as a combination of the two. Two participants described that they believed that their preterm birth could have been linked to unfaithful partners and possibly jealous other women. Another two participants described their religious beliefs that it is 'God's wish' or plan for the preterm birth to occur, whilst the remaining three descriptions include beliefs about witchcraft. There were however also reasoning's that seemed to involve integrations between the cultural or traditional beliefs (witchcraft) and religious beliefs, as illustrated by Participant 6's description "*I believe it's someone bewitched me, I ask God why. If someone, maybe it's the ancestors they punish me, maybe it's the God He is punishing me ...*".

b. Prematurity notably impacted certain cultural traditions

It was found that prematurity had an influence on certain cultural traditions. Two traditional practices were mentioned recurrently throughout the data, one being 'Imbeleko', and another tradition being assistance from the grandparents in raising children. It was found that most

participants' families usually took part in the isiXhosa tradition of 'Imbeleko'. Imbeleko is a ceremony that is performed within the first two weeks of an infant's life whereby the mother remains in the family home until the umbilical cord falls off. Once the umbilical cord detaches, the family ceremoniously buries the cord with the purpose of both thanking or honouring ancestors for the safe arrival of the infant, as well as introducing the new infant to the clan and ancestors. The mother and infant may not be visited in the time after the child is born, up to the ceremony of Imbeleko. It is only upon the ceremony that the mother and infant may be visited for the first time by other members of the community and extended family. Unfortunately for most of the participants, this ceremony could not take place, as said by Participant 7, "*I didn't have a choice*" when asked if she had participated in the tradition. Furthermore, Participant 1 explains: "*We have this thing where we bury the umbilical cords, so with them, but his was taken out by the operation so we couldn't really do that*". Additionally, as the preterm infants of the participants stayed in hospital for a lengthily period, the umbilical cords fell-off whilst the infants were in hospital and were, in most cases, disposed of by staff, as explained by Participant 14: "*When I went to sleep he had it but when I went to see him the following day it fell off at night and the nurses threw it away with his nappy*". Some lucky mothers were present at the time the cord detached and were able to retrieve the cord so to carry out a burial ceremony at a later stage.

Additionally, it was found that another interrupted 'tradition' was that of the participants' parents caring for the children for a period of time. This was mentioned amongst the participants whose families reside in more rural settings in a different province, although the reasoning for this tradition differed. Some participants reported that they had moved to more urban settings in order to find work opportunities, but would like their children to grow up in similar settings to their upbringing, and so their children reside with their grandparents from young childhood to school-going age. Other participants reported that this caregiving pattern was due to the belief that older adults were more capable of caregiving, as illustrated in Participant 6's sentiment: "*They just said come, they want to take care of him, they say I'm going to kill my baby and I'm not going to kill my baby and I'm not going to send my baby to the Eastern Cape and they said when I come and I must leave the baby there and I told them I'm not going to leave my baby in the Eastern Cape because the first one my mother said she wants to take care of him so I never experienced that baby, it was 3 months and I went to Joburg*". It was found that because the infants of the participants were preterm, all participants whose families practice the tradition of older family members caring for their children, felt more reluctant to allow their parents to care for their child. Mothers discussed either not sending their children to their grandparents or letting them go at an

older age than usually expected as the preterm infants had specified caregiving needs for which the mothers had received education, especially from health care staff at the hospital where the baby was born.

c. The use of traditional medicines was, in most cases, affected by the infants' preterm status

Fourteen of the fifteen participants discussed having previously participated in traditional health practices. Those practices mentioned include ingesting traditional medicines as well as placing a pouch, containing a combination of different herbs, around the infant. The pouch, hung around the infants' neck or around his/her waist, is used as a protective mechanism to ward-off potential harm or unwelcome spirits. Both the pouches and medicines were made and given to the participants by traditional healers within their communities. One mother shared that she uses a topical cream/oil prepared by a traditional healer that is placed on the infants' head in order to ward off unwanted spirits. The mothers who believed in the protective properties of the herb pouch continued to make use of them with their preterm infants, however this was not the case with the traditional medicine. The fourteen participants described a specific type of traditional medicine used for infants as being a bottle of an unknown mixture of liquid that is usually given to all infants within the community in order to address, relieve and prevent stomach upsets (including gas, reflux, irregular stools and general infant unrest). Two mothers described their belief in the medicine assisting with preventing the milk in the infants' stomach from turning sour, and another mother described that this traditional medicine is used to clean the stomach after the passing of the meconium. According to the participants, most term infants in the isiXhosa culture receive and use this bottle of medicine within a few weeks or a month after birth in a preventative manner, irrespective of signs of illness (stomach upsets) or not. The fourteen participants shared different views on the use of the traditional medicines. Four of the fourteen participants gave their preterm infants the traditional medicines under advisement of other family members, traditional healers and their respective church elders. One participant used only topical traditional remedies whilst the other nine participants were cautious to use the traditional medicines with their preterm infants. It was found that these nine mothers were told during their hospital stays that the infants were not to receive medicine (traditional or western) unless directed so by a medical doctor, up until the age of six months chronological age. Additionally, the four mothers that used the traditional medicine whilst their infants were still under the age of six months did not recall being cautioned against the use of medicines during their hospital stay.

Six participants reported that, as advised by health professionals, they will only introduce the traditional medicines after the age of six months or older, whilst three participants remained undecided on the use of traditional medicines with their preterm infants, even though they had used these medicines with previous full-term children or family members. It appeared that the preterm status of their infant had affected their use of these traditional medicines, as Participant 12 illustrated in her statement: *“If she was normal I would go to traditional bottles”*.

5.2.2. Unprompted Themes:

Unlike the previously ‘naturally occurring’ themes within the broad experience of having and caring for a preterm infant, the following areas were prompted for by questions that aimed at eliciting the participants’ experiences within the following areas: Communication and general development, feeding, perceptions about prematurity, information related to prematurity and findings related to mothers’ perceptions about their role and other role players in communication development.

Communication and development:

a. Poor maternal education regarding infant development and interactions with prematurity

Six of the fifteen participants reported that they thought that prematurity may affect their infant’s development, however the participants did not discuss more specific understandings of how the infant’s development may be affected. In interviews where milestones were discussed some mothers went on to express that they think that their developmental milestones might occur at a later stage. However, seven participants expressed perceptions that milestones such as sitting and first words occur between five to nine months and within close range of each other, illustrating a compact view of development. It was found that the participants’ estimations for the infants’ first spoken words were around six to eight months of age, when the typical milestone for a first word is expected around twelve months chronological age. Knowledge of the physical milestones, such as sitting, was more appropriate with corrected-age estimations. Regarding feeding milestones, all mothers were planning on introducing soft foods at an appropriate age as all mothers had been informed in this regard at their clinics.

One mother reported that she was scared to hurt her infant whilst trying to teach him how to sit, as she remarks: *“I think he is still too young for that. I did try to put him in a couch the other day*

and I put towels next to his sides but I wasn't sure but I'm also scared that he could break his back, so at least when he is six or seven months then I will think about that" (Participant 4). Furthermore Participant 4 also shared her concerns regarding her infant's development and her perception of his vulnerability to other disorders, as she explains *"I still now or sometimes when I look at other children I feel like why did I have to give birth to a premature baby. Is he going to be fine? Is he going to grow up like other children? I'm worried about him, something like I'm worried of certain diseases like autism or Down's syndromes. I've read about those stuff, so I'm worried about those things."*

Feeding:

a. Tube feeding was described as a negative experience

Of the fifteen participants, eight discussed tube feeding. Seven of the eight participants described tube feeding as a negative experience, largely due to the perception that a tube-fed infant is perceived to be an 'ill' infant. Participants described that it was difficult and stressful to see their infants in incubators with the feeding tube, drips and other monitors. Additionally, participants described that it was difficult for them to see their infants struggle with the discomfort of the tube, as described by Participant 1, *"he was really struggling on the tube because it was on his cheek and he would pull it out and they would have to put it back again and it really hurt him"*. Two other participants, described their concerns about tube feeding affecting future feeding abilities, as Participant 5 illustrates – *"the cup was fine, I think the tube was something else, it was overwhelming and I thought she won't be able to breastfeed and then obviously it would take a while for her to feed, like um with solid food..."*. One participant however, described that she found tube feeding 'easy' as all of the milk was ingested, in comparison to more laborious cup feeds as she explains – *"It was easy to feed them with the tube, and then I was struggling when they said I should feed them with the cup, with the tube they drink all the milk but with the cup they don't get all the milk, if they say 30 ml, the rest they don't get"* [Participant 15].

b. Participants described mixed experiences with cup feeding

As previously illustrated in Participant 15's account, she found cup feeding to be a difficult transition, as it does not guarantee that the infant will ingest the full amount of milk that she receives. This same experience was shared with two other participants, as Participant 10 illustrates: *"It [cup feeding] was not nice because he was not drinking all the milk like with the tube, and then he lost some weight"*. Additionally, another participant found holding and

positioning the infant during cup feeds difficult. Contrarily, seven of the participants found cup feeding to be a positive transitional experience, for example Participant 6 expressed: *“I felt happy [when her infant was introduced to cup feeding] because he was eating, and he is eating the healthy milk”*, similarly Participant 14 shared that *“It was lovely to see him swallowing on his own”*. In the hospital the moms were reportedly encouraged to express milk for tube and cup feeding, however some mothers expressed difficulties with breast milk supply. Therefore in most cases, formula was used for feeds.

c. The majority of participants are using mixed feeding methods at home, most commonly breastfeeding with supplemented bottle-feeding (formula feeds).

Five of the participants were using exclusive breastfeeding at the time of the interview, whilst an additional five participants reported that they were trying to breastfeed but were supplementing with formula feeding (using a bottle) due to poor breast milk production. A further three participants were using only formula feeding with a bottle, whilst one participant reported that her infant preferred cup feeding. When asked, mothers didn't report significant difficulties with feeding, however six mothers reported incidences of frequent vomiting or reflux (largely associated with formula feeds).

Findings related to participants' perceptions of prematurity

a) Participants' understanding of the term 'premature':

All participants demonstrated an understanding that a 'preterm/premature' infant is an infant born before term or full gestational age. Most mothers referred to this as an infant being born before "time". Three participants additionally shared their understanding of preterm infants also being underdeveloped, as demonstrated by Participant 1's remark: *“I think basically he was born before his time, he is not developed, he was supposed to be in tummy busy developing, he hadn't developed yet...”*.

b) Participants remarks regarding prematurity:

Two mothers had previous exposure to preterm infants in their families and one mother had been expecting a preterm birth as she was carrying twins. As discussed previously, one participant reported that she had felt 'embarrassed' regarding her infant's preterm status due to the small size of the infant. Similarly, Participant 5 suggested possible feelings of initial "offence", as she explained *“The only time that I was sensitive it was after birth because she was too small at the*

time and I just could not understand because I was at home eating my um... Vitamins and stuff and I could not understand why she was early, 'cause I would understand if I was drinking and stuff alcohol then the baby would be premature. But then since I was home and stuff, ya I couldn't understand why, but I don't take offence now". All participants made remarks regarding their surprise at the small size of the infants, and some participants added their surprise at the unexpected forms of their infants. Participant 8 demonstrated this as she described "...the first time she [her infant] looked like a baboon.." whilst Participant 12 described "...she [her infant] was too scary. She was like a bird or something., but she wasn't looking like a human being....I didn't know a human being is coming from so far..."

