

**EXPLORING THE HELP-SEEKING BEHAVIOUR OF MOTHERS
WITH PREMATURE BABIES IN PUBLIC SECTOR HOSPITALS**

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**Full thesis submitted in fulfilment of the requirements for the Degree of
Masters in Child and Family Studies in the Centre for Interdisciplinary
Studies of Children, Family, and Society,
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Abstract

Help-seeking behaviour is important so that an individual does not reach a stage of helplessness and hopelessness. For mothers, who had premature babies, this becomes very important because the mother is potentially vulnerable or challenged with the care of her fragile baby. These challenges can cause emotional distress to the mother and can affect her ability to seek help. The information regarding the help-seeking behaviour of mothers with premature babies in public hospitals is not well documented. This study aimed to explore the help-seeking behaviour of mothers who had given birth to premature babies in public sector hospitals. This study used a qualitative methodology using an exploratory approach. A sample of 21 participants were recruited which included 15 mothers who had premature babies and 6 healthcare workers working in the Neonatal intensive care unit. Participants were recruited at a public sector hospital in Cape Town. Purposeful sampling was applied when selecting participants. Face-to-face interviews were conducted which included unstructured, open-ended questions. Data was collected via audio recordings as well as written interviews with the consent of participants. The data was transcribed verbatim in a 6-step general phase of interpretation. Ethical consideration was applied in this study namely informed consent, self-determination, minimization of harm, anonymity, and confidentiality. The findings of the study indicated that mothers of premature babies struggled with the overwhelming emotions around the birth of her baby which caused emotional distress. Mothers expected healthcare workers to assist them during this difficult time however healthcare workers struggled to provide this support as they were strained by being overworked due to a shortage of staff combined with struggling to understand the emotions around having a premature baby. This caused a strain on the mother-healthcare worker relationship. This strained relationship caused a lack of education about resources available to the mother to access which hindered her inability to seek help.

KEYWORDS

First thousand days

Mother

Maternal health

Maternal mental health

Help-seeking behaviour

Premature baby

Developing countries

Healthcare worker

Primary healthcare

Public sector hospital

Nurturing care

DECLARATION

I, Nazeefah Safi, declare that the Masters by Research thesis titled '*Exploring the help-seeking behaviour of mothers with premature babies in public sector hospitals*' is my own work. All sections of the dissertation and concepts developed by another author have been referenced, this thesis contains no material that has been submitted previously, in whole or in part, for the award of any other academic degree.

Date: October 2022

Nazeefah Safi



Signed:

ACKNOWLEDGEMENTS

The completion of this degree marks the end of what was an exciting yet very emotional journey for me. They say it takes a village to raise a child, it took a village for this academic baby to reach completion.

- Gratitude goes to the Almighty for granting me not only the opportunity but the strength to pursue and complete this journey. It was challenging however I was blessed in so many ways.
- To my children for always being so tolerant and patient with me during this journey. I appreciate your resilience through this process.
- My husband, Husain. The Almighty has truly blessed me with an amazing partner. Thank you so much for always supporting me, encouraging me, and wiping my tears when I wanted to give up. You have sacrificed with me, and this journey would not have been possible without you.
- Professor Roman. Your expertise and supervision were unsurmountable. You pushed me to be my best, to display my best and truly be a master in my topic. When this journey felt overwhelming, and it did many times, you always knew how to simplify it which avoided me from drowning. I feel blessed that I was under your supervision.
- And lastly to all the mothers of premature babies who trusted me with their emotions. I hear you; I see you. I know the journey is tough and not relatable to many. I know you feel forgotten and isolated but know that the God only tests his strongest soldiers.

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CHAPTER 1

INTRODUCTION

1.1 Background and Rationale

Motherhood is a journey that most women expect to go through at some point in life (Veronez et al., 2017) including the expectation of carrying a baby to term. The way her birth unfolds can have a lasting effect on this journey (Hastings-Tolsma et al., 2018). However, this expectation may not be realized because the baby may arrive much earlier than expected. These are premature babies defined as a baby born alive before 37 weeks gestation (WHO, 2012). The trauma of her birth is now met with the fears of the unknown of whether her baby will suffer any long-term complications from being born too soon (Veronez et al., 2017). These babies are born small and challenged physically and neurologically which requires individualized care (Mahwasane et al., 2020). Giving birth to a premature baby is a traumatic experience that culminates in many negative emotions such as shock, guilt, and unhappiness (Veronez et al., 2017). The situation becomes very challenging for the mother as the premature baby requires immediate hospitalization, separating mother and baby, while the mom also experiences shock at the fragility of the baby. These experiences are unexpected, and the mom then struggles to cope (Veronez et al., 2017). The fragility of her baby is unexpected which makes it even harder for her to cope (Veronez et al., 2017). This can result in anxiety which can affect the mother–infant bond and her ability to seek help. (van Schalkwyk et al., 2020). Help–seeking behaviour is a response to illness (Biddle et al., 2007). This response is linked to questions of ‘when’ and ‘how’ and is not usually attributed to positive change (Biddle et al.,

2007; Gulliver et al., 2012). Individuals naturally seek help from people around them like family or friends as opposed to a healthcare worker (Gulliver et al., 2012). Help-seeking behaviour includes various pathways to care which begins in the community and ends with treatment by a healthcare worker (Biddle et al., 2007). When seeking help in a healthcare setting means receiving help from a healthcare worker or receiving a service for any challenges associated with mental health (Magaard et al., 2017). This could refer to therapy or counselling on either an inpatient or outpatient basis (Magaard et al., 2017). Help-seeking behaviour in mothers is linked to four different pathways that could be linked to barriers to accessing the necessary care (Anderson et al., 2006). Education about mental health is imperative in assisting the mother in identifying the different pathways before reaching out to a healthcare worker (Fonseca et al., 2015). These pathways include accepting a diagnosis, perceptions of the causes of the distress, reactions to being referred for any treatment, and perceptions of their child and other mental health services (Anderson et al., 2006). These mothers are fully aware of the emotions and distress they are currently in, and accepting it as a problem means attaching a diagnosis to it (Anderson et al., 2006). A consensus revealed that the majority of mothers believe that their emotional distress is caused by external factors namely poverty, abuse, and managing challenged children (Anderson et al., 2006). Tested with either the physical or psychological health of their child results in maternal distress as they somewhat feel responsible and therefore carry around emotions such as guilt and blame (Anderson et al., 2006). The resistance to seeking help also means that it is required for her to make internal changes which they deem as futile (Anderson et al., 2006). According to their understanding, their emotional distress is caused by external factors that, if removed, would alleviate their emotional distress. They also perceive emotional distress as part of normal life (Anderson et al., 2006). If they are able to physically complete any daily task, it is not considered serious enough to warrant help (Anderson et al., 2006; Biddle et al., 2007). Help is only necessary

when it reaches a point of self-harm (Anderson et al., 2006; Biddle et al., 2007). The role of the healthcare worker is imperative in providing the necessary support during this difficult time by keeping the line of communication open which can positively contribute to increasing her confidence to care for her baby as well as seek any help (van Schalkwyk et al., 2020; Veronez et al., 2017). It is imperative that healthcare workers who are managing their baby approach the situation with utmost care and sensitivity with regard to communication with her about the changes in their babies' condition (Veronez et al., 2017). All of them expressed feelings of disappointment with healthcare workers as they show no interest in their well-being, and they often feel ignored if any of their emotions are expressed to a healthcare worker (Anderson et al., 2006). These mothers have also emphasized that there is no relatability to healthcare workers as they have no life experience (Anderson et al., 2006). There is also a huge fear of being judged in their motherly role by healthcare workers which might risk their kids being taken away (Anderson et al., 2006). Healthcare workers attach any form of emotional distress to a specific diagnostic model taught to them and this is how patients are treated by them (Anderson et al., 2006). This model causes reluctance in mothers to seek help with healthcare services (Anderson et al., 2006). They feel misunderstood and just want to be heard and prioritized (Anderson et al., 2006). Attaching them to a diagnostic model makes them feel unheard and unmotivated which leads to a risk of not seeking help (Anderson et al., 2006). If the role of a healthcare worker is not fulfilled towards her in providing the support and help, she needs, it will result in her detaching herself from her environment (Anderson et al., 2006). The risk of maternal depression is higher in a mother with a premature baby (Misund et al., 2014). 49% of mothers still experience trauma one year after the birth of their preterm baby (Jubinville et al., 2012). Focus is placed on a mother's physical health as opposed to her mental health (Atif et al., 2015). Maternal mental health interventions are non-existent in LMIC despite recommendations from the WHO to integrate them into primary healthcare settings

(Atif et al., 2015). Mental health is being side-lined in these countries due to managing communicable and non-communicable diseases which leave 76-85% of patients with mental health issues, untreated (Atif et al., 2015). Maternal mental health issues are a cause of disease-related disability which leads to poverty, social grant reliance, and unemployment (Freed et al., 2012). South Africa is considered a middle-income country based on its economy; but the health system is considered worse than some lower-income countries (Coovadia et al., 2009). Throughout history, the South African healthcare system has been flawed within the public sector (Coovadia et al., 2009). Since 1994, there has been uneven distribution of healthcare workers that are poorly skilled (Coovadia et al., 2009). Bed shortages across all public hospitals are present (Chopra et al., 2009). When giving birth at a public hospital women expressed feelings of isolation, and loneliness during birth, labor, and post-partum (Hastings-Tolsma et al., 2018). They expressed care as unsympathetic and felt ignored (Hastings-Tolsma et al., 2018). Rudeness and aggression were common among healthcare workers (Hastings-Tolsma et al., 2018). Some of their negative emotions are also linked to unsupportive care by healthcare workers (Simpson & Catling, n.d.). When a woman gives birth, this results in her being discharged six hours after vaginal birth and three days after a c-section (Chopra et al., 2009). Due to a shortage of beds, the primary healthcare system is unable to assist effectively with the demand for preterm birth (Rhoda et al., 2019). Healthcare workers also experienced frustration due to staff shortages and lack of adequate equipment in the NICU which can result in compromised adequate care for the preterm baby. (Mahwasane et al., 2020). Research focusing on mothers with premature babies and help-seeking behaviour shows that this area of research has not been explored. However, exploring the help-seeking behaviour of mothers with premature babies is important as it will allow insight into any barriers to care that could be restricting access to any possible resources they should require from healthcare workers in the public healthcare sector. There are no set interventions in place in South Africa for mothers

and preterm infants (Rhoda et al., 2019). This research will focus on the help-seeking behaviour of mothers who gave birth to premature babies in public sector hospitals.

1.2 Theoretical framework

This study used the Health Belief Model and Nurturing Care Framework which was best suited. The Health Belief Model was created between 1950 and 1960 by a group of researchers who faced challenges within the public healthcare sector (Rosenstock, 2016). This model links psychological theories to explain a person's ability to decide when presented with various choices or when placed in an unpredictable situation (Maiman & Becker, 2016). Applying this model to predict behaviour allows the assessment of changes to an individual's behaviour in relation to their environment as opposed to an isolated reaction (Maiman & Becker, 2016). The Nurturing Care Framework refers to 'A framework for helping children survive and thrive. (WHO, 2018).' The framework aims to implement policies and services to help parents and caregivers provide nurturing care for babies, with primary care at the core (WHO, 2018). It highlights the important role that all sectors, including the health sector, must play to support the healthy development of the child (WHO, 2018). Having a preterm baby is a traumatic experience that can have negative effects on maternal mental health and her ability to seek help in the healthcare setting from a healthcare worker. Applying the two theories assessed whether there were any barriers preventing the mother from seeking help as well as barriers preventing healthcare workers to offer help to these mothers.

1.3 Problem statement

The public healthcare sector in South Africa accounts for most of the population using healthcare services (Ballot et al., 2010). Giving birth in this setting could be disadvantageous as the healthcare system is challenged with a shortage of beds, staff, and inadequately trained staff in mental health (Gelaye et al., 2016; Mahwasane et al., 2020). The risk of maternal depression is higher in a mother who has given birth to a premature baby (Misund et al., 2014) as opposed to a mother who has given birth to a full-term baby, which can result in post-partum adjustment issues (Ayers et al., 2021; Hastings-Tolsma et al., 2018). Lack of support from healthcare workers will result in her detaching herself from the whole environment (Veronez et al., 2017) and her ability to seek help. Previous studies explored challenges women faced with their mental health after having a premature baby and not on their help-seeking behaviour (Anderson & Cacola, 2017; Misund et al, 2014). These studies were not specified to any public healthcare setting and therefore provided an opportunity to explore the challenges of mothers with preterm babies in a public hospital setting. This study explored the help-seeking behaviour of mothers who had premature babies in public sector hospitals.

1.4 Research question

What is the help-seeking behaviours of mothers who had premature babies in public sector hospitals?

Sub-questions of the study

(1) What are the perceptions, experiences, beliefs, and attitudes of mothers who birthed premature babies in a public sector hospital?

- (2) What kind of help do mothers need from a healthcare worker following the birth of their premature baby?
- (3) What resources are available to assist mothers who had premature babies in a public sector hospital?
- (4) How do healthcare workers assist mothers who birthed premature babies?
- (5) How do mothers seek help in a public sector hospital after having a premature baby?

1.5 Aims and objectives

1.5.1. Aim of the study

The aim of the study was to explore the help-seeking behaviour of mothers who had premature babies in public sector hospitals.

1.5.2. Objectives of the study

The objectives of the study were to:

- (1) Explore the perceptions, experiences, beliefs, and attitudes of mothers who had premature babies in a public sector hospital.
- (2) Explore the kind of help mothers need from a healthcare worker following the birth of their premature baby.
- (3) Identify and explore the resources to assist mothers who had premature babies in a public sector hospital.
- (4) Explore how healthcare workers assist mothers who birthed premature babies.