Additionally some participants reported specific beliefs about the traits of preterm infants. Participant 1 shared that in her experience, her culture holds specific beliefs about premature babies as she shared: "*They [preterm infants] are believed to be very special babies, premature in our culture, it's a huge huge thing because it's very rare, its rare so you don't really you don't really, in my community or the people I have been exposed to I didn't really know about premature babies until my sister had one*". Participant 10 shared the belief that preterm infants are "smart", and also shared her belief that preterm infants grow to be "silly" and fall ill easily. Participant 16 shared her belief that preterm infants are "hyper" and "talkative".

Information about prematurity:

a. All sources of information reported were from persons, not paper based

The participants were asked about the sources of information that they received regarding prematurity, infant caregiving, speech- and language development both during their hospital stay and afterwards at home. All of the resources discussed involved personnel, as opposed to pamphlets, posters, books and other sources. Sources of helpful information for the mothers during their infants' and their own stay at Tygerberg hospital included the nursing staff, the Speech-Language Therapists (regarding feeding), staff running the KMC wards and groups, as well as the other mothers in the wards at. Only one mother reported that she had used a book, as well as internet sites on her cell phone, to learn more about prematurity and her infant.

b. Information they did not feel confident about was washing the infant

When the participants were asked about information felt they needed after discharge, seven of the fifteen participants reported that they are not confident with washing their infants and would thus appreciate more information regarding this task. An additional seven mothers reported that they

felt they had a large amount of input and did not need additional information. One mother reported that she would like to have received information about her infant's development and developmental milestones that she can expect in the future.

Findings related to mothers' perceptions of their role and other role players in communication development

All mothers showed agreement that they are important in influencing their children's development. Three mothers reported that they perceived themselves to be the most important role-player in their child's development, with the involvement or stimulation from others playing a lesser role. Nine participants reported that they perceive other adults within the infant's environment as additional important role-players within the child's development. Participants mentioned that these other role players also "*talk*" and "*sing*" to the infant. Other role-players mentioned involved other caregivers, including a maternal grandmother, father of the child, a nanny, a maternal sibling and the infant's siblings.

Chapter 6:

DISCUSSION

The following chapter presents a discussion of the findings in relation to current literature. The findings are discussed first within relation to each sub-aim of the study, as set out in Chapter 5, followed by a summary of key points relating to the overall aim. Due to the explorative descriptive nature of the findings, an unavoidable degree of informational overlap exists within the discussion.

Although the following discussion relates the findings to the current literature, the purpose of this study is not to generalize the findings, but to explore the phenomenon of having and caring for a preterm infant within low-socio economic circumstances as experienced by a group of isiXhosa speaking mothers.

6.1. Discussion of the findings in relation to each sub-aim

6.1.1. The mothers' perceptions of prematurity

In order to describe the participants' perceptions regarding prematurity, their understanding of the term 'premature', their beliefs regarding the reason for the preterm birth, and their general beliefs and attitudes towards prematurity were considered.

Although all participants showed an understanding that 'premature birth' meant that the infant concerned was born before a full-term pregnancy (usually considered as 40 weeks) was completed or "before time", only few discussed their understanding that preterm infants are also underdeveloped. All participants, except for one, mentioned that the medically related cause or explanation for the preterm birth of their infants were provided to them by a medical doctor at Tygerberg Hospital. The participants integrated these medical explanations with their own religious and traditional beliefs to form their own understanding of their preterm birth. Even with medical explanations, three participants experienced feelings of embarrassment or disappointment, suggesting that they associated negative perceptions with prematurity. The literature suggests misconceptions regarding the cause of preterm birth and general misunderstandings of prematurity-associated risks are not uncommon. An American public survey revealed that the majority of their sample (N = 1967) held the perception that preterm birth was caused by 'risky' maternal behaviour (Massett, 2003). Furthermore, with all three participants in the current study that held initial negative perceptions or attitudes toward preterm birth, these negative associations were related to the small size of the infant, suggesting that they hold beliefs or perceptions relating a larger sized infant to health and maternal accomplishment. In contradiction, two participants held positive perceptions regarding prematurity in their shared belief that preterm infants are "smart". Although the participants shared many characteristics, e.g. home language and socio-economic status, differing beliefs about preterm infants and children were held. Therefore, this information suggests that, although participants may seem to belong to the same broadly defined 'cultural' or social group, their beliefs may differ and be influenced by many additional factors. It is important for health care professionals who work with mothers of preterm babies to explore their clients' perceptions regarding pre-term birth in an open, non-judgemental manner so that the necessary information and re-assurance can be provided, and more positive perceptions can be constructed.

Although there were differing beliefs regarding behavioural or personality traits of preterm infants, one perception shared amongst all participants was that of vulnerability. Such perceptions of vulnerabilities resonate with Allen et al.'s (2004) suggestions that parents of preterm infants often hold the perception that their preterm infant is more vulnerable (medically vulnerable) than their full-term counterparts. All participants expressed concern regarding their infants' health and wellbeing after hospital discharge. The participants were largely concerned with keeping their infant warm and were concerned about their infant falling ill. Furthermore, participants demonstrated their perceptions of their infants' vulnerability through behavioural or caregiving changes that they made due to their infants' preterm status (for example mothers were generally more cautious in leaving their infant in the care of others). Furthermore, the working mothers also shared their reluctance to return to work until the infant is older due to the perceived vulnerability and small size of their infants. This shared perception of vulnerability was however only within the domain of (physical) health. Although all mothers perceived their infants to be medically vulnerable, only six of the fifteen participants perceived their infants' developmental health to be equally vulnerable. Misunderstanding of the risks of prematurity was also evident in one participants' perception of her preterm infant being at higher risk of Autism or Down Syndrome. Similarly, a study that explored parental perceptions of risk associated with preterm birth in an American setting, found that many parents were concerned about morbidities un-related to their infants' preterm diagnoses (Fletcher et al., 2017).

These findings are suggestive of the existence of stigmas attached to prematurity and infant size within some communities, i.e. that some perceive small preterm infants to be related to poor maternal wellbeing, as well as an incomplete understanding of prematurity itself. The findings suggest that more than half the participants did not think that prematurity may affect their infants' development, suggesting poor maternal education in this regard. It is evident that although these mothers (who have experienced preterm birth themselves and are now taking care of a preterm infant) understand the concept of preterm birth being birth before full term, they are not equipped with the knowledge regarding the relationship between prematurity and development (i.e. adjusted milestones and risk of developmental delay). It can be argued that since the study included only mothers of infants between the ages of 3-6 months (or 0-3 months chronological age), that education might be performed at a later stage, however research has suggested that poor knowledge regarding developmental risks and early intervention programmes are contributors to poor patient attendance of follow-up and early intervention services (Ravarian et al., 2018). This information suggests that if mothers do not perceive their child's development to be at risk and

aren't aware of interventions available to them, less importance is placed on follow-up appointments, which may lead to non-attendance of medical and developmental follow-up appointments. Missed follow-up appointments increase the chances of missing/ late identification of developmental delays and missed maternal education opportunities. Such findings suggest a need for early maternal education regarding the risk of developmental delays, adjusted development, early intervention and the importance thereof in attending necessary follow-up appointments. Due to the pertinent need for such information and the risk of poor follow-up attendance, such intervention and information should be provided to the mother or caregiver prior to hospital discharge after the infants' birth. The road-to-health booklets provide an easy and readily-accessible platform for mothers to monitor their infants' development (literacy is not essential as pictures are used), however they are designed to include full-term infant developmental milestones. Thus, education regarding individualised developmental expectations and monitoring is necessary. This could be implemented within the patients' own road-to-health booklet for convenience, however maternal training and education is essential.

6.1.2. The mothers' perceptions and experiences of giving birth to and caring for their preterm infant

The findings of the current study reflect what seems to be universal properties of the experience of having and caring for a preterm infant. The participants' initial reactions and experiences were described to be those of fear and shock, with many mothers describing the birth circumstances as "scary" and "traumatic". The findings suggest that the mothers were often unprepared for how their infant would look as many mothers described their shock and stress relating to the small size of their infants. Furthermore, most of the participants' stress in these early stages revolved around their concerns of their infants' medical stability and whether or not they will live. Such stress regarding their infants' health was often exacerbated by the sight of the medical monitors, machines and feeding tubes, which mothers perceived to relate to illness or poor health. Such results mirror those of Steyn et al. (2017) in their explorations of the experiences of parents of preterm infants in the NICU of a private hospital in Johannesburg, South Africa. Steyn et al. (2017) found that initial experiences of preterm birth were traumatic for the parents, with parents showing high levels of stress. Furthermore Steyn et al. (2017) found that parents were unprepared for how vulnerable their infants appeared, also relating stress to the small size of the infants and overwhelming perceptions of the hospital machines. These findings emphasize the psychological impact of preterm birth on a mother, highlighting the role and need for personnel trained to assist

with such experiences (i.e. counsellors or psychologists). As nurses are those with whom the mothers have most contact, thus training within the domain of mental health would benefit both nurses and patients (e.g. identification of maternal depression or anxiety, basic counselling skills and identification of those who need to be referred for further assistance).

The mothers' experiences whilst in the hospital setting were largely stressful and negative. Such findings are echoed by Whittingham et al.'s (2014), who explored preterm parents' experiences and support preferences. The negative experiences described by participants in the current study can be related to the traumatic birthing experience followed by periods of stress about their infants' health. There were however also positive experiences within the hospital setting. Such positive experiences often came from the emotional support received by the nursing staff and other mothers in the wards. Again Steyn et al.'s (2017) study had similar results in that the relationship between the nursing staff and parents were an important factor in influencing the parents' hospital experiences. This information highlights the importance of the nurses and other hospital staff's role, and the impact thereof on patient and family wellbeing. In contrast to negative hospital experiences, most mothers in the current study showed a 'change' in their experiences upon going home. Most mothers reported that, although not without concerns, they were experiencing motherhood in a more positive light at home. Maternal support was a large influencing factor within this positive change. Those who did not receive support at home (financial support, caregiving support and/or emotional support) did not appear to undergo this 'change' from a more negative to a more positive experience. These mothers who received little childcare support at home and continued to report their experiences in a negative light appear to be at higher risk for affected maternal wellbeing (e.g. postnatal depression). If not attended to, affected maternal wellbeing and stress may impact negatively mother-infant interactions (i.e. reduced frequency and length of interactions). Reduced mother-infant interactions may hamper infant development.

6.1.3. The mothers' experienced interactions/influences between preterm birth and culturally specific beliefs and practices

As described in the previous chapter, the influence of culture on beliefs about prematurity, as well as the influence of prematurity on cultural practices, were noted in the participants' stories. Most mothers held traditionally or culturally influenced beliefs regarding the cause of the preterm birth, supporting that cultural and traditional beliefs influenced maternal perceptions and

interpretations of life events. This echoes findings from a study by Barratt & Penn (2009). These authors investigated caregiving experiences for children with cerebral palsy within a rural setting in South Africa, where the findings suggest that cultural and traditional factors impacted caregiving experiences. Within the current study, participants showed that the preterm status of their infant impacted traditional and healthcare practices. Almost all mothers in the current study had used traditional medicines with their other full-term children, family members or themselves prior to the birth of their preterm infant, however it appeared that mothers were more apprehensive to use such medicines with their new infants because of their preterm status. This finding is suggestive of maternal perceptions of infant vulnerability, but may have also been influenced by advice given by the nursing staff at the hospital warning against traditional and western medicine use with the preterm infants. Furthermore, due to likely unawareness of the cultural tradition of 'Imbeleko', the umbilical cords of most of the infants were disposed of by hospital staff instead of saved for the ceremony. This led to mothers not being able to take part in the cultural tradition of umbilical cord burial after they returned home with their babies. This finding illustrates just one consequence of health care providers' lack of knowledge or awareness regarding patients' cultural or traditional beliefs and practices, thus emphasizing the importance of such knowledge in sensitive and respectful patient care.

6.1.4. The mothers' perceptions and experiences of feeding their preterm infant

The mothers reported different experiences with different feeding methods, with the most negatively experienced method to be tube feeding. The negative experiences of tube feeding were largely related to the perception that tube feeding is suggestive of illness, whilst oral feeding signalled positive progress for most participants. This finding is similar to that of Thoyre (2001), who found that due to nurses' monitoring and concern regarding oral intake, mothers related oral intake to hospital discharge (i.e. 'healthier' infants were those receiving oral feeds and were close to discharge). Additionally, one participant in the current study shared her concerns regarding tube feeding negatively affecting later feeding abilities. These concerns and perceptions were found to add to maternal stress within the hospital environment. Such concerns and perceptions can be related to misconceptions regarding the rationale for tube feeding (e.g. underdevelopment as opposed to illness), and thus may be eased by thorough maternal education regarding tube feeding.

Most participants perceived the transition from tube- to cup feeding as positive progress and expressed positive remarks regarding cup feeding. Those participants who discussed negative

cup-feeding experiences reported that they experienced difficulties with feeding positioning as well as concerns regarding compromised nutritional intake due to spillage. The concern regarding inadequate nutritional intake was not an uncommon find in literature. For instance, a study by Reyna, Pickler and Thompson (2006) that investigated maternal feeding experiences of preterm infants after discharge, also found many reports of maternal concern regarding intake with evolving feeding methods. Once again, such concerns may be mediated by maternal education, specifically related to the monitoring and calculation behind oral intake and spillage.

Regarding feeding methods after discharge, it was largely found that mothers were using mixed feeding methods. The most frequently occurring feeding combinations were those of breast- and bottle-feeding (breast milk with supplementary formula), as some mothers experienced poor breast milk production and some mothers were returning to work and had to leave their infants in the care of others. Although the general maternal reports suggested that the mothers did not experience feeding difficulties at home, many participants mentioned incidences of infant reflux or regurgitation. The participants however didn't perceive this to be a 'negative' feeding experience. The only reoccurring concern that was found in relation to feeding after discharge were those regarding their abilities to keep to the 2-3 hourly feeding schedules. The previously mentioned study by Reyna et al. (2006) also found themes of maternal concerns regarding adhering to the feeding schedules. After discharge only one third of the mothers were exclusively breastfeeding whilst those other mothers due to return to work in the time period shortly after the interviews, reported that they would then use formula feeding supplement to breast feeding whilst their infants were in the care of others. These findings were similar to those of Czechowski and Fujinaga's (2010) study of the prevalence of breastfeeding of preterm infants within the first six months in Brazil, where the researchers found that the breastfeeding prevalence was well below that suggested by the World Health Organization (WHO). The WHO advocates for exclusive breastfeeding for the first six months of life whenever possible. Breastfeeding is known to have many benefits, including positive influences on mother-infant attachment, being an excellent source immunological and nutritive properties and it comes with no financial cost (Czechowski & Fujinaga, 2010). However, negative breastfeeding experiences (such as with those mothers experiencing difficulty with milk production, a common find with prematurity) may have negative impacts on mother-infant bonding (Pascoe, Bissessur, Mayers, 2016). The area and experience of infant feeding is thus important in child and maternal health, and one in which should be followed-up after hospital discharge.

6.1.5. The mothers' perceptions and experiences of communication with their infant

Although prompted for, participants did not provide much discussion regarding communication with their infants. This is likely due to the young age of the participants' infants, as the infants ranged between term/zero to three months corrected age. During this age, infant communications are mostly subtle and difficult to recognize or classify as overt 'communications'. Maternal reports of infant interactions consisted of smiling, cooing and their infants' response to the recognition of their (the participants') voices. Although mothers showed understanding of infant crying being related to discomfort (hunger, wet nappies etc.), the mothers did not appear to perceive crying as a form of infant communication but rather a result or reaction to such discomfort. When maternal communication with the infant was explored, most mothers briefly reported that they talked or sang to their infant. These commonly shared interactions were also reported in a study conducted by Pascoe et al. (2016) which looked at mother experiences of communication with their preterm infants. Overall, it appeared that the participants experienced positive interactions with their infants and communicated verbally and non-verbally with their infants naturally without purposeful thought of developmental stimulation at this young age. Although mothers naturally communicated with their infants, communication did not appear to be a caregiving focus at this stage, but rather mothers focussed on feeding and infant health. Again Pascoe et al. (2016) similarly found that maternal interactions and communication were not the focus of initial caregiving, but increased with infant age and responsiveness.

6.1.6. The mothers' perceptions of their role in their child's caregiving and early communication development

All mothers reported interacting with their infants, mostly through speaking and singing. Additionally, all mothers agreed that they themselves are important influencers in their infant's development. These findings were echoed within Pascoe et al. (2016) previously mentioned study. Although participants described their verbal interactions with their infants, talking and singing with them, yet they scarcely discussed their understandings of how they can influence communication development. This suggests that the participants are aware of their abilities to influence child development, yet they do this in an intuitive and spontaneous manner, and perhaps without realising how their behaviours impact on child development.

6.1.7. The mothers' perceptions of other important role-players in their child's caregiving and early communication development

The mothers perceived other important developmental role-players to be those who were frequently within the child's immediate environment, such as the father of the infant, the grandparents of the infant residing in the same home and caregivers assisting with daily childcare. Perceptions of role-players largely consisting of caregivers illustrate an understanding that interactions (verbal and physical) contribute to developmental stimulation. This finding demonstrates the mothers' innate understanding or recognition of the importance of interaction and stimulation in infant and child development.

6.1.8. Information that the mothers of feel they need after hospital discharge and within the infants' first year of life

The participants reported one reoccurring topic on which they felt they needed more information on – washing their infant safely. In-hospital cleaning of preterm infants often consists of gentle wiping with water-soaked cotton wool, whereas full term infants are often bathed in a shallow collection of water. Although some mothers mentioned receiving some input in this regard, most felt unequipped with the knowledge of when and how to do. These concerns reflect a focus on the child's physical and medical wellbeing within the first few months of life, which was present throughout the data. At hospital discharge however, the infants are usually still small in size although medically stable (for example between 2-3kilograms), thus it is understandably stressful to care for a small and vulnerable infant in conditions very different to a medically 'safer' hospital setting. Additionally, as the mothers did not feel they needed information about infant development, this suggests that the mothers were not yet prepared to receive such information.

6.2. Discussion of additional findings:

Section 6.2. below reflects on those findings that do not fall within a specific sub-aim.

6.2.1. The influence of religion

The influence of religion was seen to affect participants' perceptions over many domains. Religious views were evident within maternal beliefs about and understanding of their preterm birthing (and thus to the meaning they made of this experience), as well as proving to be a large

source of emotional support throughout the experience. Such findings of mothers of preterm infants relying on religion as a form of reasoning and support were also found by Arzani et al.'s (2015) research. Major positive elements of the participants' hospital stay with their infants are thus the prayer facilities and religious groups meetings that were readily available, enabling participation in the form of religious support.

6.2.2. The influence of socio-economic related factors

Socio-economic related factors such as housing structure (warmth) and financial support were noted to influence mothers' behaviours (e.g. having to return to work to earn an income) and contribute to maternal stress, as some mothers worried that their homes may not be warm enough for their infants. Although this influence of socio-economic related factors was evident they were not highlighted by the participants. It was expected that, when prompted regarding factors that make caregiving more difficult, participants would highlight those related to low socio-economic circumstances due to the perceived hardships endured those living in low-SES circumstances, however this was not the case. This may have been influenced by the medical context of the study, however in Barratt and Penn's (2009) previously mentioned study, the authors also found that poverty-related hardships were not highlighted as had been expected. In consideration of the participants' socio-economic background, this unexpected 'lack of complaint' of socio-economically related factors could be due to an 'accustomation' to poverty and its consequences. It could be that the participants do not consider these as factors that are contributing to the difficulty of the experience, a dismal thought.

6.3. Summary:

Overall, mothers described what can be thought of as 'universal', as well as culturally-specific experiences of having and caring for a preterm infant. Universally shared experiences were those of traumatic birthing experiences, coupled with unpreparedness for the initial vulnerabilities of the preterm infant, stressful hospital stays exacerbated by medical machinery, tubes and monitors and negative experiences with tube feeding. Although hospital stays were stressful, mothers shared the benefits of the available support systems including the hospital staff, KMC and educational groups and support from other mothers whom were in similar situations. Religion too was a strong influence regarding support and making sense of maternal circumstances. Culture was an additional influence in the mother's reasoning and beliefs about the cause of their preterm

birth experience. Furthermore, cultural traditions (i.e. Imbeleko and traditional medicinal use) were notably affected by the preterm status of the infant. These instances highlight the important interaction between culture and healthcare that may influence patient care and wellbeing, as well as the remarkable effect of culturally incongruent healthcare has on the experiences of patients. Given the great linguistic and cultural diversity of South Africa, as well as the relative lack of diversity among members of some health professions, it is crucial to quality health care that health care professionals learn about the cultures and practices of their clients. This can best be done through many different mediums, such as research or active immersion or knowledge-seeking from members of the patient communities.

Furthermore, a strong theme throughout all areas was that of the maternal perceptions of child vulnerability. Parental perceptions of child vulnerability (PPCV) appears to, in this circumstance, be limited to the infants' medical health. Within the domain of communication and development, the scarcity of mention of developmental sequelae in the data could suggest a seeming lack of concern, or rather awareness, about the developmental risks involved with prematurity at the time of the interviews. As previously discussed, this finding is likely due to the lack of education of mothers concerning the risks of delayed development in preterm children and the strong focus of medical health in infant wellbeing. However, this finding may be impacted by the young ages of the participants' infants. Although most mothers did not think that prematurity may affect childhood development, their caregiving concerns and maternal behaviours indicated they perceived their infants to be medically vulnerable. Parents' perceptions of their preterm infants being medically vulnerable even after hospital discharge is a common theme throughout the research literature (Esteroff et al., 1994; Perrin, West & Culley, 1989, Allen et al., 2004). The findings of Allen et al. (2004), who investigated parents of preterm infants' perceptions of vulnerability, found that maternal perceptions of vulnerability affected maternal perceptions of child development, for example mothers who held perceptions of their preterm infant being vulnerable felt that their infants were developing slowly. Furthermore, PPCV was also related to higher rates of maternal anxiety. Allen et al. (2004) also found that due to PPCV mothers of preterm infants were more reluctant to leave their child in the care of others, as was evident in the current study. Thus, these findings suggest mothers of preterm infants are at higher risk for both PPCV and maternal anxiety. It is therefore important that healthcare professionals working with mothers within this population are made aware of and trained to recognise PPCV and maternal anxiety, as well as how best to address such experiences and when referrals to more qualified individuals are necessary.