(5) Explore how mothers seek help in a public sector hospital after they had given birth to a premature baby

1.6 Research Methodology

This research used a qualitative approach. This approach allows the researcher to explore social phenomena by providing an in-depth understanding (Leavy, 2014). This research methodology was chosen as it allowed the researcher to explore the help-seeking behaviour of mothers of premature babies who gave birth a public sector hospital. The study followed an exploratory approach. Exploratory research adopts an open, flexible approach by filling the gaps in a topic that has been under-researched or new (Leavy, 2017). In this study, a size total of twenty-one participants were recruited. The sample included six healthcare workers as well as fifteen mothers of premature babies within a neonatal intensive care unit in a public hospital in Cape Town. Purposeful sampling was used. This type of sampling allows a deliberate selection of specific individuals needed to address the purpose and questions related to this study (Leavy,2017) which are mothers with premature babies and healthcare workers in a public hospital setting. An interview schedule is used as the primary tool in this study (Leavy,2017). This includes a few open-ended, unstructured questions that provides an in-depth understanding of participants' views and opinions (Leavy,2017). Data is collected in the natural setting of the participant (Leavy,2017). Interviews were conducted to collect data. People are naturally conversational which draws on the interview method as a conversation tool (Leavy,2017). This method increases the chances of questions being answered by the participant in a natural, organic manner (Leavy,2017). Interviews were conducted face-to-face (Leavy,2017) while adhering to Covid-19 protocols such as social distancing and masks were kept on all the time by the researcher and participants. This focused on reasons behind the lack

of help-seeking behaviour of mothers of premature babies in public hospital settings from both groups of participants namely mothers of premature babies and healthcare workers. Data from the interviews were collected via audio recordings as well written interviews. Data analysis was done via the general phase of interpretation (Leavy,2017).

1.7 Significance of the study

Giving birth to a premature baby could have a negative impact on maternal mental health which compromises help-seeking behaviour. The majority of the population in South Africa seeks healthcare within the public sector. This strain can affect the quality of healthcare and blur the availability of possible resources. In 2015 the United Nations set out Sustainable Development Goals which equates to 17 goals required to transform the world and most importantly end poverty, and inequality and allow people access to healthcare and prosperity (WHO, 2022). The health of a mother is dependent on some of these Sustainable Development goals such as good health and well-being, zero hunger, and gender equality. Applying these goals will not only affect her physical and mental well-being but also the healthy development of her baby. Added to the application of the goals is also to provide access to adequate resources to ensure her overall well-being. Awareness of resources aswell as accessibility to these resources will assist in seeking help when she needs it.

1.8 Definition of terms

First 1000 days of life: The first 1,000 days of life - the time spanning roughly between conception, and one is the second birthday - is a unique period of opportunity when the foundations of optimum health, growth, and neurodevelopment across the lifespan are established (UNICEF, 2013)

Mother: A role that focuses on the nurturing and development of a child (Mayer, 2009)

Maternal mental health: A state of well-being in which a mother realizes her abilities, can cope with normal stresses of life, can work productively and fruitfully, and is able to contribute to her community (Herrman et al., 2005)

Maternal depression: non-psychotic depressive disorder. It is linked to antepartum depression as well as postpartum depression (Gelaye, Rondon, Araya, & Williams, 2016)

Help-seeking behaviour: Refers to a complex decision-making process instigated by a problem that challenges personal abilities (Cornally & McCarthy, 2011).

Premature baby: a baby born alive before 37 weeks gestation (WHO, 2012).

Resource-constrained environments: We define resource-constrained environments broadly (e.g., low-income communities, low bandwidth environments). These environments provide unique constraints (e.g., cultures where people are unfamiliar with or afraid of technology, and environments where power and network connectivity are scarce and expensive) (Anderson et al., 2012)

Nurturing care: Nurturing care is provided by parents, families, and caregivers daily (Black et al., 2021; Richter, 2019). Nurturing care is a simple concept that starts from the conception that can include something as simple as singing or talking to your unborn child (WHO, 2018).

1.9 Thesis outline

Chapter one: Introduction

This forms the introductory chapter of the chapter. The background and rationale are briefly discussed. Research aims and objectives are stipulated. The theories that support the study are mentioned namely The Health Belief Model and the Nurturing Care Framework. These theories focus on concepts that will form the groundwork of your study. This is followed by the problem study, research methodology, ethical consideration, significance of the study, and lastly definition of terms.

Chapter two: Theoretical framework

This forms the theoretical framework. The chapter discusses in depth the two theories that were used to support the study. The Health Belief Model supports the help-seeking behaviour of mothers with premature babies in the public health sector. In addition, the Nurturing Care Framework focuses on mothers of premature babies and their needs as well as premature babies and their needs. These theories are used to support as well as explain, predict, and understand the help-seeking behaviour of mothers with premature babies in public sector hospitals.

Chapter three: Literature review

This chapter reviews all the literature that was done before relating to the study. There was no literature on the help-seeking behaviour of mothers with premature babies in public sector hospitals per se. Past literature was broken in into different headings that relate to help-seeking behaviour, mothers, premature babies, and public sector hospitals. The literature discussed supports the two theories namely the Health Belief Model and the Nurturing Care Framework.

The critical evaluation of theories applied to existing literature displays the investigators' understanding of the concepts that relate to the help-seeking behaviour of mothers with premature babies.

Chapter four: Research methodology

This chapter describes the methodological processes that are linked to the study. Provides an overview of the research design, research setting, population and sampling, data collection tools and analysis, and lastly ethical considerations.

Chapter five: Discussion and findings

This chapter focuses on presenting the findings followed by the discussion. Interviews were transcribed and assigned codes. Themes were created from the codes and discussed under the relevant headings and sub-headings in detail. The literature and theories are applied to support the findings of the study by answering the research question.

Chapter six: Summary, conclusion, and recommendations

This chapter presents the summary, conclusion, and recommendations of the study based on the main findings of this study.

CHAPTER TWO

THEORETICAL FRAMEWORK

2.1 Introduction

This chapter presents the theoretical framework supporting the study. Two different theories have been applied namely The Health Belief Model as well as the Nurturing Care Framework of WHO. The chapter will begin by exploring the Health Belief Model and the four components namely perceived susceptibility, perceived seriousness, perceived benefits of taking action and benefits to action, and lastly cue to action. Lastly, the Nurturing Care framework will be defined and discussed. The application of both theories will be discussed by the researcher as the final step of this chapter.

2.2 The Health Belief Model

Developed between 1950 and 1960, the Health Belief Model is one of the oldest and most popular health behaviour theories (Nobiling & Maykrantz, 2017; Rosenstock, 2016). The model explores the possibility of a patient being motivated to seek primary or secondary prevention services and programmes in response to disease (Nobiling & Maykrantz, 2017). During the period between 1950 and 1960, the public healthcare sector faced many challenges (Rosenstock, 2016). Disease prevention was the focus which resulted in a strained healthcare system during this period (Rosenstock, 2016). Patients struggled to accept a diagnosis of the disease which had a domino effect on compliance with treatment and communication between patients and healthcare workers (Rosenstock, 2016). Healthcare workers observed that even

though resources were provided to patients that were free of minimal cost to diagnose disease, they were still hindered in utilising these services (Rosenstock, 2016; Smith, 2009). The constant hindrance in seeking help provided a gap to developing a theory to try and understand this behaviour of individuals not affected by the disease, preventing disease, and lastly, whether there are any possible barriers to accepting and utilising healthcare services if offered at minimal cost or free of charge (Rosenstock, 2016). A group of social psychologists who were researchers, created a set of practical solutions to overcome these challenges which led to the creation of the Health Belief Model (Rosenstock, 2016). During the early stages of the model, the group of researchers deduced that the individual's circumstances, not his environment, influenced his behaviour (Rosenstock, 2016). However, the individual environment will be represented or portrayed during his reaction to disease prevention (Rosenstock, 2016). They collectively agreed that the following factors need to be present for the individual to warrant action, namely (1) the individual needs to believe that he is susceptible to the disease (2) the severity of the disease will be mild and won't largely affect his life (3) taking action in response to disease will reduce severity (4) belief that there is a possibility of being asymptomatic with a current illness (Rosenstock, 2016). These factors make up the four components of the Health Belief Model namely perceived susceptibility, perceived seriousness, perceived benefits of acting, and barriers to taking action as well as a cue to action (Maiman & Becker, 2016; Rosenstock, 2016).

2.2.1. Perceived susceptibility

An individual may believe that they would never contract a condition, some might agree their susceptibility to disease will depend on statistics and some may believe that they will contract the disease (Maiman & Becker, 2016; Rosenstock, 2016). Risk factors play a huge role in the

way an individual perceives susceptibility to an illness (Maiman & Becker, 2016; Rosenstock, 2016). Mothers in lower-income groups perceive that certain risk factors result in issues with mental health that prevents them from seeking help (Anderson et al., 2006). These factors include poverty, domestic violence, or a child that is challenged both emotionally and physically (Anderson et al., 2006). These women perceive that if these risk factors are alleviated, mental distress would be alleviated (Anderson et al., 2006). This aligns with the hypothesis made at the inception of the Health Belief Model that states external factors may influence the individual's behaviour and not his current situation however these factors projects during the reaction to disease prevention (Rosenstock, 2016). Acceptance of perceived susceptibility will vary from person to person based on three different viewpoints (Maiman & Becker, 2016; Rosenstock, 2016).

2.2.2 Perceived seriousness

Perceived seriousness can be defined by the psychological effect of the thought of disease as well as the challenges it comes with affecting the quality of life (Maiman & Becker, 2016; Rosenstock, 2016). This perception can lead to questions of death, physical and mental impairment, disability, occupation, and social relationships with family and friends (Rosenstock, 2016). The clinical profile of the disease will determine how an individual will perceive the seriousness of the disease (Maiman & Becker, 2016; Rosenstock, 2016). Mental health is categorised as either 'functional' or 'dysfunctional' (Anderson et al., 2006). 'Functional' refers to being afflicted by mental distress but being able to complete daily tasks, which is perceived to not be serious (Anderson et al., 2006). 'Dysfunctional' refers to the impaired physical and emotional function and suicidal thoughts (Anderson et al., 2006). Emotional distress is perceived as a normal part of life and only warrants help when it reaches

a point of self-harm (Anderson et al., 2006). Mothers experiencing emotional distress are aware of their emotions however refrain from seeking help due to the perception that it's not linked to a psychological condition that requires treatment (Freed et al., 2012). There is a cognitive component between both perceived susceptibility and seriousness as both depend on information given about a disease (Rosenstock, 2016).

2.2.3. Perceived benefits of taking action and barriers to take action

Acceptance of the susceptibility of an individual to disease will warrant action to treatment provided the disease is serious (Rosenstock, 2016). The type of action to treatment will depend on reducing the severity of the disease (Rosenstock, 2016). This is influenced by the individual's beliefs in what action will reduce susceptibility and severity (Maiman & Becker, 2016; Rosenstock, 2016). Early detection and treatment of mental health disorders will positively affect the physical and emotional development of the child and a healthy family environment (Freed et al., 2012). However, screening for mental health disorders won't necessarily result in treatment regardless of the cost (Smith, 2009). There are negative factors referred to as barriers that can hinder the individual from taking action in treating disease (Nobiling & Maykrantz, 2017; Rosenstock, 2016). Utilization of services linked to mental health is hindered by the following barriers: sociocultural (stigma), navigating the healthcare system (finding the correct provider), lack of education, race, ethnicity, and religion (Maiman & Becker, 2016; Nobiling & Maykrantz, 2017; Rosenstock, 2016). An individual going through a mental health disorder wants assistance from a healthcare worker (Mbuthia et al., 2018). The issue at hand is that healthcare workers are inadequately trained to detect, manage, and treat mental health disorders (Anderson et al., 2006; Freed et al., 2012). Mothers feel like they are placed in a box of diagnosis which results in a disconnect from the healthcare worker,

as they feel misunderstood (Anderson et al., 2006). There is also the perception that seeking help for mental health disorders might compromise maternal status which places a mother at risk of losing her child. (Anderson et al., 2006). All healthcare workers are viewed as one system that has the authority to label a mother unfit to care for her children (Anderson et al., 2006). Mental health disorders stir up emotions of embarrassment and the fear of being labelled ‘mentally unfit’ and being isolated by society (Forsterling, 2009; Agapidaki et al., 2015; Smith, 2009). Additionally, mothers raised in traditional society have the belief that expressing emotions is not normal practice (Suchman et al., 2019). Traditional belief systems link the mothering role to being emotionally strong therefore disclosing any sign of emotional distress displays a sense of weakness (Freed et al., 2012). Education about mental health disorders is imperative in help-seeking behaviour (Fonseca et al., 2015). Attention to education promotes healthy child development and allows the mother to identify symptoms of mental health disorders as well as elicit necessary family support (Black et al., 2017; Biddle et al., 2007). The most effective programmes are those that remove barriers and increase access to services (Black et al., 2017). Lack of education by a healthcare worker about mental health disorders can lead to the wrong diagnosis and inadequate treatment and management (Freed et al., 2012). Being raised in a traditional society can limit the expression of emotions as it is not considered normal practice (Suchman et al., 2019). Overcoming these barriers also depends on the individual’s motivation to get action (Rosenstock, 2016).

2.2.4. Cue to action

This refers to the trigger that will initiate an individual to seek help from disease (Rosenstock, 2016). Motivation to seek help will stem from perceived susceptibility and perceived seriousness and the pathway to help will stem from perceived benefits (minus the barriers)

(Rosenstock, 2016). The pathway to action depends on two factors namely internal (symptoms and bodily perceptions) or external (social media, magazine or newspaper advertisements, and social interactions) (Maiman & Becker, 2016; Rosenstock, 2016). For example, if a female doesn't believe she is susceptible to breast cancer, she will not have regular check-ups done unless she becomes symptomatic. Her symptoms will trigger a pathway to getting help. If a female does believe she is susceptible to breast cancer, she will act and have regular check-ups done. Symptoms of a mental health disorder do not warrant an individual to seek help unless symptoms worsen and they start to become suicidal which can start to halt daily tasks (Anderson et al., 2006; Biddle et al., 2007). The worsening of the condition forces help and the realisation of the problem at hand (Biddle et al., 2007). Once this threshold is broken, individuals reach a point of acceptance of a problem (Biddle et al., 2007). Similarly, a prolonged mental health disorder results in an individual's quality of life decreasing by affecting their day – to – day physical functioning (Smith, 2009; Anderson, 2006). The deterioration in health won't necessarily warrant any pathway to help (Smith, 2009). However, the untreated mental health disorder will have a negative effect on physical health which places an extra strain on the healthcare system (Smith, 2009). Education about mental health disorders is always focused on the postpartum period as it is heightened during this time (Fonseca et al., 2015). The reality is that her emotional distress reaches a peak at this point and focus on mental health should be deemed a priority once conception takes place (Fonseca et al., 2015) In the case of having a preterm baby, any postnatal programme will be unsuccessful as these mothers would rather spend all their time in the NICU with their baby (Henderson et al., 2016). Awareness around mental health should start before this to positively affect women to seek help a lot earlier as opposed to later (Fonseca et al., 2015). Mental health literacy is a tool that can assist help-seeking attitudes which will positively affect help-seeking behaviour (Magaard et al., 2017).