A summary of the factors that were commonly found to have influenced the participants' experiences of having and caring for their preterm infants can be found in Table 5 and Table 6 below. The information is formatted to fit within the pre-described systems of Bronfenbrenner's transactional model applied to childhood development. Within each 'system' of the model there exist those factors that form protective factors (i.e. supporting childhood development), and those that pose as risk factors to development. Thus, the following tables represent a) the summarised protective factors, and b) the summarised risk factors.

Table 5: Summary of emergent protective factors to maternal wellbeing and thus infant development

Protective factors for maternal wellbeing in a vulnerable population in South Africa
1. Microsystem: <i>Mother herself</i>
<ul style="list-style-type: none"> • Majority of participants experienced a change from more negative to positive experiences after going home with their infants. • Religious beliefs and practices provided most mothers with a source of support in coping and rationalising their preterm birth experiences. • Witnessing their (the mothers') infants' progress and developments throughout and beyond their hospital stays showed to improve mothers' spirits, contributing to the aforementioned 'change' from a negative to positive experience.
2. Mesosystem: <i>Context of mother and child</i>
<ul style="list-style-type: none"> • Hospital context: <ul style="list-style-type: none"> ○ KMC and educational groups provided caregiving information, experience and support to the mothers. ○ The nursing staff at the hospital proved to be a large source of emotional, caregiving and educational support for the mothers in the hospital, often easing maternal concerns. ○ Other mothers in the same hospital wards and groups were found to be a large source of emotional and informational support. • Home: <ul style="list-style-type: none"> ○ Caregiving support (with the infant and household chores), largely provided by close family members such as mothers (often the infants' maternal grandmother) was a large positive factor in easing maternal stress. ○ Emotional support from family, friends and community members proved a large influence in maternal coping in general. ○ Financial support from family members and partners assisted in easing some caregiving stresses. ○ Informational support from family, friends and community members assisted in easing caregiving concerns.
3. Exosystem: <i>Community</i>
<ul style="list-style-type: none"> • Community members assisted with caregiving and caregiving advice.

4. Macrosystem: <i>Economic context and governmental policies</i>
<ul style="list-style-type: none"> • Receiving child grants: Although only discussed by three participants, the grant was sought to provide financial assistance. • Maternity leave: All working mothers in the study received maternity leave that allowed them to be with their infants for their first four months of life. This allowed opportunity for all above-mentioned protective factors to impact maternal wellbeing, such as learning about childcare and receiving support from hospital staff and other mothers.

Table 6: Summary of emergent risk factors to maternal wellbeing and thus infant development

Risk factors for maternal wellbeing in a vulnerable population in South Africa
1. Microsystem: <i>Internal maternal perceptions and experiences</i>
<ul style="list-style-type: none"> • Threats to maternal health during pregnancy and the preterm birth process are known to increase maternal stress. • Negative experiences in the hospital: <ul style="list-style-type: none"> ○ Machines surrounding the infants in the hospital were generally perceived as suggesting illness (unwell infants), contributing to maternal stress. ○ Tube feeding was perceived as suggesting illness (unwell infants) and described as a negative experience. ○ Hearing about the passing away of other infants contributed to maternal concerns and stress. • Concerns regarding maternal duties within the home environment: <ul style="list-style-type: none"> ○ Concerns regarding feeding their infants regularly within the prescribed schedules, specifically during the night. ○ Concerns about washing their infant safely and appropriately.
2. Mesosystem: <i>Context of mother and child</i>
<ul style="list-style-type: none"> • Context (familial and physical) of their home: <ul style="list-style-type: none"> ○ Mothers showed concerns of having “cold” homes ○ Lack of caregiving and emotional support at home appeared to negatively affect maternal stress and caregiving experiences. • Hospital context: <ul style="list-style-type: none"> ○ It was apparent that not all mothers received the same information against traditional medicinal intake within the infants’ first six months of life. ○ Hospitals were associated with periods of high maternal stress.
3. Exosystem: <i>Community</i>
<ul style="list-style-type: none"> • Some mothers felt pressure from family and community members to carry out maternal duties in a certain way, for example in seeking traditional healthcare. • Maternal reluctance to leave their infants in the care of others, thus possibly limiting sources of caregiving support that was otherwise seen as assisting with maternal coping. • Affected participation in traditional practices: <ul style="list-style-type: none"> ○ Not participating in Imbekelo: Non-participation in a traditional ceremony could interfere with community interaction, again possibly affecting community support. ○ Reluctance to travel with the infant for other sources of support (e.g. grandparents in another province), as mentioned previously may be limiting caregiving support.

4. Macrosystem: *Economic context and governmental policies*

- Financial difficulty:
 - Although not highlighted, financial difficulties were mentioned in affecting the amount of times mothers or family members could visit at the hospital, in mentions of cold homes and in some mothers having to return to work with their infants only being around one month corrected age.

An overview of the protective and risk factors mentioned above suggests that a large portion of the ‘protective factors’ stemmed from, and were influenced by, the involvement of hospital staff, including nurses and other healthcare practitioners (such as SLP’s). Recognition of such achievements by the hospital staff is due in this regard. Furthermore, it is evident that a portion of the ‘risk factors’ at the microsystem and mesosystem levels may be mediated by informed actions of healthcare personnel during the mother and infants’ hospital stay. Hospital staff members can utilise existing effective points of interaction (e.g. in the ward or bedside, in KMC and in informational groups) to address those negative experiences and emotions through education and counselling. Such suggestions will be further discussed in the following conclusionary chapter.

Chapter 7:

CONCLUSION

7.1. Summary

The current study aimed to explore those maternal experiences of having-, caring for- and feeding a preterm infant within a vulnerable population. More specifically, this experience pertained to the mothers' experiences in the hospital and a short time at home within the infants' first few months of life. The research provided valuable insight into such maternal experiences, including influential factors serving as stressors or positive influences. The findings of the research may be useful in guiding or prompting future research as well as providing evidence for clinical implications.

Preterm delivery is considered to be a significant, and rising, concern in the domain of maternal and child health (Beck et al., 2010). Preterm infants constitute a large portion of NICU and therapeutic caseloads due to their medical and developmental vulnerability. Current models for both NICU care and early childhood intervention emphasize the involvement of the mother or primary caregiver (Craig et al., 2015). In order to do so, practitioners should have an understanding of the daily living experiences of these mothers. Thus, knowledge generation in these areas are essential in providing information necessary for evidence-based practice. In overview, the findings highlighted the universality of the shared experiences of having and caring for a preterm infant, as well as population-specific influences affecting such experiences. Whilst there were many shared experiences, the diversity of each experience emphasises holistic and unique approaches to every individual case. Furthermore, the current study has provided insight into the stress that mother's face having and caring for a preterm infant, placing mothers at risk for maternal anxiety and high rates of PCV. These findings stress the significance of the roles of hospital staff and support systems both in hospital and at home. Additionally, the findings highlight population-specific factors at many influential levels affecting such maternal experiences (both positively and negatively). This information can be used to structure relevant and effective interventions where necessary. Lastly, those findings pertaining to the interactions between prematurity, healthcare professionals and traditional practices can be seen as highly valuable in the search for information to assist in building a more culturally competent healthcare system. This is a trending aim for healthcare systems around the world, and particularly important in a diverse South African setting.

7.2. Limitations

Methodology:

- There were six instances where the researcher could not attend the participants' medical follow-up appointment. Although measures were taken to mediate this logistical difficulty (where a discussion was held with the pediatrician regarding relevant information potentially missed in the medical appointment), this remains a methodological inconsistency. Information that may have resurfaced in both the medical appointment and interview could have been missed if not mentioned by the pediatrician in discussion, for example education about corrected development.
- As an 'outsider' of the sample population in both culture and language, this may have acted as a barrier for the participants, influencing the nature of the information shared. Additionally, due to most participants speaking a different language to that of the researcher, the researcher may have missed information that might otherwise have been expanded on or further explored. Although an interpreter and cultural broker was employed to bridge such limitations, there is still a chance that some information may have been lost in the interpretation process.

Generalization:

- Due to the relatively small scope of the study (smaller sample size and a specified population), the results cannot be generalized to all isi-Xhosa-speaking mothers of preterm infants residing in urban areas and within low socio-economic conditions. However, due to the growing realization of the importance of research in the areas of mother- and infant health in different cultural and social settings, the findings of the study is felt to be important for healthcare professionals working in the South African context, especially to neonatal nurses, doctors and SLPs. Furthermore, the findings of the current study may imply clinical implications within the research site and other sites with a similar patient population.

7.3. Recommendations for future research

The findings suggest opportunities for future exploration of the phenomenon explored. A thorough description of the methodology allows for replication of the study with differing

variables. It would be interesting for research in this domain to take place at later stages in the child's life, such as one year after the infant's birth and so on. Research with older infants may focus more on the area of communication and general infant/child development. Later comparisons between such studies would provide insight into the evolution of maternal experiences and influential factors, as well as exploring when mothers feel prepared for- and/or curious about such developmental information. Furthermore, due to the traditional insights, similar studies with those from different cultural backgrounds may assist in knowledge generation for supporting the education of healthcare practitioners towards culturally competent services.

7.4. Clinical implications of findings

In reiteration, the findings highlight that there are many factors affecting a mother's experience of having, caring for and feeding a preterm infant, both universally shared and population-specific. Such factors discussed may have a large impact on maternal wellbeing, and thus infant wellbeing and development, including the stress evoked by foreign medical equipment, difficulties with feeding, possible lack of maternal support in the home environment and specific cultural traditions that parents wish to (safely) partake in. It is important for healthcare practitioners working with these mothers to have access to such knowledge in order to provide appropriate and respectful education and understanding regarding traditional healthcare beliefs and practices. Continued in-service training opportunities with NICU staff working with the described population can be used to convey this pertinent information. As having and caring for a preterm infant is particularly stressful for mothers, NICU and other hospital staff working with these mothers should be trained in basic mental health screening and/or identifying those mothers particularly vulnerable to maternal anxiety and depression. Additionally, it would be useful for a referral system to be set up for qualified mental health staff (e.g. counselors and psychologists) to assist mothers in such high-stress situations. Furthermore, a simple and cost-effective manner of identifying those mothers in need of social and psychological assistance may be incorporated in those high-risk follow-up appointments/clinics. These clinicians should be aware of such maternal stress and stressors in order to screen for maternal wellbeing within the infants' medical follow-up appointment.

Additionally, the educational role of the clinicians and hospital staff should include that of infant and child development as affected by prematurity. It was evident that mothers did not have clear knowledge regarding the effects of prematurity on development and corrected developmental milestones. Although these infants were still young (three to six months chronological age), awareness of such developmental delays is important at all stages of development. It is widely known that many mothers and infants are lost to follow-up appointments for many reasons, thus if not provided at an early stage, mothers may miss this information entirely. Unawareness of such risk may result in late recognition of difficulties. Early detection and intervention of developmental delays is key in reducing the effects on quality of life in other areas (e.g. early intervention for language delays to minimize the effect on school performance). This was identified as a knowledge gap that could be addressed by the SLP or other hospital staff (such as nurses, Occupational Therapists and Physiotherapists), in a delicate manner so not to induce more maternal stress and potentially affect mother-infant bonding and interaction in negative ways. Similarly, the SLP should engage in staff-education about preterm development so to ‘train’ those nurses who are with the mothers for the majority of the time spent in hospital. It was evident in the findings that during the mothers’ lengthy stays in hospital, informational support was sought and appreciated. Similarly, the negative maternal tube-feeding experiences may be mitigated by involvement of the SLP in the NICU with tube feeding. The SLP would thus have an opportunity to educate the mother and other hospital staff in the NICU about tube feeding, address any related concerns and involve the mothers where appropriate (something that is strongly encouraged in NICU’s worldwide (Graig et al., 2015)). This may assist in reducing the stress/negativity of the tube feeding experience.

Furthermore, it is increasingly evident that healthcare providers are often unaware of their patients’ cultural beliefs, practices and traditions that could be negatively impacted throughout the course of intervention (such as the importance of preserving an umbilical cord and the consideration of practices and beliefs surrounding traditional medicines). Thus, the findings of the current study and other similar research can help illuminate important patient perceptions, which can have a dramatic impact on the quality of services delivered. Educational training regarding the importance of the umbilical cord and other infant-related traditions should be conducted with staff members working with newborn infants in order to avoid clashes between traditional beliefs and practices and modern healthcare. Such information can assist in providing healthcare providers with the information needed to improve the cultural competency of the healthcare system, as stressed in a large amount of recent literature (Govender et al., 2017). Such

information will be beneficial to both acute care settings as well as early childhood intervention programs.

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APPENDIX A: EPOCHE

According to Harry (1996, p. 292), “in qualitative research, the researcher is seen as the research ‘instrument’; hence, self-awareness and explicit examination of the researcher role are crucial”. There are often tensions between the identities of the ‘researcher as a person’ and ‘researcher as interviewer or collector’, as one must separate the roles carefully. Thus the researcher as a person and as the instrument also has an unintended effect on the outcome of the research. It is here that Harry (1996) emphasises the importance of self-awareness, especially in circumstances, such as this study, where there is an expected power differential between the researcher and the participant. Unfortunately in the setting of this research the power differential is stressed by the stigmatised status of the participant group.

Harry (1996) suggests that one’s research acts, purposes and decisions are influenced by our own personal belief systems constructed by our ‘identities’, and in the article discusses the unpacking of these identities as an important step in qualitative research. According to Creswell (1998), this is the step by which the researcher engages with the philosophical assumptions of phenomenology, recognising that to each, one’s experience of their own objective reality is shaped by their individual experiences. Creswell (1998) names this process ‘bracketing’, whereby one reflects on their own personal views and biases that could affect the research, and aims to bring an awareness to this in order to limit their effect on the research. Harry (1996) however suggests that the researcher must rather not eliminate the effects of personal identities or personas, but rather document them. I will therefore attempt to reflect and explore my own identities and ethnicity that form my viewpoints and biases. These viewpoints and biases will be documented in this epoche.

The Merriam-Webster definition of an epoche is “the methodological attitude of phenomenology in which one refrains from judging whether anything exists or can exist as the first step in the phenomenological recognition, comprehension, and description of sense appearances: transcendental reduction”. Thus to suspend my own judgement, I must analyse and bracket my own views and biases that could have a negative effect on the research process (data collection and analysis). This will allow me to engage with the research participants and the data as warmly but in an objective manner so not to affect the data collected.

As my study looks at various aspects of a population, so shall I explore those in relation to myself. I will explore my 'identities' as discussed by Harry (1996) formed as macrocultures and microcultures. As "Culture provides the backdrop against which the individual researcher will act" (Harry, 1996, p. 295), this is an enormously complex phenomenon, and one that I find myself increasingly aware of, especially when it comes to the current research study where I will have to intimately engage in interviews with participants of a different culture to my own. I thus explore my own 'cultures' as follows.

(Note: Written before data collection)

Researcher as a South African: "Born Free"

My nationality stands as South African, but being a "South African" means very different things to many different people. Being a South African, to me, essentially means being part of diversity. I could go on about the 12 official languages and range of unique cultures, but I experience diversity in many ways every day. In both my schooling class and university classes there were individuals from many different backgrounds, not one the same. People grew up in different places, lived in different provinces and even countries, spoke different languages, had different skin tones, spoke in different accents and valued different things. This to me was being South African, not experiencing two of the same people.

I myself belong to a group of English-speaking white South Africans and grew up in a Christian middle-class home. My parents were unmarried and very young when I was born. I could only imagine the trials they faced becoming who they are. As a result, I like to believe I was largely raised by my maternal grandmother, influenced by her more conservative Christian values. As a white South African I experience difficulty reflecting on this 'identity', as it is the first identity noticed by a stranger, and in my own experience, it comes with its own stigma. Harry (1996) acknowledges that one of the most stigmatising stereotypes reflect historical racial prejudices. It is without ignorance that one has to acknowledge the impact that unjust past racial clashes have had on the non-white communities, and as a white South African in today's aptly named 'rainbow nation', one is faced daily with the guilt of the actions of one's ancestors. I was born in 1995, so-named the 'born free' era, the first generation to be born out of apartheid. As a white 'born free' woman I cannot pretend to know any different as my life, and that of my parents and grandparents, was not limited by the unjust distributions of social and economic entities before 1994. As a young child I had friends of different race, unbeknown to the milestone that it

represented – the first generation where we (different races) were allowed to play together. To me as a young child, I didn't know any better, and ignorantly, nor did I even notice the difference at that stage. I regret that I only first became aware of the South Africa's jaded past at the age of 10. My family had never mentioned apartheid or drawn any attention to racial differences at home. At school a classmate who was of colour mentioned that they could no longer be a friend as her father had warned her that white people were 'bad people' in his eyes. I went home with many questions and then learned about South Africa's past. Those history lessons led to a painful awareness of the impact of the apartheid era on non-white communities, and I selfishly admit that now we are also a generation dealing with the 'backlash' thereof. The history changes the way that I myself am seen in the eyes of the previously oppressed. More so, it changes the way I see those older than 24 years, to have lived through such painful circumstances, spurring feelings of guilt. Unfortunately, this awareness also changes the interactions between individuals of different race, a phenomenon that must be approached with great sensitivity.

In addition to being a white South African, I am largely part of the 'Western' culture. This brings with it another stigma as the 'westernisation' of this African country is also apparent in every day experiences. I am aware of the large differences in cultural values of other traditional African cultures, for example, my culture values individuality and independence whereas other cultures in southern Africa favour a collective, community approach. In my own community independence, such as living and providing for one's self, is celebrated. I would even go as far as to say that some instances of reliance on others is almost 'shamed'. However I have noticed that in other African cultures there appears to be a strong sense of community reliance and co-dependence. As working in health-care facilities is part of my daily South African experience, I see the clash between the western method of health-care provision and the stark need for informed care for those patients with different cultural backgrounds. For practitioners and researchers alike, the cultural gaps are often perceived as barriers. My attitude towards this is that one cannot be ignorant of the cultural differences, but must recognize and account for these differences in an appropriate manner in order to accommodate patients, clients or participants to the best of one's ability.

Because of the differences in race and culture discussed, I feel that I will be seen as an 'outsider', someone who does not share any background with the participants. I do however feel comfortable working with my chosen population as in my studies I have worked with the chosen population (for the study) for four years. I have also been taught and made aware of cultural sensitivity both

as part of my undergraduate degree and as part of my upbringing. After I became aware of South Africa's history my grandmother instilled in me empathy, awareness and open curiosity of racial and cultural differences. I thus feel that I have grown up with a diverse group of people and attempted to learn more about different cultures, and despite my naivety, don't feel intimidated by the seemingly large background differences between myself and the participants.

Researcher as Young Woman

As a young woman from a western backdrop, I have noticed that there has been recent change worldwide that is allowing women to do work and develop in areas that were previously restricted to them. In brief mention of such a complex topic, the world today is still fighting gender roles and stereotypes, but in a nation with so much diversity, gender roles mean different things in different cultures.

Something I will share with these women is gender. In the words of Harry (1996) shared gender could "afford the possibility of greater intimacy and reciprocity". In being a woman, there are many unique feelings and experiences that we can all share, however one cannot ignore the different gender roles associated with being a woman. Within my cultural background, gender roles are evolving, there is less pressure on women to fulfil the role as 'mother' and 'housemaker', and more encouragement to explore career role options. I was raised free of gender role enforcement, allowing me to choose my own path for myself. Because of my young age and limited life experience I would describe my 'young woman' identity as being an independent, working woman who is trying to establish herself academically. My 'identities' and roles will however change with age and life experiences, for example I feel strong maternal connections and know that I will want to fulfil the role of a mother and caretaker in the future. From my experience of diversity, some cultures appear to have clear expectations of a woman rather than flexible ones, for example a woman as the child-bearer, mother, caretaker and one who takes care of the household; and some of these roles may discourage individualism and independence.

Unfortunately my young age will likely make this gender-role gap larger. I am still a young women in my early 20's, usually an age period marked with labels such as 'ignorance', 'naivety', and 'inexperience'. Another obstacle that I will have to face throughout this research, and perhaps one of the largest, is that I am not a mother. I must thus accept that I cannot possibly fully understand the full emotion and intensity of the experience that I am exploring. However, even though my gender role, age, and lack of motherly experience may appear to set me far apart

from the participants, I find my characteristics to be empathetic and maternal in constitution. I have always felt drawn to infants and have been fortunate enough to have always had infants in my life. My youngest sibling is 16 years younger than myself, with seven of my cousins aging from a few months to 8 years old. I have therefore been able to experience infancy very closely, and thus on some level I may be able to reciprocate with participants' sharing of information. The mention of a shared experience or knowledge can be advantageous in helping set participants at ease and possibly encourage the sharing of information. Although I admit to being young and naive and still having a lot to learn, I do have some experience with the area of prematurity as well. I grew up in a household with my aunt and uncle who were in junior school when I was born. Both of them were born prematurely (28 and 32 weeks). Learning about their experiences as children and watching them experience later life with complications of premature birth formed a special interest in the area for myself. I have also had the opportunity to work with young infants who were premature and talk with mothers of premature infants during my undergraduate studies.

My identity as a "Young Woman" may therefore be stereotyped or perceived in different ways by others. I must therefore prepare myself to be seen as an 'outsider' to the mothering community.

Researcher as Student

My third 'identity' is that of a student. I am a new graduate in my field and am currently furthering my studies. To other professionals, education might make me an 'insider', although my novice status, young age and little experience might limit this, therefore maybe influencing research decision making. However those who aren't professionals might see the 'researcher as student' in a very different light.

My status as an educated researcher might lead to perceptions of intimidation for those who do not have tertiary or secondary educations. This educational status risks a power divide forming between the participant and the researcher, bringing in possible ethical dilemmas, for example, will the participants feel pressured into participating despite best efforts at informed consent? Educational status often carries with it an assumed social class status. The way one presents themselves may lead to different perceptions. An apparent social class divide, especially in a country with a jaded divisional history, can be harmful to the nature of interactions amongst those of different social classes.

My own culture, social class, religion, education, gender and age have constructed my ‘identities’. These various ‘identities’ interact to construct the way I make decisions. Within this self-awareness exercise I have become more aware of how I may present to my participants, and how my own experience may affect the research decisions that I have made and will make in the future. It has also allowed me to think of the sensitive nature certain topics should be cautiously approached, and that I must without doubt acknowledge my own inexperience and naivety when it comes to the research process itself, as well as the research topic and participants. I must thus make a conscious effort to continue to be aware of this and allow for multiple views to contribute to important decisions.