2.3 Nurturing care framework:

‘A framework for helping children survive and thrive, to transform health and human potential (WHO, 2018)’.

This framework is a set of policies and services to help parents and caregivers provide nurturing care to babies, with primary care being the focal point (WHO, 2018). The framework focuses on essential factors that are required for child development which include healthcare, good nutrition, safety and security, opportunities for early learning, and being cared for by affectionate and responsive caregivers (Richter, 2019). The healthy development of a child depends on the assistance of all sectors including the health sector, which this framework emphasizes (WHO, 2018)

2.3.1. What is Nurturing care?

Nurturing care is provided by parents, families, and caregivers daily (Black et al., 2021; Richter, 2019). This type of care starts from the conception that can include something as simple as singing or talking to your unborn child (WHO, 2018). An unborn child can hear from the second trimester of pregnancy and will be able to recognize their mother's voice by birth (WHO, 2018). The health of a mother is vital for foetal development which requires a safe, secure, and loving environment that includes good nutrition and stimulation (WHO, 2018). However, the sad reality for developing countries is the fact that maternal mental health is sidelined due to financial and human resources which directly affects the nurturing care she gives to her baby (Atif et al., 2015). From conception till two years old, is a critical time in the growth of a child as 80 percent of brain development occurs (WHO, 2018; Richter, 2019). Babies are born with all their neurons (WHO, 2018). By the time they reach the age of 2, these neurons would have made connections with their caregiver (WHO, 2018). These connections are

formed by reacting to stimulation given by their caregiver (WHO, 2018). A lot of growth and development takes place during this critical time which can place a child at risk of poor development if not cared for properly (Bust, 2020). The quality of care an infant receives in the first 1000 days is imperative in their growth into children, adolescents, and adults (Bust, 2020).

2.3.2. Nurturing care in premature babies

30 million vulnerable new-borns are left behind in terms of essential care (WHO, 2019). All neonates need essential care when they are born, however small and sick babies require specialised and inpatient care delivered by adequately trained healthcare workers in a hospital setting (WHO, 2019). The WHO actioned a report to assist in essential neonatal care as well as intensive inpatient care for very small and sick babies (WHO, 2019). This report highlights three important aspects of a child's life: survive, thrive, and transform (WHO, 2019).

Survive: in 2017, more than 2,5 million new-borns passed away, most of them from prematurity. This was due to poor quality of care or no care at all.

Thrive: around 30 million new-borns require specialised care in a hospital setting every year. The only way these babies can survive and become part of families and communities is if they receive good-quality inpatient care in a hospital.

Transform: skilled and adequately trained healthcare workers is imperative in these babies' survival. Awareness also needs to be centred around the reality and prevalent risks of neonatal mortality in our communities.

Impact with equity: investment in caring for these small babies would result in 1.7 million babies being saved each year. Agreed that maternal and new-born care is essential, however, this needs to align with special care and intensive care for small and sick babies.

Counting: for change to happen, we need to focus on adjustments in data collection whereby focus needs to be given to service coverage, quality, and outcomes as well as positive utilisation of existing data.

A baby born too soon is at risk of death, stunting, developmental delays, disability, cardiovascular and other non-communicable diseases (Black et al., 2021). Premature babies require an increased amount of nurturing care which equates to 24 hours a day, 7 days a week (WHO, 2018; WHO, 2019). Due to their separation from their mothers, they receive less care (WHO, 2018). The fragility, size, and lack of response from her baby induce emotions of anxiety and stress as they are challenged on how to manage their baby (WHO, 2018). The environment in the NICU only heightens these emotions of anxiety and insecurity around caring for their babies (van Schalkwyk et al., 2020). She feels helpless as she places the care of her baby in the hands of healthcare workers while she observes closely (van Schalkwyk et al., 2020). The negative emotions will result in the mother giving less attention to her baby which then places the baby at risk of developmental delays (WHO, 2018). The state of her mental health will result in how she responds and empathises with her baby as well as how she manages her own emotions (WHO, 2018). The bond between her and her baby is crucial in the development of the child, especially during this critical time (Bust, 2020). Besides the development of her child, this bond is crucial in making a positive impact on her maternal well-being by reducing maternal pain and stress (Bust, 2020). The NCF is a clear depiction that focusing on early childhood development is the best investment a country can make for

economic growth (WHO, 2019). However, it can't be ignored that it's a critical time for the mother as her health is a vital component for the development of her baby (Bust, 2020). The first 1000 days of life is the window period to implement programmes to assist a child as well as the mother to survive and thrive (WHO, 2018; WHO, 2019; Bust, 2020). The convention on the rights of the child states that all children have the right to the highest quality of care (WHO, 2019). Additionally, the respectful maternity care charter states that women also have the right to healthcare and the highest attainable level of health (White Ribbon Alliance, 2011).

How do you create a nurturing environment for a mother?

2.3.3. Enabling policies

Global policies encourage healthy environments by protecting families when they are confronted with economic and social adversity (WHO, 2018). Policies provide an environment whereby a caregiver feels supported which will strengthen the relationship between caregiver and child (WHO, 2018). Family-centred care is providing the family with confidence and the necessary skills to care for these babies once they are discharged (WHO, 2018). Workplace policies include paid maternity leave, childcare, parental leave, and on-site facilities to express breastmilk (WHO, 2018; Richter, 2019). Implementation of the NCF into daily life, both in families, communities, services, and policies, will greatly have an impact on economics, socio-political and climatic issues including unanticipated events such as pandemics and other humanitarian issues (Black et al., 2021). South African policies struggle to align with international policies (Bust, 2020). Like international policies, emphasis is focused on maternal nutrition however we can't ignore the social aspect such as poverty, crime, violence, lack of education, and HIV/AIDS ((Bust, 2020; Richter, 2019).

2.3.4. Supportive services

The primary healthcare system has adequate reach to the mother to provide support, guidance, and awareness (WHO, 2018; Richter, 2019). Nurturing care should be included in the curriculum for healthcare workers (WHO, 2018). The healthcare sector has an important role to play in fostering and supporting nurturing care (Richter, 2019). In this scenario, healthcare workers are responsible to provide a supportive and nurturing environment for the mother before birth, at birth, and during the post-partum period by providing adequate information, advice, and support. (WHO, 2018; Richter, 2019). The focus should be on bonding and breastfeeding for both mother and baby as this will positively affect the development of the child combined with the hormonal changes from breastfeeding which will assist in reducing maternal stress (WHO, 2018). A nurturing environment for the mother will have a positive effect on her mental health which will positively affect the care and development of her baby (Black et al., 2021; WHO, 2018; Richter, 2019). However, in South Africa, there is the current challenge of inadequately trained healthcare workers to manage maternal stress (Gelaye et al., 2016). Added to this is the fact that healthcare workers struggle to manage the emotional distress of mothers of premature babies (Suchman et al., 2019). This leads to these mothers feeling unsupported (Hastings-Tolsma et al., 2018). Involvement across various sectors is required for the implementation of the framework (WHO, 2018). These sectors include health, nutrition, education, child protection, social protection, labour, and finance (WHO, 2018). In developing countries, the focus is always on the physical health of a mother as opposed to her mental health (Atif et al., 2015). One-third of women who have been pregnant or have experienced childbirth have been affected by mental health disorders (WHO, 2018). Mental health in developing countries has not been identified as a global crisis due to time and effort focusing on other diseases combined with a shortage of healthcare workers that are inadequately trained (Atif et al., 2015; Gelaye et al., 2016).

2.3.5. Empowered communities

Community and faith groups provide support, home visits, information, assistance, and providing points of contact with other mothers in similar situations considering beliefs and societal norms (Black et al., 2021; WHO, 2018). In South Africa, the public healthcare system only relies on a formal legislative framework (Coovadia et al., 2009). No effort has been made to be inclusive of community assistance (Coovadia et al., 2009). Community healthcare workers are a vital pillar of support to mothers in low-income groups by providing support, and information that facilitates access to social services but more importantly, confidante (Bust, 2020). Therefore, understanding the affected health status of women means understanding how cultures and economies undermine their status within communities (Atif et al., 2015). Besides health policies for women, health policies are extremely important in improving their social status for holistic healthcare to be implemented (Atif et al., 2015).

2.3.6. Caregivers and capabilities

A mother's birth and postnatal experience are linked to interactions she has with healthcare workers (Simpson & Catling, n.d.). A healthcare worker's role is to observe the mother's interaction with her baby and respond to and guide her (WHO, 2018). This can be done by praising the mother which will increase her confidence to care for her baby and induce her wanting to spend more time with her baby (WHO, 2018). Encourage her to talk to her baby more by providing age-appropriate recommendations for communication (WHO, 2018). Support and guidance to the mother through this journey with her baby in the NICU leans on healthcare workers (WHO, 2018). Keeping the line of communication open with both the healthcare worker and the mother will encourage her to seek help if needed (van Schalkwyk et al., 2020). Healthcare workers assisting mothers of premature babies expressed that the

mother–baby relationship in this group is more challenging as opposed to term babies (Minde, 2000). This causes the inability of healthcare workers to manage the emotional difficulties that these mothers face in NICU (Suchman et al., 2019). However, mothers receiving care in public sector hospitals expressed emotions of being disrespected, unsupported, and ignored by healthcare workers (Hastings-Tolsma et al., 2018; Simpson & Catling, 2015). When mothers seek help from healthcare workers, they are met with a lack of care which further results in a prolonged illness (Chopra et al., 2009). A current obstacle highlighted by the WHO is the lack of skilled healthcare workers in both obstetric and neonatal care (WHO, 2018). Governments need to prioritise the recruitment of adequate healthcare workers (WHO, 2018). The highest levels of anger were found in mothers who had negative interactions with their healthcare workers during birth and labour (Simpson & Catling, 2015).

2.4 Conclusion

Giving birth to a premature baby is a traumatic event that can have a negative impact on the mental health of the mother. This can be concerning as the state of her mental health is an important factor in being able to care for her child. Proper education and a nurturing environment for a mother of a premature baby can positively affect how she manages and cares for her baby as well as how she manages her own emotions. Mental health issues are always linked to emotions of shame, embarrassment, and denial. These emotions can hinder help–seeking behaviour. Applying the Health Belief Model allows an understanding of the various reasons help–seeking behaviour can be hindered in a public healthcare setting with access to resources that are either free or of minimal cost to the patient. The inception of the model was sparked by a healthcare system that only focused on disease prevention. Disease prevention is important; however, it can result in the challenge of acceptance when a patient is afflicted by a

disease, and this can affect treatment, compliance, and communication between patients and healthcare workers. As the model states, various factors influence a patient to accept the disease and take action to get treatment. This leads to exploring the next theory namely the Nurturing care framework which emphasizes that the health and development of a baby are dependent on the mental and physical health of the caregiver which is the mother. Premature babies spend an adequate amount of time in a hospital after birth, an environment that's filled with healthcare workers tending to these small and fragile babies. As a mother, this scenario is scary and intimidating as you observe how your baby is cared for by someone else. The only pillar of support the mother has in the hospital is the healthcare workers that are present daily. These healthcare workers need to provide a nurturing environment for the mother so that she can take care of her baby adequately. By applying both the Health Belief Model and Nurturing Care Framework it can be assessed whether there are any barriers to seeking help by mothers of premature babies in public sector hospitals healthcare workers.

CHAPTER THREE

LITERATURE REVIEW

3.1. Introduction:

This chapter reviews the literature and policies that explore the help-seeking behaviour of mothers of premature babies in public sector hospitals. The chapter begins by discussing the literature that explores and is not limited to the first 1000 days of entering motherhood, the risks of a premature baby as well as the needs of a premature baby. In addition, care and support for the mother and baby are discussed. This includes preconception care, help-seeking behaviour as well as barriers to seeking help. Lastly, the chapter concludes by reviewing the role of a healthcare worker as well as the public healthcare system in South Africa. All these discussions are aimed at understanding the help-seeking behaviour of mothers of premature babies in public hospitals.

3.2. First 1000 days:

Eighty percent of a child's brain develops between pregnancy and the age of two, a critical period also known as the first 1000 days (WHO,2018; Bust, 2020). Healthy brain development requires a safe, secure, and loving environment with adequate nutrition and stimulation from parents and caregivers (WHO, 2018). Lack of good nutrition can affect physical growth, muscle mass development, brain development, cognitive functioning, socio-emotional adjustment, and risk-taking behaviour (Bust, 2020). In addition to nutrition, cognition is vital during the first 1000 days as it is linked to mental health, problem-solving, and earning capacity (Bust, 2020). The quality of care an infant receives during the first 1000 days is imperative to

their growth into children, adolescents, and adults (Bust, 2020). Babies are born with all their brain cells called neurons (WHO, 2018). By the time they reach the age of two, these neurons would have made connections with their caregiver (WHO, 2018). These connections are formed by reading into stimulation given to them by their caregivers (WHO, 2018). Globally, newborn mortality still poses a huge crisis as most children are at risk of dying in their first year of life which still relates to one of the main causes of preterm birth (WHO, 2018). In South Africa, various other factors affect development and growth during the first 1000 days (Bust, 2020). This includes poverty, crime, violence, inadequate public education system, and HIV/AIDS (Bust, 2020). Emphasis is given to nutrition, but we can't ignore the social aspect during this critical time of a child's development (Bust, 2020). Currently, it is argued that research on the first 1000 days does not align with the south African belief system (Bust, 2020). In South Africa parents reached a consensus that the most influential age in their child's development is around 12 years (Bust, 2020). To them, this age was considered crucial in protecting them from teenage pregnancy, gang violence, and substance abuse (Bust, 2020). These factors were considered as bigger threats than the ones exposed to during pregnancy and early childhood (Bust, 2020). This is evident that international policies can be conflicting with local beliefs (Bust, 2020). Focusing on early childhood development is imperative not only for human development but to decrease health inequities (WHO, 2018). Ignoring this important aspect will have a significant impact on the economic and social cost which will transcend through generations (WHO, 2018). The first 1000 days is the window period to implement programmes to assist a child to survive and thrive (WHO, 2019). In addition to the growth and development of the child, what happens to the mother during the first 1000 days?