My exploration of other cultures

After data collection – amidst data immersion

After I completed my data collection in 2018, I started working in January 2020. With this I moved to a small farming town and started working at a healthcare clinic servicing the rural areas in the KZN province. Surrounded by a Zulu-speaking culture I decided I needed to learn more about the culture. I visited a traditional Zulu ‘kraal’, learned a little about their everyday life, their values and aspirations, and their traditions. With this came their beliefs related to traditional healers and clashes with western medicine. This experience was invaluable in allowing first-hand insight into being immersed into what felt like a different world. In spending a day in this ‘other world’, I reflected on the value of this cultural immersion into the insight into the data I had collected. This experience provided me the insight into the ‘western world’ from the perspective of an African culture. The Zulu people with whom I spent the day were proud of the way they lived and preferred to not be influenced by western influences, such as conventional jobs and supermarket food. The Zulu individuals with whom I spoke acknowledged the threat of disease and the need and place for westernised medicine but maintained that their traditional healers are still very much part of their ‘healthcare regimen’.

Furthermore, the insight into their everyday living allowed a different perspective of their priorities and how they differed from my own. These experiences enabled deeper insight and understanding into the information provided by my participants. I know that the Xhosa and Zulu-speaking cultures are very different, however such insight, appreciation and almost ‘understanding’ could be transferred.

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APPENDIX B: PARTICIPANT DEMOGRAPHICS

	A	B	C	D	E	F	G	H	I	J
	Participant	Participants' Age	Other children (excl infant)	Infants' age at interview	Gestational age	Corrected age at interview	Residential area	Occupation	Marital status	Home environment
1										
2	Participant 1	22 NA		4 months	26 weeks	3 weeks	Bracknell		Single	
3	Participant 2	34 NA		3 1/2 months	29 weeks	1.5 months	Khayelitsha		Single	
4	Participant 3									
5	Participant 4	26 9 years old		5 months	28-29 weeks	3 months	Mfuleni		Single	
6	Participant 5	24 NA		5 months	33 weeks	3 months	Delft		Single	
7	Participant 6	26 10 years old		5 months	31 weeks	3 months	Bloekombos		Single	
8	Participant 7	29 NA		2 months	29 weeks	term	Goodwood		Single	
9	Participant 8	35 NA		6 months	5 months* (?)	2 months	Khayelitsha		Single	
10	Participant 9	36 4 years (2 deceased)		2 months	28 weeks	term	Khayelitsha		Single	
11	Participant 10	24 NA (1 deceased)		3 months	27-28 weeks	term	Strand		Single	
12	Participant 11	36 2 (14 years, 10 years)		3 months	29 weeks	term	Kraaifontein		Single	
13	Participant 12	26 NA		5/6 months	between 28-31	3 months	Strand		Single	
14	Participant 13	24 NA		5 months	32 weeks	3 months	Khayelitsha		Single	
15	Participant 14	26 1 (5 years) (2 deceased)		6 months	27 weeks	3 months	Strand		Single	
16	Participant 15	35 2 (14 years, 9 years -living with		4 months	32 weeks	2 months	Stellenbosch		Married	
17	Participant 16	30 2 (7 years, 4 years)		3 months	31 weeks	1 month	Khayelitsha		Single	
18										
19	Range	22 - 36	0 - 3 children	3-6 months	26-33 weeks	term-3 months	9 communities	4 working		
20										

APPENDIX C: DISCUSSION SCHEDULE

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

APPENDIX D: HREC APPROVAL LETTER



Health Research Ethics Committee (HREC)

Approval Notice

New Application

15/06/2018

Project ID :6707

HREC Reference #: S18/04/068

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

Dear Ms Kristen Buys,

The **New Application** received on 05/06/2018 12:45 was reviewed by members of **Health Research Ethics Committee 2 (HREC2)** via **expedited** review procedures on 15/06/2018 and was approved.

Please note the following information about your approved research protocol:

Protocol Approval Period: **This project has approval for 12 months from the date of this letter.**

Please remember to use your **Project ID [6707]** on any documents or correspondence with the HREC concerning your research protocol.

Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review

Please note you can submit your progress report through the online ethics application process, available at: Links Application Form Direct Link and the application should be submitted to the HREC before the year has expired. Please see [Forms and Instructions](#) on our HREC website (www.sun.ac.za/healthresearchethics) for guidance on how to submit a progress report.

The HREC will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility, permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Please consult the Western Cape Government website for access to the online Health Research Approval Process, see: <https://www.westerncape.gov.za/general-publication/health-research-approval-process>. Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.

For standard HREC forms and instructions, please visit: [Forms and Instructions](#) on our HREC website <https://applyethics.sun.ac.za/ProjectView/Index/6707>

If you have any questions or need further assistance, please contact the HREC office at 021 938 9677.

Yours sincerely,

Francis Masiye ,

HREC Coordinator,

Health Research Ethics Committee 2 (HREC2).

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 E: NHRD (TYGERBERG HOSPITAL) APPROVAL LETTER



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).

A handwritten signature in black ink, appearing to read 'GG Marinus', written over a horizontal line.

DR GG MARINUS
MANAGER: MEDICAL SERVICES

A handwritten signature in black ink, appearing to read 'D Erasmus', written over a horizontal line.

DR D ERASMUS
CHIEF EXECUTIVE OFFICER

Date: 13 July 2018

Administration Building, Francie van Zijl Avenue, Parow, 7500
tel: +27 21 938-6267 fax: +27 21 938-4890

Private Bag X3, Tygerberg, 7505
www.capegateway.gov.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 DB Erasmus

TITLE CEO

DATE 13 July 2018

APPENDIX F: EXAMPLE OF A PARTICIPANT SUMMARY

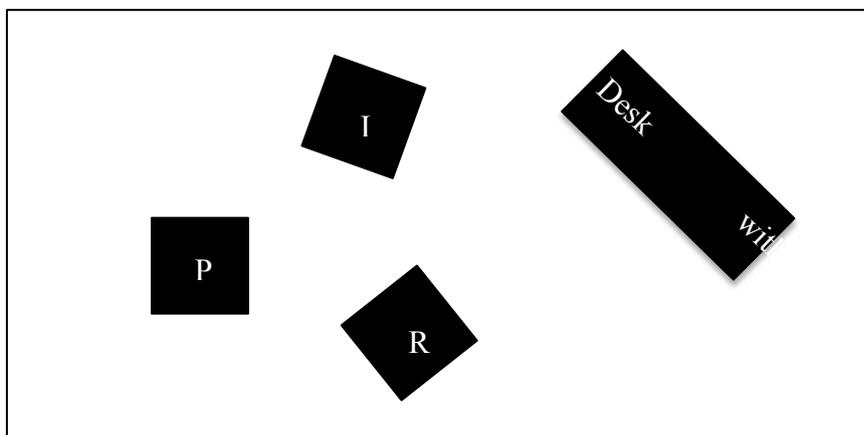
Interview 4

■ August 2018

The interview took place on the ■ of August 2018 in a quiet consultation room (room ■) in the paediatric out-patient wing of Tygerberg Hospital, near the room of the follow-up clinic. The interviewer first acquired permission to attend the medical follow-up appointment in order to gather relevant background information about the state of the infant and establish comfort. The participant was attending a medical follow-up appointment for one of her preterm infants. The appointment was entirely of a positive nature and the infant was healthy and happy, thus the mother could be invited to participate. After the doctor's appointment the participant was offered to take part in the study and agreed to the interview. It was noted in the doctor's appointment that she spoke largely isiXhosa and had difficulty understanding the English questions.

Once in the participant was in the consultation room the isiXhosa research assistant introduced herself and her role, and read and explained the details of the study to the participant and gave her an opportunity to ask questions relevant to the study and to the interview process. No questions were asked and the participant appeared comfortable with the interview process and set-up. The researcher, assistant and participant sat in a 'circle' formation facing one another indirectly so to not appear 'confrontational'.

Rapport was established in the introduction of the study and gathering of consent. The participant was also offered tea/coffee and snacks – to which she expressed gratitude - for comfort prior to starting the interview. The transcription begins after rapport was established and consent was obtained, and starts with the gathering of important biographical information, then leading on to the interview. Terminology was also covered prior to commencement of interview, including words such as 'communication' and 'interaction'.



Biographical Picture

The participant is a ■ year old single mother of two - a ■-year old ■ and her preterm infant. Her preterm baby was born at ■ weeks gestation weighing ■ and is now ■ months old (■ months corrected age). Her ■ lives with her ■ in ■ – she tries to visit them every two weeks. The participant currently lives in ■ in a tin house with her boyfriend and preterm infant. She completed high school and works as a ■ at a fast-food franchise. She is currently back at work after 4 months unpaid maternity leave. She receives little caregiving assistance from the partner (he does sometimes contribute to financial expenses) and a friend watches her infant whilst she is at work. She leaves her friend with ■ formula to feed her infant whilst she is away. She helps support her parents financially.

Notes

Doctors consultation: No mention of corrected development or developmental expectation, only questions regarding medical stability from the participant. Infant appears to be developmentally ‘on-par’ for ■ corrected age. The doctor confirmed to the participant that ■ is developing well.

Interview: The participant was quite emotional during the interview and mentioned that she was finding caregiving quite stressful. She proceeded to cry when she was asked to describe her overall experience as well as when asked about sources of support (in hospital, at home and financially), she didn’t appear to have a lot of emotional support available closely to her, ■
■ Despite these emotional episodes she held, rocked and smiled at her baby throughout the interview. However, although she was emotional, intervention in the form of a referral (i.e. to psychology) was not deemed necessary.

The participant has a speech disfluency, which appeared to worsen as she got emotional, as well as limited her expressions. Although she was aware that the researcher was a speech therapist, the participant did not bring this up. Furthermore, she did not mention concern regarding speech or communication with or of her infant.

APPENDIX G: 'IN-VIVO' CODES

ATLAS.ti Report

Transcript analysis - 2

Code groups grouped by Codes (selection)

Report created by Kristen on 26 Nov 2018

o "prematures change"

Quotations:

9:44 It can be difficult sometimes because I was very scared and he is premature and you know with premat...

1 Code groups:

◇ In-Vivo codes

o participant 16 :- I was a bit hurt because I wasn't expecting her when she arrived, I did not even have clothes for her or anything for her

Quotations:

15:65 participant 16 :- I was a bit hurt because I wasn't expecting her when she arrived, I did not e...

1 Code groups:

◇ In-Vivo codes

o I was scared because sometimes he was so sick

Quotations:

9:14 I was scared because sometimes he was so sick

1 Code groups:

◇ In-Vivo codes

o It was difficult I'm telling you, because I didn't expect it and I've never seen a premature baby before so it was shocking to me , I was in shock, like really in shock.

Quotations:

11:9 It was difficult I'm telling you, because I didn't expect it and I've never seen a premature baby be...

1 Code groups:

◇ In-Vivo codes

o It was traumatic, it was very very traumatic

Quotations:

- 1:6 It was traumatic, it was very very traumatic

1 Code groups:

- In-Vivo codes
-

- o **My youngest brother was scared to touch her, he could not touch her she was too small**

Quotations:

- 10:25 My youngest brother was scared to touch her, he could not touch her she was too small

1 Code groups:

- In-Vivo codes
-

- o **now I have to look after her because some other people will, they will never know, they will act like she is a normal baby but she is not, but she is normal, but she is a premature and all that stuff**

Quotations:

- 7:5 now I have to look after her because some other people will, they will never know, they will act lik...