3.3. Motherhood

Throughout the duration of the first 1000 days, education is focused on her body's ability not only to bare new life but also to maintain the health of her baby (Pentecost & Ross, 2019). The apartheid era tainted motherhood by linking it to teenage pregnancy and pregnancy out of wedlock (Pentecost & Ross, 2019). Apartheid might be over and new policies are in place, however, women of colour in South Africa are still victims of gender-based violence and are largely held responsible for their reproductive choices (Pentecost & Ross, 2019). Becoming a mother in South Africa is influenced by so much history (Pentecost & Ross, 2019). A female's body is viewed not only as a host for a foetus but also as a vector of disease (Pentecost & Ross, 2019). Campaigns around maternal health are active but always focus on her body being the host for future generations, a future that she is not focused on (Pentecost & Ross, 2019). The state of her mental health is always ignored as the health of the baby is more important (Atif et al., 2015). The risk of mental health challenges is high during pregnancy and the post-partum period (Frieder et al, 2008). This has a negative effect on her family life, the mother-infant bond as well as the future mental health of her child (Frieder et al, 2008; WHO,2018). Her life is currently filled with so many challenges, all she lives for is getting through each day (Pentecost & Ross, 2019). Research shows that South Africa has the resources to provide adequate antenatal care but somehow only 41% of mothers show up for these appointments (Pentecost & Ross, 2019). This is linked to cultural barriers, transport difficulties, lack of education, or maternal irresponsibility (Pentecost & Ross, 2019). Despite her challenges to show up, she is still verbally abused and labelled 'unfit' or a 'bad' mother by healthcare workers in the public health sector (Pentecost & Ross, 2019). These are labels assigned to the very same person that is carrying the future generation of the country (Pentecost & Ross, 2019). The Nurturing Care Framework, therefore, emphasizes that healthcare workers are responsible for creating a nurturing environment before birth, at birth, and post-partum as the mother's

health impacts foetal development (WHO, 2018). A nurturing environment will positively affect her mental health which will influence the care she gives her baby (WHO, 2018). This type of care will in turn positively affect the development of her child (WHO, 2018). How can a healthcare worker create this nurturing environment for her when interacting with her (WHO, 2018)?

- Observe her interactions with her baby and respond and guide her.
- Praise the mother as this will build her confidence
- Encourage her to talk to her baby by providing age-appropriate recommendations for communication.
- Encourage her to spend adequate time with her baby

Motherhood is a journey that most women expect to go through at some point in life (Veronez et al., 2017) including the expectation of carrying a baby to term. However, this expectation may not be realized because the baby may arrive much earlier than expected. The way a birth unfolds can have a lasting effect on a mother (Hastings-Tolsma et al., 2018). There is always that window of birth that can be traumatic which draws a mother into a hole of emotions such as anger, disappointment, and loss (Simpson & Catling, 2015). 20 – 40% of women globally experiences trauma during birth which is defined differently by every female (Simpson & Catling, 2015). One notable factor that contributes to birth trauma is a baby born too soon (C. Anderson & Cacola, 2017). The trauma of her birth is now met with the fears of the unknown of whether her baby will suffer any long-term complications from being born too soon (Veronez et al., 2017). Birthing a premature baby leads to an immediate separation that is both physically and emotionally challenging for the mother (Veronez et al., 2017). The dissociation results in a lack of confidence to communicate and care for her small and fragile baby (van

Schalkwyk et al., 2020; Veronez et al., 2017). This can result in anxiety which can affect the mother–infant bond and her ability to seek help. (Van Schalkwyk et al., 2020).

3.4. Risks of having a premature baby

There is a risk of death for all newborns, in the first few days after birth however this risk of death increases when born too soon (Lawn et al., 2013). The Global Strategy for women, children, and adolescent health highlights that newborn mortality is still high as most children are at risk of dying within their first year of life (WHO, 2018). One of the main causes is preterm birth (WHO, 2018). The current rate of premature birth will result in most people experiencing this tragedy once in their life or knowing someone close to them that will go through it (WHO, 2012). A premature baby is defined as being born alive before 37 weeks gestation (WHO, 2012). This can further be divided into extremely preterm (< 28 weeks), very preterm (28 to < 32 weeks), and moderate to late preterm (32 to < 37 weeks) (WHO,2012). Every year, 15000 babies are born prematurely and this increases over time (WHO, 2012). More than 60 % of these preterm births occur in Africa and Asia (WHO, 2012). Premature births are currently the leading cause of death in children under the age of five (WHO, 2012). Who are these vulnerable newborns that come so early? Factors that result in preterm birth are divided into three categories (Ramokolo et al.,2019):

(1) Maternal conditions: extrauterine infections, maternal trauma, worsening maternal disease, HIV, pre-eclampsia/eclampsia.

(2) Foetal conditions: IUGR (intra-uterine growth restriction), infection/inflammatory response syndrome, foetal anomaly, multiple foetuses.

- (3) Placental conditions: placental abruption, placenta previa, other placental abnormalities

There are additional factors besides physiological and access to care that contribute to a baby being born too soon which include: poverty, ethnicity, gender bias, maternal age, educational status, educational status of a caregiver, disability, and low literacy of the caregiver (WHO, 2019). Developing countries are more vulnerable as they face challenges within the healthcare sector, and this contributes further to the neonatal mortality rate which is still a current challenge (WHO, 2019). Neonates born in a developing country usually die when born before 28 weeks gestation (WHO, 2019). In South Africa, health initiatives for females are vertical only focusing on one risk factor at a time (Tomlinson et al., 2014). This approach is not conducive as these mothers experience multiple risk factors at a time (Tomlinson et al., 2014). A horizontal approach needs to be adopted so that women are screened for benefits on all spectrums to improve health outcomes during pregnancy (Tomlinson et al., 2014).

3.5. Needs of a premature baby

The birth of her small baby results in an immediate separation which robs the mother of bonding and breastfeeding (van Schalkwyk et al., 2020). These babies are born small and challenged physically and neurologically which requires individualized care (Mahwasane et al., 2020) and results in an immediate NICU admission after birth. This type of specialised and supportive care can only be done in a hospital setting by adequately trained healthcare workers (WHO, 2019). For these babies to survive, care is required 7 days a week, 24 hours a day (WHO, 2012; WHO, 2019). The amount of neonatal care will depend on which category of prematurity they were born in (WHO, 2012). The birth of a premature baby, however, becomes complicated as they are challenged with temperature instability, feeding difficulties, infections,

low blood sugar, and breathing difficulties (Lawn et al., 2013). Health challenges such as cerebral palsy, chronic lung disease, vision and hearing loss, and intellectual impairment affect the lifecycle of these babies long after discharge (WHO, 2012). Besides specialised care from healthcare workers, care from the mother is essential in the growth and development of these babies. A mother is responsible for providing essential care to her newborns such as breastfeeding, warmth, and a clean environment (Lawn et al., 2013). The Nurturing Care Framework is a framework that helps children survive and thrive to transform health and human potential (WHO, 2018). The framework is a guiding tool to initiate policies and services to help parents and caregivers provide nurturing care at the core (WHO, 2018). The Framework also highlights the important role that all sectors including the health sector must play to support the healthy development of the child (WHO, 2018). Preterm babies need nurturing care more but somehow receive less of it (WHO, 2018). This is due to the emotional distress the mother is caused by separation and the fragility of her child (Veronez et al., 2017). The responses of these small babies are less predictable which requires guidance on how to interact with them (WHO, 2018). The absence of nurturing care in premature babies will put them at risk of developmental delays (WHO, 2018). In 2019 the World Health Organisation released a policy called, 'Survive and Thrive: Transforming care for every small and sick newborn. This policy states majority of newborns can survive and thrive provided they are given quality care which includes inpatient care (WHO, 2019). This deduces the implementation of nurturing care in the healthcare sector to create a healthy and safe environment for the mother to tend to the needs of her premature baby (WHO, 2018). The financial implications of preterm birth are huge not only for the family but also for a country to manage (Ghimire et al., 2021). The rate of premature birth is increasing yearly and can be reduced by focusing on maternal care and women's health to reduce the death rate of premature babies (WHO, 2012).

3.6. Care and support for mom and baby

For a mother to love and care for her baby, support and love need to be given to her also (Bust, 2020). Premature babies require extra care and attention; however, statistics reveal that 30 million vulnerable new-borns are left behind in terms of essential care (WHO, 2019). This is concerning as the only way they can survive and become part of families and communities is if they receive quality patient care (WHO, 2019). Besides the care for her baby, the mother also requires care and support while she navigates through this difficult time (Veronez et al., 2017). Research states that the survival and well-being of both mother and child are linked (WHO, 2019). Investing in their care could save 747 400 babies which results in a 50% reduction in neonatal mortality (WHO, 2019). This continuum of care would optimize health, promote efficiency, lower costs, and reduce duplication of resources (WHO, 2019). Allowing a mother to voice her experiences is key in the creation of care that embodies humanistic, family-centred service (Hastings-Tolsma et al., 2018).

3.6.1. Preconception care

The quality of care a woman receives before and in-between pregnancies are vital in ensuring a mother and baby remain healthy (Goossens et al., 2018). Preconception care is defined as, 'a set of interventions that aim to identify and modify women's health or pregnancy outcomes through prevention and management (WHO, 2012). Once a woman reaches adolescence, preconception care should be initiated due to preterm birth being a risk factor when it is absent (WHO, 2012). Education around pre-conception care is usually done by healthcare workers, however, this has not been attainable (Goossen et al., 2018). Interventions around preconception care include family planning, nutrition, and physical activity, tobacco, alcohol, and substance abuse, occupational and environmental exposures, family history and genetic risks,

infectious diseases and immunisations, medical and psychosocial conditions and lastly, medication (Goossen et al., 2018). In covering these interventions, some barriers make pre – conception challenging to overcome by both mother and healthcare worker (Goossen et al., 2018). Barriers to pre-conception care for the mother include lack of awareness and unfamiliarity with the pre-conception care concept, not fully planning a pregnancy, perceived absence of risks, perceived sufficient knowledge, and interactions with healthcare workers (Goossens et al., 2018). In addition to that, the barriers to preconception care for healthcare workers include confusion over who will provide pre-conception care to the patient, lack of training, perceived importance (refers to not being convinced of the importance), lack of resources (money, space, time, manpower) and added workload (Goossens et al., 2018). The pathway to nurturing care starts with the mother and extends into communities via support, enablers, and specialised services (WHO, 2018). Community healthcare workers have been identified as vital pillars of support in low-income groups (Bust, 2020). They provide support, and information, facilitate access to social services as well as act as confidants for a mother (Bust, 2020). Community healthcare workers are linked to lower rates of hospitalisation, stunting, maternal depression, higher levels of exclusive breastfeeding, increased vocabularies, and enhancement of the mother-infant bond (Bust, 2020). According to the Nurturing Framework, community healthcare workers provide support, home visits, information, and providing points of contact with other mothers in similar situations considering local beliefs and societal norms (WHO, 2018). This care she projects is not only dependent on her physical health but also her mental health which is important yet ignored when caring for her baby (Atif et al., 2015; WHO, 2018).). A mother just wants to be heard and prioritised without any judgment (C. M. Anderson et al., 2006). The low-income group in South Africa lives through chronic stress that causes poor physical and mental health (Suchman et al., 2019). This amount of stress projects further in affecting the cognitive, emotional, and physical development of the

child (Suchman et al., 2019). Giving birth to a premature baby is a traumatic experience that culminates in many negative emotions such as shock, guilt, and unhappiness (Veronez et al., 2017). The situation becomes very challenging for the mother as the premature baby requires immediate hospitalization, separating mother and baby, while the mom also experiences shock at the fragility of the baby (Veronez et al., 2017). The immediate separation from her baby robs her of skin-to-skin contact and breastfeeding immediately after birth (Henderson et al., 2016). The dissociation results in a lack of confidence to communicate and care for her small and fragile baby (van Schalkwyk et al., 2020; Veronez et al., 2017). The challenge of communicating with their baby combined with hospitalisation hinders the bonding process (Anderson & Cacola, 2017; van Schalkwyk et al., 2020). Mothers also have this assumption that the NICU is strict and governed by various restrictions hence becoming passive onlookers while their babies are cared for by healthcare workers (van Schalkwyk et al., 2020). This assumption and environment only heighten her emotions of anxiety and insecurities around caring for her baby (van Schalkwyk et al., 2020). These experiences are unexpected, and the mom then struggles to cope (Veronez et al., 2017). The fragility of her baby is unexpected which makes it even harder for her to cope (Veronez et al., 2017) which means the mother needs help. With the correct support from the healthcare team, a mother can eventually start to feel confident and hopeful (Veronez et al., 2017).

3.6.2. Help seeking behaviour

‘Help – seeking behaviour refers to a complex decision-making process instigated by a problem that challenges personal abilities ‘ (Cornally & McCarthy, 2011). To seek help can also be a response to illness and resources outside of oneself to accomplish a task or solve a problem (Biddle et al., 2007; Ogan et al., 2015). This response is linked to questions of

‘when’ and ‘how’ and is not usually attributed to positive change (Biddle et al., 2007; Gulliver et al., 2012). Individuals naturally seek help from people around them like family or friends as opposed to a healthcare worker (Gulliver et al., 2012). Help – seeking behaviour includes various pathways to care which begins in the community and ends with treatment by a healthcare worker (Biddle et al., 2007). To seek help in a healthcare setting means receiving help from a healthcare worker or receiving a service for any challenges associated to mental health (Magaard et al., 2017). This could refer to therapy or counselling in either an inpatient or outpatient basis (Magaard et al., 2017). Help - seeking behavior in mothers are linked to four different pathways that could be linked to barriers in accessing the necessary care (Anderson et al., 2006). Education about mental health is imperative in assisting the mother in identifying the different pathways before reaching out to a healthcare worker (Fonseca et al., 2015). These pathways include accepting a diagnosis, perceptions of the causes of the distress, reactions to being referred for any treatment, perceptions of their child and other mental health services (Anderson et al., 2006). The Health Belief Model states that for an individual to take action to prevent disease, the individual needs to believe that they are susceptible, severity of the disease is mild and won’t largely affect their life, action will reduce severity and lastly have the belief that they can be asymptomatic with a current illness (Rosenstock, 2016). These mothers are fully aware of their emotions and distress they currently in, accepting it as a problem means attaching a diagnosis to it (Anderson et al., 2006). A consensus revealed that majority of mothers believe that their emotional distress is caused by external factors namely poverty, abuse and managing challenged children (Anderson et al., 2006). The founders of the Health Belief Model stated that it was the personal circumstances of the individual, not the environment that will influence the individuals behaviour however his environment will be represented or portrayed during the reaction (Rosenstock, 2016). Tested with either the physical or psychological health of their

child results in maternal distress as they somewhat feel responsible and therefore carry around emotions such as guilt and blame (Anderson et al., 2006). The resistance to seek help also means that it is required from her to make internal changes which they deem as futile (Anderson et al., 2006). They also perceive emotional distress as part of normal life (Anderson et al., 2006). If they can physically complete any daily task, it is not considered serious enough to warrant help (Anderson et al., 2006; Biddle et al., 2007). Self – medicating in terms of cigarettes or narcotics becomes an option to manage the emotions she is currently experiencing (Nobiling & Maykrantz, 2017). Masking her emotions like this decreases the maternal sensitivity with her baby (Suchman et al., 2019). Help is only necessary when it reaches a point of self-harm (Anderson et al., 2006; Biddle et al., 2007). At this point the quality of life would have drastically decreased which can result in poor physical health and an additional strain on the healthcare sector (Smith, 2009). The emotional turmoil for a mother of a premature baby causes her to lack the ability to manage and process her emotions (Veronez et al., 2017). Between her baby born too soon and separated from her to her questioning her role and capabilities of a mother results in her lack of ability to seek any help (van Schalkwyk et al., 2020). Screening tools has been identified as useful tool to detect mental health issues however it won't necessarily result in treatment regardless of cost (Freed et al., 2012; Rosenstock, 2016). Screening tools can be beneficial in this group of mothers however in South Africa there is still the additional challenge of mothers not attending regular antenatal appointments (Id et al., 2019). Research states that due to missing antenatal appointment only 36% of women don't receive antenatal steroids required for her baby (Ballot et al., 2010). This is very concerning as it is required to improve neonatal outcomes (Ballot et al., 2010). The immediate NICU admission will result in her not attending any postnatal programmes as she will spend her time bonding with her baby (Henderson et al., 2016). Forming a collaboration with psychologists in the public healthcare sector could be a

useful tool in utilization of mental health services (Smith, 2009). Their role would be to consult as well as train healthcare workers on how to manage emotional distress as developing countries still face the current challenge of the inability of healthcare workers to manage maternal distress (Smith, 2009; C.M. Anderson et al., 2006).

3.6.3. Barriers to seeking help

Seeking help can be met with various barriers that can hinder the process to care (Fonseca et al., 2015). The Health Belief Model highlights that even though preventative screenings are offered for free or at a minimal cost, patients were still hesitant in taking part in these screenings (Rosenstock, 2016). These barriers are divided into three categories (Fonseca et al., 2015)

(1) Knowledge

- Lack of education regarding mental health and how to identify symptoms.
- No knowledge of available services, treatment options as well as benefits.

(2) Attitudinal barriers

- Stigma: the fear of being isolated from the community and being labelled as unstable (Biddle et al., 2007).
- Medication: the fear of being dependant on anti-depressants.
- Cultural appropriateness: it's not common practice for mothers raised in traditional societies to express their feelings (Suchman et al., 2019).

(3) Structural barriers

- Financial and work constraints
- Childcare responsibilities: insufficient time to attend appointments
- Family status: mothers that are married or in a relationship are less likely to seek help

- Access to healthcare

The mothering role is linked to being emotionally strong (Freed et al., 2012). Disclosing any distress can be viewed as a sign of weakness (Freed et al., 2012). This extends into it being culturally inappropriate to talk about your feelings (Suchman et al., 2019). This is evident that in order to understand the affected health status of a women, means understanding how cultures and economies undermine their status within communities (Atif et al., 2015). In developing countries most mothers work in the informal sector which relates to acquiring a trade as a source of income (Richter, 2019). This type of work requires them to be away from home which challenges them with managing childcare and minimal time to attend any appointments if help was sought (Richter, 2019). Stigma is also a prevalent barrier in seeking help (Biddle et al., 2007). Seeking help makes the problem at hand public and alludes to it being serious which links to the fear of being labelled mentally ill or being unstable (Biddle et al., 2007; Freed et al., 2012; Magaard et al., 2017). Stigma is societies misunderstanding of mental health and the negative reactions linked to it (Forsterling, 2005). This negative reaction causes the individual challenged with mental health issues to lose hope and the confidence to get better (Forsteling, 2005). Similarly, there is a resistance in being placed in a box being assigned a diagnosis and being placed on medication (C. M. Anderson et al., 2006). This barrier prevents a mother from just being heard without any diagnosis being attached to her (C. M. Anderson et al., 2006). Education around mental health poses another challenge in the awareness and acts as a barrier in utilization of any services offered. Mental health literacy is defined as ‘knowledge and beliefs about mental health disorders which aid their recognition, management and prevention’ ((Magaard et al., 2017). Currently awareness is active during the post-natal period due to the risk of post-natal depression however the conversation around mental health needs to start from the time of conception (Fonseca et al., 2015).

The WHO defines maternal mental health as ‘a state of well-being in which a mother realises her own abilities, can cope with normal stresses of life, can work productively and fruitfully, and is able to contribute to her community’ (Herrman et al., 2005). The risk of maternal depression is higher in a mother with a premature baby (Misund et al., 2014). 49% of mothers still experience trauma one year after the birth of her preterm baby (Jubenville et al., 2012). Focus is placed on a mother’s physical health as opposed to her mental health (Atif et al., 2015). Maternal mental health interventions are non-existent in LMIC despite recommendations from the WHO to integrate into primary healthcare settings (Atif et al., 2015). This is concerning as it is a major public health concern that adversely affects maternal morbidity (van Heyningen et al., 2017). Being a mother in a LMIC comes with many risk factors that predisposes them to mental health issues, such as (van Heyningen et al., 2017):

- Socioeconomic factors: unemployment and poverty
- Unintended, unwanted pregnancies, previous pregnancy loss due to termination, miscarriage or stillbirth or special needs child
- Food insecurity
- Trauma linked to life threatening events

Mental health is being side-lined in these countries due to managing communicable and non-communicable diseases which leaves 76-85% of patients with mental health issues, untreated (Atif et al., 2015). Maternal mental health issues are a cause of disease – related disability which leads to poverty, social grant reliance and unemployment (Freed et al., 2012). In South Africa, policies are guided by local and international policies as well as local history (Pentecost & Ross, 2019). However, so many of these policies have not implemented and there is no urgency to do so (Coovadia et al., 2009). The policies that are implemented is

steered towards her physical health to benefit the health and development of her baby when the focal point needs to be her mental health as this is the pinnacle point that contributes to the health of her foetus (Pentecost & Ross, 2019; WHO, 2018).

3.7 Role of a healthcare worker

The role of the healthcare worker is to provide support, advice, and information to a patient, and this is also relative to a mother of a premature baby (WHO, 2018). They are required to provide the necessary support during this difficult time by keeping the line of communication open which can positively contribute to increasing her confidence to care for her baby as well as seek any help she needs (van Schalkwyk et al., 2020; Veronez et al., 2017). A women's birth experience is linked to interactions with healthcare workers, not just the nature of her birth (Simpson & Catling, 2015). The nature of the interaction with a healthcare worker can affect the mother's long-term memory linked to birth trauma (Simpson & Catling, 2015). All of them expressed feelings of disappointment with healthcare workers as they show no interest in their well-being, and they often feel ignored if any of their emotions are expressed (Anderson et al., 2006; Simpson & Catling, 2015). When a mother seeks help from a healthcare worker she is met with a lack of care, lack of advice, and perceived rudeness which then acts as a barrier to seeking help which can lead to her condition worsening and being prolonged (Chopra et al., 2009). All healthcare workers are viewed as one system that lacks relatability to life and have the authority to label a mother unfit and take her kids away (C. M. Anderson et al., 2006). The nursing profession in South Africa started in the 19th century and training was done by missionaries (Coovadia et al., 2009). Nurses were trained to moralise and save as opposed to nurture or care for the sick which resulted in creating an ideology that they were rude (Coovadia et al., 2009). However, this ideology is a current reality in the healthcare system (Coovadia et

al., 2009). Nurses are currently linked to unfavourable behaviour, especially in sexual and reproductive health (Coovadia et al., 2009). These mothers have also emphasized that there is no relatability to healthcare workers as they have no life experience (Anderson et al., 2006). In addition, healthcare workers also expressed difficulty in managing the emotional distress of mothers of premature babies (Suchman et al., 2019). When it comes to maternal mental health, healthcare workers are only focused on risk factors and are inadequately trained to address them. (Anderson et al., 2006; Freed et al., 2012). In South Africa, inadequately trained healthcare workers can be traced back to 1994 (Coovadia et al., 2009). This affects the distribution of health services in maternal health, mental health, and child health to be carried out (Coovadia et al., 2009). Healthcare workers attach any form of emotional distress to a specific diagnostic model taught to them and this is how patients are treated by them (Anderson et al., 2006). Resources are present but healthcare workers are not adequately trained to manage maternal distress (Chopra et al., 2009). This results in no health education given to mothers (Chopra et al., 2009). During the 1990's many nursing schools closed (Coovadia et al., 2009). This eventually led to a shortage of healthcare workers in developing countries (Naicker et al., 2009). The amount of qualified healthcare workers is therefore not adequate to meet the needs of the country (Naicker et al., 2009). However, so many of these healthcare workers are also migrating out of the public healthcare system (Naicker et al., 2009). This is linked to poor salaries, lack of established posts, underfunding of health facilities (poor working conditions), civil unrest, and risks to personal security (Naicker et al., 2009). The shortage of healthcare workers has also led to the inception of many NGOs to assist with healthcare on a community level (Coovadia et al., 2009). Within Africa, there are 2.3 healthcare workers per 1000 people (Naicker et al., 2009). These factors are concerning and currently are still challenges that the government is trying to overcome as it places a lot of strain on the healthcare system (Coovadia et al., 2009).

3.8. Public sector hospitals in South Africa

The Global Strategy for women's, children and adolescent health states that half of the world's population lacks access to healthcare services (WHO, 2018). 800 million people spend more than 10% of their household budget on healthcare (WHO, 2018). South African history is laced with discrimination which has transcended into modern-day South Africa as well as the public health sector (Coovadia et al., 2009). After apartheid, the public health sector changed drastically (Coovadia et al., 2009). It evolved into an integrative and comprehensive healthcare system aiming to erase the history of apartheid and to provide essential care to disadvantaged communities (Brady et al., n.d.; Coovadia et al., 2009). Even though major positive shifts have been made to the healthcare system, common problems such as health inequity remain, which is linked to apartheid (Brady et al., n.d.; Coovadia et al., 2009). This is evident in different races displaying vast differences in rates of disease (Coovadia et al., 2009). For example, the rate of HIV/AIDS is higher in the black community as opposed to the white, Indian, and coloured communities (Coovadia et al., 2009). Infant mortality is higher in the black population (Coovadia et al., 2009). This statistic is evidence of basic household living conditions (Coovadia et al., 2009). South Africa is considered a middle-income country based on its economy; but the health system is considered worse than some lower-income countries (Coovadia et al., 2009). The public healthcare system is currently under strain (Econex, 2013). This is due to the majority of the population seeking healthcare within the public sector as well as the added strain of immigrants from neighbouring countries (Econex, 2013). South Africa has 216 public sector hospitals which equate to approximately 28 000 beds (Econex, 2013). This limits resources as well as staff, as patient numbers exceed what the staff can manage (Econex, 2013; Ballot et al., 2010). 84 % of women in South Africa give birth in the public healthcare system (Chopra et al., 2009). When a woman gives birth, this results in her being

discharged six hours after vaginal birth and three days after a c-section (Chopra et al., 2009). When giving birth at a public hospital women expressed feelings of isolation, and loneliness during birth, labor, and post-partum (Hastings-Tolsma et al., 2018). They expressed care as unsympathetic and felt ignored (Hastings-Tolsma et al., 2018). Rudeness and aggression were common among healthcare workers (Hastings-Tolsma et al., 2018). Due to a shortage of beds, the primary healthcare system is unable to assist effectively with the demand for preterm birth (Rhoda et al., 2019). Healthcare workers also experienced frustration due to staff shortages and a lack of adequate equipment in the NICU which compromise adequate care for the preterm baby. (Mahwasane et al., 2020). Why is the South African public healthcare system so flawed? During apartheid management positions in healthcare were only occupied by white males (Coovadia et al., 2009). From 1994, this changed to include women and black people (Coovadia et al., 2009). The implementation of this was problematic because inexperienced individuals are placed in senior management posts which results in a lack of transformation and effective and efficient management (Coovadia et al., 2009). The level of inexperienced individuals stems as far as the minister of health (Coovadia et al., 2009). Positions in the system are appointed because of loyalty rather than being experienced to manage the role they are assigned to do (Coovadia et al., 2009). Poor stewardship, leadership, and management of the health system have led to so many flaws such as policies not being implemented, lack of human resources in rural areas, variable leadership, and management at different levels of health, quality of care in the public sector and uneven distribution of health services from province to province (Coovadia et al., 2009). There is no unity, and no accountability, and currently South Africans are convinced they are still products of apartheid (Coovadia et al., 2009). This train of thought deems very problematically as it won't effectively activate change and manage current problems (Coovadia et al., 2009)

3.9 Conclusion

To conclude the chapter, it can be deduced that the literature on help-seeking behaviour has only focused on mothers and not on mothers of premature babies. Additionally, there is no literature on mothers who had premature babies in public sector hospitals in South Africa. Therefore, this study is needed to provide an understanding of having a premature baby in a public sector hospital and how it influences her ability to seek help. The following chapter will be examining the methodology of the study.

CHAPTER 4

METHODOLOGY

4.1 Introduction

This chapter will cover the research methodology used in the study. The study begins by stating the aims and objectives and the qualitative approach applied to meet the aims and objectives. The methodological process includes a research approach, sampling, data collection tools, and analysis as well as ethical considerations.

4.2 Research question, aim and objectives

A research question is the question or questions that will guide the research project (Leavy, 2017; Creswell & Creswell, 2018). Once the research statement and objectives have been established, research questions can be devised from the objectives (Leavy, 2017). A researcher is not limited to the number of research questions, which can be anywhere from one to three questions (Leavy, 2017).

The following research question was formulated for this study:

- What are the help-seeking behaviours of mothers who had premature babies in public sector hospitals?