1 Code groups:

- In-Vivo codes
-

- o **Participant 2 :- I'm scared to use that medicine, I just go to clicks and buy things for colic over the counter when they have cramps. I'm very scared to use traditional medicine especially on babies**

1 Code groups:

- In-Vivo codes
-

- o **Participant 12 :-It's difficult to have a premature baby, very difficult you have to be strong**

Quotations:

- 11:58 Participant 12 :-It's difficult to have a premature baby, very difficult you have to be stron...

1 Code groups:

- In-Vivo codes
-

- o **Participant 13 :-I was hurt**

Quotations:

- 12:9 Participant 13 :-I was hurt

1 Code groups:

- In-Vivo codes

○ **Participant 14 :- I was scared and stressed, I was not fine at all**

Quotations:

🕒 13:16 Participant 14 :- I was scared and stressed, I was not fine at all

1 Code groups:

◊ **In-Vivo codes**

○ **Participant 14 :- Yes, I had to sit and kangaroo him until he weighs 2.5kg's so I couldn't do a lot of things**

Quotations:

🕒 13:26 Participant 14 :- Yes, I had to sit and kangaroo him until he weighs 2.5kg's so I couldn't do...

1 Code groups:

◊ **In-Vivo codes**

○ **Participant 15 :-How was it different? I was how can I say, I was disappointed, because I always have big babies but I did understand to the old one's, I did not have hypertension then with these one's I did**

Quotations:

🕒 14:15 Participant 15 :-How was it different? I was how can I say, I was disappointed, because I alway...

1 Code groups:

◊ **In-Vivo codes**

○ **She was small also, it was embarrassing because if you compare her to other children then it's like you don't feed her, or your baby is, you know mos how we are, so I decide not to tell . I'm just going to keep quiet**

Quotations:

🕒 10:8 She was small also, it was embarrassing because if you compare her to other children then it's like...

1 Code groups:

◊ **In-Vivo codes**

○ **Tube feeding - overwhelming**

Quotations:

🕒 4:19 the cup was fine, I think the tube was something else, it was overwhelming and I thought she won't b...

1 Code groups:

◊ **In-Vivo codes**

○ **'Cause Hospitals can be really, really depressing**

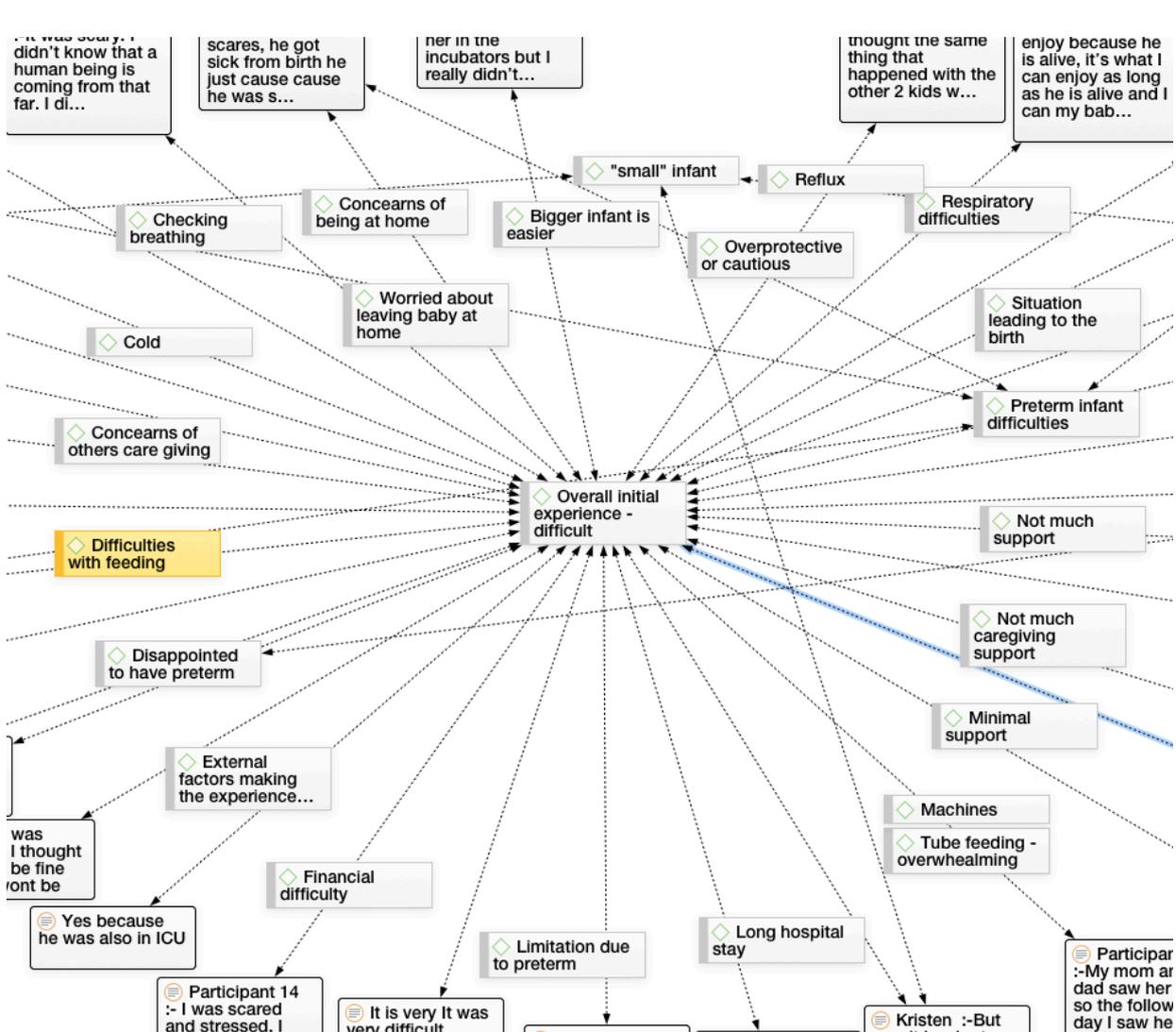
Quotations:

🗨️ 1:16 'Cause Hospitals can be really, really depressing

1 Code groups:

🔗 **In-Vivo codes**

APPENDIX H: EXAMPLE OF A RELATIONSHIP TREE



As the relationship tree is within the analysis software it is not possible to import the entire figure into the current document. Above is an image of their initial layer of the relationship tree, including the theme (in the centre) and related codes surrounding this centre. As can be seen, 'links' or relationships can be seen between codes (those that have similar quotations within). On the next page is an image of the second layer of the tree, illustrating the quotations linked to each code.

APPENDIX I: INFORMATION AND CONSENT FORM

I.1. English

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

TITLE OF THE RESEARCH PROJECT:

The perceptions of mothers of preterm infants at Tygerberg Hospital regarding communication, feeding and general caregiving, in low socioeconomic settings within the drainage areas of Tygerberg Hospital.

REFERENCE NUMBER: 6707

PRINCIPAL INVESTIGATOR: Kristen Buys

ADDRESS:

Division of Speech-Language and Hearing Therapy, Room 4069
Faculty of Medicine and Health Sciences
Francie van Zijl Drive
Tygerberg 7505

POSTAL ADDRESS:

Stellenbosch University
Faculty of Medicine and Health Sciences
Division of Speech-Language and Hearing Therapy
PO BOX 241,
Cape Town
8000

CONTACT NUMBER: For Speech-Language and Hearing Therapy Department at Stellenbosch University: +27 21 938 9494

We would like to invite you to take part in a research project which involves an interview. This document explains what the study is about. Please ask me any questions about any part of this project that you do not fully understand. It is very important that you clearly understand what this research is about and how you could be involved. Your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

We want to know more about the experience of mothers, of having and caring for a premature baby. We also want to know about what you think about your baby's communication and feeding. Knowing this might help other mothers in the future.

If you agree to take part in the research, you will join in an interview (a conversation with me) where I will ask you a few questions about your experiences about having a preterm baby (a baby that was born early and that weighs little). This interview will be in this quiet room/space in the pediatric outpatient clinic in Goud Laan on the 3rd floor of Tygerberg Hospital (West side) next to consultation room 11 where you had your appointment with the doctor. The interview will be voice-recorded so that the researcher can listen to it afterwards. You have to give permission for this recording. I will ask between 15 and 30 mothers to talk to me.

Why have you been invited to participate?

We want to know about the experiences and thoughts of mothers (of preterm babies) here in the Northern Suburbs. I am asking you if you want to participate because you are a mother of a preterm baby and you bring your baby to Tygerberg Hospital to see the doctor.

What will your responsibilities be?

I will ask you some questions. You must please answer the questions as honestly as possible. You must please tell me everything you would like to say. We will talk for about 45 minutes.

Will you benefit from taking part in this research?

Unfortunately, you will not get any benefits from the study, but moms and babies in the future might be helped by the information that you share with me. There are some eats and drinks for you for your wait.

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

There are no risks to you or your baby in the interview. I will not tell your name or your child's name to anybody and your information will be safe.

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

You do not have to take part in this research (have an interview with me) if you do not want to. Nothing will change at the hospital if you take part or if you do not take part. You will still have the same doctor and the same appointments. Nothing will change.

Who will have access to your hospital file information (medical records)?

Only me and my supervisor (her name is Berna Gerber) will be able to see your information (your hospital file). Only me and my supervisor will see this information (your hospital file) and this information will be kept safe and not shared with anyone.

If some of this information in your hospital file is used in a report after the research (for example if we say that most people are a specific age) then there will be no way for people to tell that you took part in the study. We won't use information that will identify you (e.g. we won't use your name).

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

It will not cost you anything to take part in this study (to have the interview with me). You will not be paid if you take part (if you have the interview with me).

Is there anything else that you should know or do?

- You can contact Ms Kristen Buys at tel 084 264 3329 if you have any further questions.
- You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by the researcher.
- You will receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I agree to take part in a research study entitled **“The perceptions of mothers of preterm infants at Tygerberg Hospital regarding communication, feeding and general caregiving, in low socioeconomic settings within the drainage areas of Tygerberg Hospital.”**

I declare that:

- I have read, or had read to me, this information and consent form and it is written in a language that I am fluent and comfortable with.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced/judged in any way.
- I understand that the interview will be voice-recorded (so that the researcher can listen to it again) and give permission for this.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) on (*date*) 2018.

.....

Signature of participant

.....

Signature of witness

Declaration by investigator

I (*name*) declare that:

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

Signed at (*place*) on (*date*) 2018.

.....

Signature of participant

.....

Signature of witness

Declaration by interpreter

I (*name*) declare that:

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

Signed at (*place*) on (*date*)

.....

Signature of participant

.....

Signature of witness

I.2. isiXhosa

INCWADANA YEENKCUKACHA ZOMTHATHI-NXAXHEBA NEFOMU YOKUNIKA IMVUME

ISIHLOKO SEPROJEKTHI YOPHANDO:

limbono zoomama beentsana ezizalwe ngaphambi kwexesha elimisiweyo kwisiBhedlele saseTygerberg malunga noqhagamshelwano, ukuzityisa nokukhathalelwa kwazo jikelele, kwiindawo zasekuhlaleni ezikwimeko yezimali ekwiqondo eliphantsi kwimandla engathathintweni yesiBhedlele saseTygerberg Hospital.