A study can include a primary research question which is the main question that needs to be answered and add on secondary questions which focus on different components of the primary question but leaves open the questioning (Leavy, 2017; Creswell & Creswell, 2018). These

secondary questions can be used as part of the interview schedule that might be part of the research study (Creswell & Creswell, 2018). The following questions are the secondary questions linked to the study:

- (1) What are the perceptions, experiences, beliefs, and attitudes of mothers who birthed premature babies in a public sector hospital?
- (2) What kind of help do mothers need from a healthcare worker following the birth of their premature baby?
- (3) What resources are available to assist mothers who had premature babies in a public sector hospital?
- (4) How do healthcare workers assist mothers who birthed premature babies?
- (5) How do mothers seek help in a public sector hospital after having a premature baby?

4.2.1 Aim of the study

The research aim is the most important statement in the research process (Creswell & Creswell, 2018). The research aim outlines the reason for the study and the possible outcome (Creswell & Creswell, 2018). The aim of the study can provide information on the topic, the participants, the setting, and the methodology (Leavy, 2017). The aim of the study was to explore the help-seeking behaviour of mothers who had premature babies in public sector hospitals.

4.2.2 Research objectives

The objectives of the study:

- (1) Explore the perceptions, experiences, beliefs, and attitudes of mothers who had premature babies in a public sector hospital.
- (2)) Explore the kind of help mothers need from a healthcare worker following the birth of their premature baby.
- (3) Identify and explore the resources to assist mothers who had premature babies in a public sector hospital.
- (4) Explore how healthcare workers assist mothers who birthed premature babies.
- (5) Explore how mothers seek help in a public sector hospital after they had given birth to a premature baby.

4.3 Research Methodology

This research used a qualitative approach. Qualitative research is learning about social reality (Leavy, 2014). In both social and behavioural science, the qualitative approach is mostly used to explore, describe, or explain social phenomena (Leavy, 2014). This approach allows the researcher to explore social phenomena by providing an in-depth understanding (Leavy, 2014). It is a naturalistic approach to studying people in their natural settings (Hennink et al.,2020). Qualitative research helps us understand and explore the meanings individuals attach to a social or human problem (Leavy,2017)):

- **Natural setting:** This type of research doesn't involve taking participants to a laboratory but rather gaining a deep insight by interacting with the participants in the environment where the problem lies. Interaction is done between the researcher and participants over an extended period. This is one of the major characteristics of qualitative research.

- ***Researcher as a key instrument:*** the researcher collects all the data by themselves which includes conducting interviews and taking notes. They develop their protocol and interpretation is also done by the researcher.

- ***Multiple sources of data:*** qualitative research does not involve only a single source of data. Data collection is done using multiple sources such as interviews, observations, notes, documents, and audio recordings. This gets transcribed and assigned codes to generate themes for interpretation.

- ***Inductive analysis:*** this involves building codes based on the data collected. Codes are terms that are assigned to the transcribed data to generate possible themes.

- ***Participants' meanings:*** through the process of qualitative research, careful attention is given to the participant's interpretation of the problem at hand rather than the researcher's meaning of it.

- ***Emergent design:*** this means that the research process can change at any time once the data collection procedure starts. interview questions can change, and the method of data collection can alter as well as the research setting. These changes are positive as it only just develops a deeper understanding of the study.

- ***Reflexivity:*** Reflexivity refers to comments the investigator includes about their role and self-reflection on the topic. These comments should touch on past experiences and how past experiences shape interpretations; however, the investigator needs to be careful not to share too much on past experiences so that no biases are created. During

this research process, notes were recorded on observations about data collection, what the investigator has learned, and any concerns about the reactions of the participants relating to the research process.

- ***Holistic account:*** this refers to the researcher developing an idea of the problem using multiple perspectives homing in on various factors that contribute to the study. This approach emphasizes real life and how individuals react in the real world. For example, there can be various factors that can hinder a mother of a premature baby to seek help. These factors can range from age, ethnicity, fear, lack of education, and stigma (Magaard et al., 2017).

This research methodology was chosen as it allowed an exploration of the help-seeking behaviour of mothers of premature babies who gave birth in public sector hospitals. There was no previous research that was done on this specific topic. This methodology has set the benchmark for more research as well as explored new themes that emerged from the study.

4.4 Research Approach

A research approach is the process of enquiry within a qualitative research study (Creswell & Creswell., 2018). A research approach provides direction to procedures in the research study (Creswell & Creswell, 2018). Three elements make up a research design and guide the researcher on what approach to use (Leavy, 2017). These elements are (Leavy, 2017):

- (1) ***Philosophical: ‘What do we believe?’***. The researcher will usually have a set of beliefs that will assist in guiding the research design. These beliefs are focused on the social world and what it is made up of. This structure of beliefs influences the creation of the topic as well as

the entire study up until the findings and discussion. Mothers of premature babies are in minority, however, experienced a lot of emotional distress from their babies born too soon. This experience required a lot of physical and emotional support. Our public healthcare sector is currently strained due to the majority of the population utilising this sector of health. This follows with the concern of whether this minority of mothers were receiving adequate support and guidance to carry her through this challenging time of motherhood.

(2) ***Praxis: 'What do we do'?*** This refers to the practical part of the research which involves choosing the research approach conducive to the study. The research approach allowed a deeper understanding of the topic that is relatively new. The approach also allowed new themes to emerge that requires further research.

(3) ***Ethics: this ties in with your beliefs.*** Ethics will comprise fairness, truthfulness, integrity, and morality. Exploring help-seeking behaviour in mothers who had premature babies in public sector hospitals involved a lot of emotions and carried the risk of being challenging for the mother to disclose. Ethics guided the research in reducing this risk while keeping the mother and her emotions safe.

The study followed an exploratory approach. Exploratory research adopts an open, flexible approach by filling the gaps in a topic that has been under-researched or new (Leavy, 2017). This research approach usually prompts further research (Leavy, 2017). This type of research approach has been alluded to as being risky as the researcher doesn't know if the expected outcome will be achieved until they are deep into the research process (Elma et al, 2020). Regardless of the risk, exploratory research is the evolution of research with new topics emerging all the time (Elman et al, 2020). In social sciences, this approach is used for two reasons namely (1) a topic that has never been researched before and (2) an existing topic is

explored to produce more ideas (Elman et al, 2020). This approach was chosen as it allowed the researcher to get close to the participants to gain a better understanding of the participants about help-seeking behaviour of mothers who had premature babies in public sector hospitals.

4.5 Research setting

Data collected in a qualitative study is done in the setting where the issue is experienced by participants (Creswell & Creswell, 2018). The research setting allows the researcher to interact with participants and observe how they react within the context of the study (Creswell & Creswell, 2018). The study was conducted within the NICU at a public sector hospital in Cape Town, Western Cape.

The public healthcare sector is state-funded. In South Africa, the public healthcare sector is severely under strain. This is due to seventy-one percent of the population seeking healthcare within the public sector as well as added strain placed by individuals from neighbouring countries. Currently, South Africa has 216 public hospitals which equate 28 000 beds. This limits resources as well patient numbers far exceeds what staff can manage. There are more than 400 public hospitals which are divided into your regional hospitals as well as your primary care clinics.

The Neonatal Intensive Care Unit (NICU) is a specialised space designed to keep your preterm baby safe, warm, and well-fed under expert care. The NICU provides a range of levels of care: the neonatal intensive care unit (20 babies), high care (30 babies), and KMC (10 mothers with babies). Other features include breastfeeding spaces, sterile milk kitchens, and parent support facilities. Annually, 600 premature babies get admitted into the NICU.

4.6 Population and sampling

Population refers to a small group of people that the researcher will make claims about in the proposed study (Leavy, 2017). In this study, the population was mothers who birthed premature babies in a public sector hospital. The focal point of the study was on mothers of premature babies within a NICU setting at a public sector hospital and to assess if there were any barriers to seeking help.

Sampling refers to the type of participants to be included in the study (Leavy,2017). This means selecting a small number of participants from a larger population (Leavy,2017). In this study, a total of twenty-one participants were recruited. The sample included six healthcare workers as well as fifteen mothers of premature babies within a neonatal intensive care unit located within a public sector hospital in Cape Town. Purposeful sampling was used. This type of sampling allowed a deliberate selection of specific individuals needed to address the purpose and questions related to this study (Leavy,2017) which are mothers with premature babies and healthcare workers in a public hospital setting.

This type of sampling is often used in qualitative research (Leavy, 2017). Also known as a judgment or purposive sample which alludes to purposely selecting participants that link to the study at hand (Leavy, 2017). Qualitative sample size can be small hence utilising this type of sampling will allow for in-depth analysis and understanding of the topic at hand (Leavy, 2017).

4.7 Data collection tools

An interview schedule was used as the primary tool in this study (Leavy,2017). This included a few open-ended, unstructured questions that provided an in-depth understanding of participants' views and opinions (Leavy,2017). Questions included 'How are you feeling?', 'How is the relationship with your baby?', 'Are you aware of any resources available to assist you?', 'Describe a typical day in the neonatal intensive care unit?'. Questions for the interview schedule were derived from the objectives of the study. Field notes were recorded by the researcher. These field notes noted reactions and body language from the participants and assisted the researcher with possible themes for the research.

4.8 Data collection procedure

Data collection procedure refers to the various steps that were taken to collect data, the data collection tools used, and how the data will be recorded (Leavy, 2017; Creswell & Creswell, 2018). Once ethical clearance was given by the Biomedical Research Ethics committee at the University of the Western Cape, permission was sought from the gatekeepers at a public sector hospital to proceed with data collection in NICU. Once access was granted to the NICU, this allowed the researcher a specified time of eight weeks for data collection. Once the participant agreed to participate in the study, they were provided with an information sheet as well as informed consent. These documents were important in adhering to ethical guidelines. The information sheet provided a brief introduction to the participant, the study at hand, how the information will be utilised as well as anonymity in answering. This information allowed the participant to clarify anything not understood and decide whether to participate or not. Informed consent gave the researcher permission to collect data via audio recording or written notes. Data was collected in the natural setting of the participant (Leavy,2017). Interviews were

conducted to collect data. People are naturally conversational which draws on the interview method as a conversation tool (Leavy,2017). This method increases the chances of questions being answered by the participant in a natural, organic manner (Leavy,2017). Interviews were conducted face-to-face (Leavy,2017) while adhering to Covid-19 protocols such as social distancing and masks should be kept on all the time by the researcher and participants. These interviews focused on reasons behind the lack of help-seeking behaviour of mothers of premature babies in the public hospital setting from both groups of participants namely mothers of premature babies and healthcare workers.

Individual interviews were conducted with the participants. Field notes were recorded. Field notes referred to the researchers' notes after each interview that recorded reactions, and body language as well as the research site. All interviews were conducted in English and took anywhere between 10-20 minutes. All participants did not consent to be audio recorded. Some of the participants preferred their responses to be written down. Interviews were conducted in the NICU setting located in the maternity building of the hospital.

4.8.1 Interviews

An interview is a basic tool of enquiry (Seidman, 2006). The purpose of an interview is to provide an understanding of an individual's lived experience and their interpretation of those experiences (Seidman, 2006). The study used semi-structured interviews. Semi-structured interviews do not allude to a specific answer as it allows the participants to answer and narrate their own experiences and allows any interpretation of the questions asked (Leavy, 2017). Each interview question has certain probes that guided the researcher to develop certain themes to be covered (Leavy, 2017). All interview questions were formulated from the objectives of the research study.

4.8.2 Field notes

Field notes refer to the additional notes recorded by the researcher after each interview. These notes account for body language, reactions from the participants as well as activities in the research setting (Creswell & Creswell, 2018). These notes help create a better understanding of the research questions and objectives. The researcher recorded notes after each interview in addition to notes recorded at the end of each day highlighting important themes.

4.9 Data Analysis

The data was analysed using thematic analysis. Data preparation and organisation refers to preparing your data for analysis (Leavy, 2017). A colour coding system was used per interview which was allocated to the date and the participant. One colour for mothers of premature babies and one colour for healthcare workers. Initial immersion refers to scanning through the data to get a sense of what will be analysed and allows the researcher to develop ideas and a possible map of analysis (Leavy, 2017). Coding reduces and classifies data collected (Leavy, 2017). This will mean assigning a word or phrase to segments of data (Leavy, 2017). Categorising or theming is finding patterns and relationships between codes (Leavy, 2017). Lastly, interpretation is making sense of everything that was learned (Leavy, 2017).

4.9.1. Thematic Analysis

All audio recordings were transcribed. Thematic data analysis was used in the study. The following 8 steps of thematic analysis were applied in the study (Creswell & Creswell, 2018):

Step 1. Organise and prepare the data for analysis: this process involves transcribing all the interviews including, scanning through the data as well as field notes. The majority of the interviews were done via audio recordings that were transcribed.

Step 2. Read or look at all the data: this process involves familiarising yourself with the data after it has been transcribed. This can include further notes added as well as possible themes and ideas that is starting to become apparent.

Step 3. Coding all the data: this refers to organising the data. Codes are terms that are aligned to chunks of data and assign one term to that group of data. The researcher will search for words of importance that were common amongst the participants when answering the questions.

Step 4. Generating themes: themes are major headings that are generated from the codes. Similar codes are grouped to form a theme. The themes that are generated from the codes answer the research question of the study. These themes will be further discussed after analysis is completed.

Step 5. Representing the description and themes: once the themes are generated, it will be presented as major headings that will be discussed in detail in chapter five which is the results and discussion. The results of the data collected will include a detailed narrative of the specific themes highlighted.

4.10 Self Reflexivity

As a mother navigating through the emotions during data collection was challenging at times. These challenges and emotions were communicated with my supervisor. It was suggested that I keep a reflexivity journal through the process. Doing this allowed me to document my

emotions through this journey. Doing this formed part of recognising and processing my emotions.

4.11 Trustworthiness

This refers to the quality of your research, the methodology being used, and confidence in your research findings (Leavy,2017). The reader needs to trust and interpret the information and findings of your research (Leavy,2017). A reader needs to understand your research and the reasons behind it (Leavy,2017).

4.11.1. Triangulation

Refers to analysing the data from various sources to check whether there is a common theme or justification (Creswell & Creswell,2018). Interviews from both healthcare workers and mothers of premature babies were analysed to assess whether there is a common theme present relating to the topic.

4.11.2. Member checking

Member checking refers to taking the data after it was analysed and transcribed, back to the participants to double-check the accuracy of the information given to the researcher (Creswell & Creswell,2018). In this study, once all interviews were done, it was transcribed. The investigator double-checked all information supplied by participants to verify accuracy before analysis is done.

4.11.3. Vividness

Vividness produces detailed descriptions and highlights certain aspects of data. Providing these detailed descriptions allows the reader a form of relatability to the setting (Creswell & Creswell,2018). Becoming a mother is something most women will relate to at some point in their life. Focus was given on this role and emotions linked to the role which allowed the reader to attach a sense of relatability to the study.

4.11.4. Timeline

Timeline refers to spending a considerable amount of time within the setting as it will create a better understanding of the topic being studied and the participants (Creswell & Creswell,2018). The topic of this research required participants to become vulnerable emotionally. The timeline also added to the participants developing a trusting relationship with the investigator. The more time the investigator experiences in the setting with the participants adds to the accuracy and validity of the study (Creswell & Creswell,2018). A total of 8 weeks was needed for data collection.

4.11.5. Reflexivity

Reflexivity refers to comments the investigator includes about their role and self–reflection on the topic (Creswell & Cresswell,2018). These comments should touch on past experiences and how past experiences shape interpretations; however, the investigator needs to be careful not to share too much on past experiences so that no biases are created. (Creswell & Cresswell,2018). During this research process, notes were recorded on observations about data

collection, what the investigator has learned, and any concerns about the reactions of the participants relating to the research process.

4.12 Ethics consideration

Prior to data collection, ethical approval was obtained from the Biomedical Science Research Ethics Committee of the University of the Western Cape. The approval served as permission to conduct the study. Gatekeepers of the various hospitals were contacted to obtain permission to gain access to the facility. Permission was required to access participants in the neonatal intensive care unit within the hospital. Once access was provided to the participant the following ethical guidelines need to be adhered to. *Informed consent* requires comprehensive and sufficient information provided to the participant for a voluntary decision to be made by them to participate (Hennink et al.;2020). All participants were issued with consent forms that explained their participation in the study which needed to be agreed upon by them. *Self-determination* refers to participants determining their participation in research, including the right to refuse without negative consequences (Hennink et al.;2020). It was disclosed to them that the research study was voluntary which meant they could reject participation at any time with no negative consequences. *Minimisation of harm* applied to the researcher not placing the participants at risk or harming them in any way (Hennink et al.;2020). The interview process does come with certain risks to the participants (Seidman,2006). The risks can either occur during or after the interview (Seidman,2006). In depth, interviews can cause emotional discomfort to the participant which was explained to the participants (Seidman,2006). The sensitivity of the topic and extensive use of the participants' information has a risk of making the participants' identity recognizable which can cause some embarrassment to them (Seidman,2006). If any risks arose, we would have acted promptly to reduce any discomfort

that may have occurred to the participants involved. *Anonymity* protected the identity of the participant. The names of the participants were kept anonymous. Codes were applied to the real identity of the participants, and this was only known to the investigator. (Hennink et al.;2020). Confidentiality ensured that the researcher always kept all data safe and secure. The data was only accessible to the researcher. Interviews with the participants were done via audio recordings as well as written notes upon consent from the participant. As soon as the information was transcribed the audio recordings were deleted. (Hennink et al.;2020). Risk analysis ensured extra caution needed to be taken (Hennink et al.;2020). Due to Covid-19, social distancing between the investigator and participants was maintained and masks were kept on. Data was collected in a hospital setting therefore timing was scheduled to ensure that the natural flow of activities of the participants and environment was not disrupted.

4.13 Conclusion

This chapter discussed the methodological process used in the study. A qualitative research design was used to explore the help-seeking behaviour of mothers of premature babies in public hospitals. The chapter further discussed the processes involved such as data collection and tools, data analysis, trustworthiness, and lastly ethical consideration. The next chapter will present the findings of the study as well as the discussion based on the findings.

CHAPTER FIVE

PRESENTATION OF FINDINGS AND DISCUSSION

5.1 Introduction

This chapter focuses on presenting and discussing the findings on the help-seeking behaviour of mothers who had premature babies in a public hospital. The study used a qualitative approach. Semi-structured interviews were conducted with the participants. The data collected was analysed via thematic analysis. Themes were created from the codes. Four major themes were extracted as well as seven subthemes. The findings of the data collected is presented with quotes extracted from the audio recording as well as the written interviews. These quotes are echoed by both groups of participants namely mothers of premature babies as well as healthcare workers.

5.2 Presentation and discussion of findings

The results of the study are presented as they appeared from the analysed data word for word from the audio recording and written interviews obtained from semi-structured interviews. Codes were generated from the transcribed data. These codes were labelled into themes and sub – themes to support the aims and objectives of the study. The themes and sub-themes support the study, Exploring help-seeking behaviour of mothers with premature babies in public sector hospitals. Themes were formulated to understand help-seeking behaviour in mothers with premature babies. There are four themes and seven sub-themes. Theme one has three sub-themes, the second theme has three themes, the third theme has no sub-theme, and theme four has one theme.

Table 1

Themes and sub-themes

Themes		Sub-themes
1	Motherhood	Born too soon
		Mother-neonate bond
		Caring for a premature baby
2	Seeking help	Pathways to seeking help
		Support and guidance
		Resources
3	The journey through a neonatal intensive care unit	
4	Role of a healthcare worker	Relationship with mothers of premature babies.

5.2.1. Theme 1: motherhood

Motherhood is a journey that most women expect to go through at some point in their life. (Veronez et al., 2017). Her role as a mother is defined by the journey of pregnancy and childbirth which makes it unique and special (Veronez et al., 2017). The study aimed to explore the journey through motherhood. The data reflected experiences through motherhood could be so similar.

'I love being a mother, as long as I have a baby.' (Mother 11)

'I learn every day, but it is such a joyous feeling.' (Mother 15)

The mothers also highlighted that the process was challenging and could be filled with emotions of anxiety. Added to these emotions was a common notion that it was a new journey, and regardless of the number of kids, you were always learning.

'The journey is challenging as everything is new, you need to be patient.' (Mother 14)

'There is a lot of learning all the time with so many challenges and anxiety.' (Mother 12)

Beyond the emotions of motherhood, is the support that she needs as stated by a mother

'Without help makes it difficult, having help makes it easier.' (Mother 1)

The term mother is defined as a set of duties that includes joining a new family (marriage), making the home happy and healthy, producing offspring, and the responsibility of raising them (Pentecost & Ross, 2019). This translates to preserving the happiness of everyone else but herself (Pentecost & Ross, 2019). For a mother to love and care for her baby, support and love need to be given to her also (Bust, 2020). She requires social support, emotional support, family support, spousal support, financial support, and information support (Bust, 2020). As stated in the Nurturing Care Framework, the care and support a mother needs starts at conception (Richter, 2019). This care does not only affect her health positively but also the healthy development of her unborn child (Richter, 2019; WHO, 2018). Enabling nurturing care for her depends on the resilience of communities and systems (WHO, 2018). Resilience is the result of coordinated action across sectors of government, both national and provincial (WHO, 2018). The definition of a mother in South Africa is linked to teenage pregnancy, pregnancy out of wedlock, and thoughts that are vastly influenced by apartheid (Pentecost & Ross, 2019). Women of colour in South Africa are still victims of GBV and are largely held responsible for their reproductive choices (Pentecost & Ross, 2019). Her body is viewed as a host for a baby while at the same time, a vector of disease (Pentecost & Ross, 2019). In South

Africa, policies around maternal health is guided by both international and local history (Pentecost & Ross, 2019).

5.2.1.1. Sub-theme: born too soon

A baby born too soon is defined as a premature baby born alive at less than 37 weeks gestation (WHO, 2012). For a small group of mothers, the birth of her baby comes a lot sooner than expected. The study aimed to explore their emotions around their babies being born prematurely. They expressed emotions such as fear of the unknown, anxiety, and fear.

'I was scared and cried but it's all about their safety.' (Mother 14)

'I was scared, they told me I will lose the baby. I had no water left.' (Mother 8)

'I was very nervous; she is not developed properly. What if something goes wrong with her.'

(Mother 2)

Besides the emotions around the birth, they also highlighted the separation due to the NICU experience that separated mother and baby. It was evident this made the mother feel helpless in her role as a mother.

'I had to leave my baby here and cried myself to sleep every night. What kind of mother am I,

I can't even take care of her' (Mother 1)

There were also signs of relief to save a life. The life of either the mother or the baby was at risk and either one could pass away. This reflected with some of the experiences.

'Difficult, he is sick. He would have died if they didn't do the c-section' (Mother 7)

'I was relieved because I was very sick, I was close to death and trying to hold on for my baby.' (Mother 6)

Healthcare workers were responsible for educating the mother as to why her baby was born too soon. The nurses highlighted that the mother would enquire. They would explain briefly and referred to the doctors for a better explanation.

'Education is done after the baby is born. (Nurse 2)

'Mothers will enquire, the nurse will explain but will refer to the doctor for an in-depth explanation.' (Nurse 1)

Even though education was done around the events around her preterm birth, there were mothers that didn't understand any of the information given to her as expressed by one of the nurses.

'They do get explained the reasons of their preterm birth but so many mummies don't understand.' (Nurse 3)

As narrated by a healthcare worker, some pregnancies were high risk from the start so these mothers were educated throughout her pregnancy, and she was aware that her baby would be born earlier. Some preterm births were spontaneous which didn't allow any education before the baby was born.

'Some of them know they will deliver prematurely. This is due to her risky pregnancy. Everything is explained during her pregnancy. Mothers that go into sudden preterm labour are not prepared. They are usually scared and worried if her baby will survive.' (Nurse 5)

The premature birth of her baby is a traumatic event as she is not prepared for the fragility and size of her baby (Steyn et al., 2017; Veronez et al., 2017). This leads to a culmination of negative emotions such as shock, guilt, unhappiness, envy, jealousy, frustration, and the fear of the unknown. (Steyn et al., 2017; Veronez et al., 2017). Due to the trauma and the emotions around her birth, these mothers cannot mentalise (Suchman et al., 2019). Mentalising is the process whereby one can recognize and make sense of thoughts, intentions, and emotions that influences behaviour (Suchman et al., 2019). Mothers who deliver their babies prematurely either have a planned c-section due to a risky pregnancy or an emergency birth which leaves them unprepared for the events that unfold (Henderson et al., 2016). The situation becomes challenging as the baby is hospitalised immediately after birth (Veronez et al., 2017). She becomes a passive onlooker while her baby is cared for by a team of individuals (Veronez et al., 2017). This leads to a feeling of being helpless as she can't care for her baby (Veronez et al., 2017). It is therefore imperative that the healthcare workers managing her baby approach the situation with utmost care and sensitivity concerning communication with her about her baby's condition (Veronez et al., 2017). Their role is not only to manage and care for the baby but also to manage and carry her safely through this difficult time by providing a nurturing environment for her before birth, at birth, and during the post-partum period (Veronez et al., 2017; WHO, 2018). As stated in the Nurturing Care Framework, creating a nurturing environment for the mother will positively affect the care she projects onto her baby and the development of her baby (WHO, 2018). However, nursing staff in NICU find it challenging to manage the emotional distress of these mothers (Suchman et al., 2019). The reality for mothers who gives birth in public sector hospitals has highlighted that they are excluded from any decision-making process and lack information when it comes to caring for their baby (Hastings-Tolsma et al., 2018).

5.2.1.2. Sub-theme: mother-neonate bond

The bond between mother and baby can be defined as ‘the special, close relationship between the mother and her child that occurs during the sensitive period. This is a unique experience that ties mother to child (Bust, 2020).’ This bond is crucial in the development of the child, especially during the first 1000 days (Bust, 2020). There was immediate separation after the birth of their babies. This separation highlighted a delay in the bonding process; however, it is evident that an urgency to see their baby was present. Once mother and baby are united, the bond was instant.

‘They took her away on Sunday and I only saw her on Wednesday. I just needed to see her. When I saw her, she latched immediately, and it was the best feeling. I didn’t want to leave her.’ (Mother 1)

Similarly, for some, the separation delayed the bonding process and recognition between mother and baby.

*‘I think it’s coming along; we were separated all the time and we are bonding slowly.’
(Mother 6)*

*‘I googled how to bond with a baby in an incubator. I was not sure if they would know me.’
(Mother 14)*

Besides being separated after birth, the mothers got discharged to go home while their baby remained behind at the hospital. This required her to travel to and from the hospital to bond with her baby. The commute to and from NICU could delay the bonding between mother and baby.

‘The relationship wasn’t so good in the beginning because I had to travel up and down to hospital.’ (Mother 10)

The well-being of the mother is measured by her ability to bond with her child (Bust, 2020; WHO, 2018). Her well-being not only refers to her physical health but also to her mental health (WHO, 2018). The state of her mental health will result in how she empathises with her baby as well as how she manages her own emotions (WHO, 2018). Once conception takes place, a mother can form a bond with her baby in the simplest ways like singing, talking, or feeling the kicks of her unborn child (Bust, 2020; WHO, 2018). A foetus can hear its mother's voice in the second trimester and will recognise this voice once they are born (WHO, 2018). This bonding is further initiated by breastfeeding and skin-skin with the assistance of a companion to support the mother (WHO, 2018). This forms the building blocks for optimal nutrition, quality interactions, and care (WHO, 2018). This sequence of bonding is brought to a halt for mothers of premature babies due to the immediate separation from their baby at birth (Veronez et al., 2017; WHO, 2018). The immediate separation from her baby places the mother in shock as she is overcome with the worry of how she will eventually communicate with her baby (van Schalkwyk et al., 2020; Veronez et al., 2017). The mother will appear irritable and sad which will affect how she expresses warmth and affection to her baby (WHO, 2018). Her mental space will be preoccupied with worries and anxiety about infant care, and this will influence social interactions as well as interactions with her baby (WHO, 2018). Contributing to the worry is the barrier caused by hospitalisation as this can cause a delay in the mother-neonate bond (van Schalkwyk et al., 2020). This reduces her chance of skin-to-skin and breastfeeding after birth (Henderson et al., 2016). The mother-neonate bond not only positively affects the baby, but it can have a positive effect on maternal well-being by reducing maternal stress, maternal pain, and postpartum depression (Bust, 2020). A history of emotional abuse in childhood, mental health disorders, and anxiety during pregnancy are additional factors that can also affect her bond with her baby (Bust, 2020). However, in South Africa, social factors contribute to the mother-neonate bond within the first 1000 days (Bust, 2020). These social

factors include poverty, crime, violence, inadequate public education, and HIV/Aids (Bust, 2020). Local policies around the first 1000 days ignore these social factors and focus solely on the importance of nutrition during this critical time (Bust, 2020). We also can't ignore the South African belief system around the mother-infant bond not being part of African culture (Bust, 2020). The practice of creating this bond is viewed as humorous and appropriate for 'white people' (Bust, 2020). The belief is that you can only communicate with your baby when they can talk (Bust, 2020). This is evident that international policies are conflicting with local beliefs which translates to very little knowledge known in the first 1000 days in South Africa (Bust, 2020)

5.2.1.3. Sub-theme: caring for a premature baby

Premature babies are born small and are challenged physically and neurologically (Mahwasane et al., 2020). This puts them at risk of developmental delays as well as death (WHO, 2018). Caring for these babies requires extra attention and patience (WHO, 2019) which differs from a baby. Caring for a premature baby is different from caring for a baby that was born full-term. It is reflective that they required more attention and patience,

'it's not easy but you have a special connection. no-one understands this journey. You need to be patient.' (Mother 1)

'My baby needs a lot of attention.' (Mother 7)

These babies are smaller than full-term babies and this was concerning for some mothers as it caused feeding issues and sparked fears of malnutrition.