INOMBOLO YESALATHISI: 6707

UMPHANDI OYINTLOKO: Kristen Buys

IDILESI:

Division of Speech-Language and Hearing Therapy, Room 4069
Faculty of Medicine and Health Sciences
Francie Van Zijl Drive
Tygerberg, 7505

IDILESI YEPOSI:

Stellenbosch University
Faculty of Medicine and Health Sciences
Division of Speech-Language and Hearing Therapy
PO Box 241
Cape Town
8000

INOMBOLO YOQHAGAMSHELWANO: I-Candelo loNyango loKuva kunye noKuthetha
kwiYunivesithi yaseStellenbosch: +27 21 938 9494

Singathanda ukukumema ekuthatheni inxaxheba kwiprojekthi yophando equka udliwano-ndlebe. Olu xwebhu lucacisa ukuba olu phononongo lumalunga nantoni na. Nceda ubuze kum nayiphi na imibuzo ngayo nayiphi na indawo ongayiqondi ngokupheleleyo kule projekthi. Kubaluleke kakhulu ukuba uluqonde kakuhle ukuba olu phando lumalunga nantoni na nokuba ungabandakanyeka njani. Ukuthabatha kwakho inxaxheba ukwenza **ngokuzithandela ngokupheleleyo** yaye ukhululekile ukuba ungala ukuthabatha inxaxheba. Ukuba uthi hayi, oku akuyi kukuchaphazela ngokungafanelekanga nangayiphi na indlela. Ukhululekile kwakhona ukuba ungarhoxa kolu phononongo nanini na, nokuba uyavuma ukuthatha inxaxheba.

Olu phando luvunywe yiKomiti yeeNdlela zokuziPhatha kuPhando lwezeMpilo kwiYunivesithi yaseStellenbosch kwaye luza kwenziwa ngokwezikhokelo ezisesikweni zokuziphatha nemithetho-siseko eyamkelekileyo yesiBhengezo seHlabathi saseHelsinki, iziKhokelo zaseMzantsi Afrika zoKwenziwa koMsebenzi wezoNyango kunye neziZhokelo eziSesikweni zeBhunga loPhando lwamaYeza (MRC).

Lumalunga nantoni olu phononongo?

Sifuna ukufumana ulwazi olongezelelweyo malunga namava oomama, okukhathalela nokufumana kwabo abantwana abazelwe ngaphambi kwexesha elimisiweyo. Sikwafuna nolwazi lokuba ucinga ntoni ngendlela athetha natya ngayo umntwana wakho. Ukufumana ulwazi malunga noku kungaluncedo kwabanye oomama kwixesha elizayo.

Ukuba uyavuma ukuthatha inxaxheba kolu phando, uza kuba yinxalenye yodliwano-ndlebe (ingxoxo kunye nam) apho ndiza kubuza khona imibuzo embalwa malunga namava wakho wokufumana usana oluzalwe ngaphambi kwexesha elimisiweyo (usana oluzalwe ngaphambi kwexesha limisiweyo nolunobunzima bomzimba obuncinane). Olu dliwano-ndlebe luza kubanjelwa kwigumbi elinezolo/indawo kwikliniki yezigulane zangaphandle ezingabantwana eseGoud Laan kumgangatho 3rd kwisiBhedlele saseTygerberg (West Side) ecaleni kwegumbi le-11 lokuxilongela apho unedinga lakho kunye nogqirha. Udliwano-ndlebe luza kushicilelwa ngokwelizwi ukuze umphandi abenako ukulumamela emveni kokuba lugqityiwe. Kufuneka unike imvume yokushicilelwa

kwelizwi. Ndiza kucela oomama abaphakathi kwe-15 ukuya kwaba-30 ukuba bathethe nam.

Kutheni uceliwe nje ukuba uthathe inxaxheba?

Sifuna ulwazi malunga namava kunye neengcinga zoomama (abanabantwana abazalwe ngaphambi kwexesha elimisiweyo) apha kwiNorthern Suburbs. Ndiyakucela ukuba uyafuna na ukuthatha inxaxheba ngoba ungumama wosana oluzelwe ngaphambi kwexesha elimisiweyo kwaye uzise umntwana wakho kwisiBhedele saseTygerberg ukuze abonane nogqirha.

Luya kuba yintoni uxanduva lwakho?

Ndiza kubuza imibuzo ethile. Nceda uphendule le mibuzo ngokunyaniseka kangangoko unako. Nceda undixelele yonke into ongathanda ukuba ungayithetha. Siza kuthetha malunga nemizuzu engama-45.

Ingaba uya kuzuzisa ngokuthabatha kwakho inxaxheba kolu phando?

Ngelishwa akusayi kufumana naziphi na iinzuzo kuphononongo, kodwa oomama kunye neentsana bangalufumana uncedo kwixesha elizayo ngenxa yolwazi owabelana ngalo nam. Uza kufumana iziselo ezibandayo kunye namaqebengwana ngethuba usalindile.

Ingaba kukho imingcipheko ebandakanyekayo ekuthatheni kwakho inxaxheba kolu phando?

Akukho mingcipheko ikhoyo kuwe nakusana lwakho kudliwano-ndebe. Andiyi kuxelela nabani na igama lakho okanye elomntwana wakho kwaneenkukacha zakho ziya kuhlala zikhuselekile.

Ukuba akuvumi ukuthatha inxaxheba, zeziphi ezinye iindlela onazo ezinokulandelwa?

Akunyanzelekanga ukuba uthathe inxaxheba kolu phando (ukubamba udliwano-ndebe kunye nam) ukuba awufuni. Akukho tshintsho luya kubakhona esibhedlele ukuba uthatha inxaxheba okanye awuthathi inxaxheba. Uya kuhlala unogqirha omnye kwanamadinga okubonana nogqirha afanayo. Akukho nto iza kutshintsha.

Ngubani oza kufumana iinkcukacha zakho zonyango (iinkcukacha zonyango ezigciniweyo)?

Ndim nosuphavayiza wam kuphela (igama lakhe nguBerna Gerber) abaya kuthi babenako ukuzibona iinkcukacha zakho (ifayili yakho yasesibhedlele). Ndim nosuphavayiza wam kuphela abaya kuthi babenako ukuzibona iinkcukacha zakho (ifayili yakho yasesibhedlele) kwaye ezi nkcukacha ziya kugcinwa zikhuselekile kungabelwana ngazo naye nawuphi na umntu.

Ukuba ezinye zezi nkcukacha zikwifayili yakho yasesibhedlele zisetyenziswe ekunikeneni ingxelo emveni kokwenziwa kophando (umzekelo ukuba sithi uninzi lwabantu abanobudala beminyaka ethile) ngoko ke akukho ndlela banokuthi abantu bachaze ngayo ukuba wena uthathe inxaxheba kolu phononongo). Asisayi kusebenzisa iinkcukacha ezizakuchonga wena (umz. asisayi kusebenzisa igama lakho).

Ingaba uza kuhlawulwa ngokuthatha inxaxheba kolu phononongo kwaye ingaba kukho iindleko ezibandakanyekayo?

Akusayi kubakho ndleko kuwe ngokuthatha inxaxheba kolu phononongo (ukubamba udliwano-ndlebe kunye nam). Awusayi kufumana ntlawulo ngokuthatha inxaxheba (ukuba ubamba udliwano-ndlebe kunye nam).

Ingaba ikhona enye into ekufuneka ndiyazi okanye ndiyenze?

- Ungaqhagamshelana noNksz Kristen Buys kwezi nombolo 084 264 3329, ukuba unemibuzo okanye unengxaki odibane nazo.
- Ungaqhagamshelana neKomiti yeeNdlela zokuziPhatha kuPhando lwezoNyango ku-021 938 9207 ukuba kukho nantoni na ekuxhalabisayo okanye izikhalazo ezingachazwanga ngokwaneleyo ngumphandi.
- Uza kufumana ikopi yezi nkcukacha nefomu yesivumelwano oza kuzigcinela yona.

Isibhengezo somthathi-nxaxheba

Ngokutyikitya apha ngezantsi, mna ndiyavuma ukuthatha inxaxheba kuphando olusihloko sithi: **limbono zoomama beentsana ezizalwe ngaphambi kwexesha elimisiweyo kwisiBhedlele saseTygerberg malunga**

noqhagamshelwano, ukuzityisa nokukhathalelwa kwazo jikelele, kwiindawo zasekuhlaleni ezikwimeko yezimali ekwiqondo eliphantsi kwimimandla engathathintweni yesiBhedlele saseTygerberg .”

Ndibhengeza oku:

- Ndiye ndayifunda okanye ndayifundelwa le nkcazelo nefomu yemvume yaye ibhalwe ngolwimi endiluthetha kakuhle nendiluva kakuhle.
- Ndiye ndalifumana ithuba lokubuza imibuzo kwaye yonke imibuzo yam iphendulwe ngokwanelisayo.
- Ndiyaqonda ukuba ukuthatha kwam inxaxheba kolu phando ndikwenza **ngokuzithandela** kwaye khange ndinyanzelwe ukuba ndithathe inxaxheba.
- Ndingakhetha ukuyeka kuphando nanini na kwaye andiyi kohlwaywa okanye ndicalulwe nangayiphi na indlela.
- Ndiyaqonda ukuba udliwano-ndlebe luzakushicilelwa ngokwelizwi (ukuze umphandi abenako ukulumamela kwakhona) nokunika imvume yoku.
- Ndisenokucelwa ukuba ndilushiye olu phando lungekapheli, ukuba ugqirha wophando okanye umphandi ucinga ukuba oko kundifanele ngcono, okanye ukuba isicwangciso sophando andisilandeli ngale ndlela kuvunyelwene ngayo.

Sityikityelwe (*indawo*) e..... ngomhla (*umhla*) we- 2018.

.....
Utyikityo lomthathi-nxaxheba

.....
Utyikityo lwengqina

Isibhengezo somphandi

Mna (*igama*) ndibhengeza ukuba:

- Ndimcacisele u..... ngeenkukacha ezikolu xwebhu.
- Ndimkhuthazile ukuba abuze imibuzo ndaza ndathatha ixesha elaneleyo ukuyiphendula.
- Ndanelisekile kukuba uyiqonda ngokwaneleyo yonke imiba yolu phando, njengoko icacisiwe apha ngentla.
- Ndiyisebenzisile/andiyisebenzisanga itoliki.

Sityikityelwe (*indawo*) e..... ngomhla (*umhla*) we- 2018.

.....

Utyikityo lomthathi-nxaxheba

.....

Utyikityo lwengqina

Isibhengezo setoliki

Mna (*igama*) ndibhengeza ukuba:

- Ndimncedisile umphandi (*igama*)..... ekucaciseni iinkcukacha ezikolu xwebhu (*igama lomthathi-nxaxheba*) ku..... ndisebenzisa ulwimi lwesiXhosa.
- Simkhuthazile ukuba abuze imibuzo kwaye athathe ixesha elaneleyo ukuba ayiphendule.
- Ndiye ndamnika inguqulelo echanekileyo nenyanisekileyo yoko bekuthethwe kum.
- Ndanelisekile kukuba umthathi-nxaxheba ukuqonda ngokupheleleyo okuqulathwe lolu xwebhu lwesivumelwano sineenkukacha kwaye nemibuzo yakhe yonke iphendulwe ngokwanelisayo.

Sityikityelwe (*indawo*) e..... ngomhla (*umhla*) we- 2018.

.....

Utyikityo lomthathi-nxaxheba

.....

Utyikityo lwengqina