'He is smaller than other babies, he can't do things other babies can do. He always struggles to latch.' (Mother 6)

Neglecting your own needs as a mother to care for your baby was common due to the circumstances around the birth. This also led to a feeling of being overprotective and identification that the need for a premature baby is different.

'You do everything for the baby, you put yourself aside. My baby needs to be ok.' (Mother 9)

'Their needs are different; they are much smaller. I am so overprotective because they were born so early.' (Mother 14)

All newborns need essential care once they are born, however small and sick babies require in-patient specialised care delivered by adequately trained healthcare workers (WHO, 2019). Essential care for a preterm baby includes warmth as their bodies struggle with thermoregulation, feeding support, safe oxygen use, and infection prevention (Mahwasane et al., 2020). According to the nurturing care framework, premature babies need nurturing care even more and they most often get less of it (WHO, 2018). Mothers would need guidance on how to interact with their babies as the babies' responses are less predictable (WHO, 2018). The size of her baby stirs up emotions of shock as she is not prepared for the fragility and size of her baby (Veronez et al., 2017). She feels somewhat responsible for the challenges her baby is presented with which results in her carrying around feelings of blame and guilt (Anderson et al., 2006). The added fear of the unknown lingers as she constantly wonders whether her baby will suffer any long-term complications from being born too soon (Veronez et al., 2017). The Nurturing Care Framework highlights that the absence of nurturing care in premature babies can put them at a higher risk of developmental delays (WHO,2018). This factor can add extra stress to the mother as her baby is already small and fragile (WHO,2018). This further results

in her baby getting less attention from her (WHO,2018). However, in this study, it was the opposite. The fact that these babies were born early and may have any delays didn't hinder the care or attention given. If anything, it was these factors that enhanced care and attention as they felt that their babies needed it more than ever. Despite their emotions around the birth, they set them aside and focused even more on their babies. A mother just wants her baby to be healthy (Anderson et al., 2006). When the health of her baby is challenged, she feels responsible (Anderson et al., 2006).

5.2.2. Theme 2: Seeking help

'Help-seeking behaviour is a complex decision-making process instigated by a problem that challenges personal abilities (Cornally & McCarthy, 2011).' Both groups of participants were asked to express their understanding of the term help-seeking behaviour. This question caused a lot of confusion for both groups which resulted in different answers as to how they defined help-seeking behaviour. Some participants skipped the question due to a lack of understanding. Asking the mothers to define what they would define as seeking help, meant reaching out to someone or someone they can trust. It was taking the first step to getting help. In addition to that, it was also expressed that seeking help from a healthcare worker could be a possible barrier as one is unsure about the reaction received. If a healthcare worker is not receptive and helpful the problem persists.

'Speaking to someone I can trust, like my mother and sister. Someone you know will listen to you. You can go to your local clinic, but you won't be sure what type of reaction you will receive. If the reaction is negative, you won't ask again and will be stuck with your problem.'

(Mother 1)

The attitude used when seeking help vocally was a common thread that emerged from a few

'The way that you ask for help. The tone of your voice.' (Mother 4)

Seeking help was also affiliated with the healthcare workers in the hospital setting. Healthcare workers are the first point of contact if any help is required.

'Looking for help by a nurse.' (Mother 8)

Aside from seeking help from individuals close to you or a healthcare worker, stress was highlighted which results in confusion on how to seek help.

'Some who is under stress but not sure how to ask for help.' (Mother 9)

The healthcare workers also expressed their understanding of what it means to seek help. Each healthcare worker expressed a different answer in describing the term help-seeking behaviour. Some nurses defined help-seeking behaviour in context to the mothers in NICU and some nurses defined the term help-seeking behaviour in a general context. Some healthcare workers expressed; mothers received support from healthcare workers but refused to be receptive to the help.

'You give a mother all the support she needs but she doesn't take the help she gets.' (Nurse 4)

Aside from support there was a lack of understanding that was expressed.

'Someone who doesn't understand you well. You tried to help but they don't listen.' (Nurse 6)

A healthcare worker alluded that help-seeking behaviour was when a mother wants assistance with everything.

'Those mothers that want to be assisted with everything.' (Nurse 5)

It was also expressed that help-seeking behaviour refers to emotional mothers that lack the ability to communicate which in turn hindered their ability to care for their baby.

'Mothers are emotional, lack of communication and reluctant to care for the baby.' (Nurse 2)

Giving birth to a premature baby result in emotional distress for the mother making her feel very lost and helpless as she can no longer care for her child (van Schalkwyk et al., 2020). These babies are small and fragile, and care is handed over to a healthcare worker (van Schalkwyk et al., 2020). This creates a dependency on the healthcare worker as she is clueless about how to manage her baby (van Schalkwyk et al., 2020). Seeking help in a healthcare setting means reaching out to a healthcare worker (Magaard et al., 2017). This help could refer to therapy or counselling on either an inpatient or outpatient basis (Magaard et al., 2017). A lack of education or awareness about mental health can prevent a mother from getting the help she needs (Fonseca et al., 2015; Magaard et al., 2017). It is therefore so important for healthcare workers to keep the conversation around mental health open so that a patient is aware of when to seek help (Fonseca et al., 2015). Awareness and education about mental health should be done during the perinatal period so that mothers can seek help earlier rather than later (Fonseca et al., 2015). Mental health literacy is a tool that can be utilised positively to assist help-seeking behaviour (Magaard et al., 2017). Mothers in the study understood the term help-seeking behaviour as seeking help from someone they trust or a healthcare worker however they could not link help-seeking behaviour to emotional distress. Individuals perceive emotional distress as part of normal life (Anderson et al., 2006; Biddle et al., 2007). Seeking help can be referred to as a series of steps to care (Biddle et al., 2007). The first step starts in the community and ends with the treatment by a healthcare worker (Biddle et al., 2007). The healthcare workers defined help-seeking behaviour in the context of mothers of premature babies in NICU. According to them, it's the help these mothers seek despite being educated, supported, and assisted. To them, this is linked to a lack of understanding and the emotional state she is in. Healthcare workers are not adequately trained in managing mothers in emotional

distress (Anderson et al., 2006; Freed et al., 2012). Previous research states that healthcare workers show no interest in a mother's well-being (Anderson et al., 2006). When their emotions are brushed off, it results in the mother alienating herself from a healthcare worker (Anderson et al., 2006). Mothers in low-income groups highlighted that there is no sense of relatability to a healthcare worker regarding life experiences (Anderson et al., 2006). Healthcare workers only know how to assign emotions to a diagnosis which makes them feel misunderstood and leads to a disconnect (Anderson et al., 2006). Attaching them to this diagnostic model makes them feel unheard and unmotivated which reduces compliance to seeking help (Anderson et al., 2006).

5.2.2.1. Sub-theme: pathways to seeking help

Pathways to seeking help refer to the approach an individual uses to seek the help they need. Concerning the study, the investigator explored the pathway the mothers used in NICU to seek help. Similarly, it was also explored by the healthcare worker how these mothers would seek help if they needed it. Input from both groups of participants was different in how they assessed pathways to help. When a mother needed help from a nurse, they initiated it by vocally asking for assistance and received the assistance they required as expressed by some of them. The help they required assistance with was only linked to the help she needed with her baby and not herself.

'I would ask for help and I get the help that I need.' (Mother 2)

However, there are certain times when a mother vocally warranted help and is presented with a different reaction. They are met with resistance and some mothers would only seek help from specific nurses.

'I will only ask one nurse because she has nice manners. When she is not here, I will do it myself.' (Mother 10)

'I will call a nurse and ask for help, they (nurse) will take long and ask me questions.'
(Mother 13)

'The coloured nurses are so kind; I ask them for help.' (Mother 12)

Similarly, some mothers refused to ask any healthcare workers for help. This is based on reactions observed in NICU. They expressed that they would prefer to keep silent.

'You get stories, some will help. We are not explained on the procedure in case we need any help from the nurses. I don't ask for help; I am not sure of the reaction I will receive.'
(Mother 1)

The healthcare workers expressed their own understanding of how the mothers would seek help from them. A pathway to help depended on what emotional state the mother was in combined with preferences on which nurse she would approach for help. A mother would not seek help from any nurse.

'Some (mother) are nice, they (mother) will ask nicely. Some mothers will ask nurses they like. Depends on the mother's mood.' (Nurse 3)

Similarly, her emotional state affected the way she understood. This led to mothers also creating expectations from nurses.

'Each mother is different. Some mothers are aggressive, some understands. These mothers expect a lot from us.' (Nurse 1)

Coming into NICU is a new environment and the mothers were not familiar with the nurses. This required healthcare workers to build up a level of trust for her to feel comfortable to seek help. It was more likely she would seek help after a lengthy time in the NICU.

'We need to gain their (mother) trust then they will ask for assistance' (Nurse 6)

'The mothers who are in the unit for very long, they know us so they will ask for help.' (Nurse 5)

Seeking help is a series of pathways that usually only ends with a healthcare worker (Fonseca et al., 2015). These steps start with identifying internally that you are aware of an emotional problem followed by seeking support and communicating the problem to your social circle (spouse, friends, or family), and lastly an intervention with a healthcare worker (Fonseca et al., 2015). The Nurturing Care Framework states healthcare workers are responsible to provide a supportive and nurturing environment for the mother before birth, at birth, and during the postpartum period (WHO, 2018). The framework adds that healthcare workers are responsible for information, advice, and support to the mother (WHO, 2018). However, women who give birth in public hospitals in South Africa expressed feelings of loneliness and isolation during birth, labour, and post-partum (Hastings-Tolsma et al., 2018). They feel ignored and excluded from any decision-making process as well as highlighting the lack of information provided about caring for their baby (Hastings-Tolsma et al., 2018). This hinders them from seeking help from a healthcare worker (Hastings-Tolsma et al., 2018). In addition to that, the group of healthcare workers emphasized the emotional state of the mother during her pathway to help. They emphasized that the group of mothers is emotional, aggressive, and moody. They elaborated further that her emotional state affects her understanding. It was also expressed that this group of mothers has high expectations from healthcare workers. This ties in with research that stated healthcare workers expressed difficulty in managing the emotional difficulties of

mothers who have premature babies (Suchman et al., 2019). If healthcare workers are adequately trained, they will be able to provide the necessary support, care, and education (Mahwasane et al., 2020) which can spark the pathway to seeking help. Healthcare workers must keep the line of communication open around mental health which deems challenging if healthcare workers are not adequately trained (van Schalkwyk et al., 2020; Mahwasane et al., 2020).

5.2.2.2. Sub-theme: support and guidance

Providing a mother with support and guidance allows her to confidently care for her baby (WHO, 2018). The mothers in NICU required support and guidance with various issues they had. Premature babies are small. Their size and being attached to monitors can hinder the management and care that the mother wants to provide.

'Need help on how to manage my baby, like change the nappy and clean her navel.' (Mother 3)

Breastfeeding was another issue that was highlighted by many of the mothers as a challenge they need guidance with.

'Breastfeeding is my biggest problem.' (Mother 9)

Besides guidance with their baby, a mother expressed the support that she needed for herself. Narrating this to me made her very emotional.

'I need emotional help.' (Mother 7)

The healthcare workers highlighted similar challenges that these mothers need guidance with. Similarly, as the mother highlighted, breastfeeding and managing her baby was a challenge the nurses highlighted.

‘The mothers need help with managing her baby, breastfeeding and how to change a nappy.’

(Nurse 6)

‘The main things the mothers struggle here with is milk supply and breastfeeding.’ (Nurse 3)

After giving birth to a premature baby, the mother was discharged, and her baby stayed behind in NICU. This required her to travel to the hospital to see her baby. Coming daily was not always possible due to transport costs. This was highlighted only by the healthcare workers and not the mothers themselves.

‘Some come to the hospital only after two days. They can’t come every day due to transport costs.’ (Nurse 3)

‘Some mothers need money for transport to come to the hospital and to go home.’ (Nurse 4)

Both groups of participants highlighted that the main concerns mothers needed assistance with were breastfeeding and managing their small babies. One mother highlighted the need for emotional support. An additional challenge according to the healthcare workers was the need for transport fare the mothers required to travel to and from the NICU. This was an issue that was not mentioned by any of the mothers in the group.

Premature babies are at risk of developmental delays, disability, cardiovascular and other non-communicable diseases (Black et al., 2021). It’s crucial to focus on bonding and breastfeeding from mother to child as it will positively affect not only the child but also the mother (Black et

al., 2021). Breastfeeding positively contributes to hormonal changes in the mother, therefore contributing to reducing maternal stress (Black et al., 2021). Breastfeeding for three months exclusively reduces the severity of otitis media, diarrhoea, and respiratory infections, and breastfeeding for six months is linked to a reduced risk of allergic disease, obesity, and higher scores on cognitive tests (Bust, 2020). In developing countries, breastfeeding is also encouraged as it is cost-effective and provides the best nutrition for your baby (Bust, 2020). However, this becomes challenging as these mothers are separated from their premature babies daily for an evitable amount of time. Some of them can't afford to travel and see their babies in NICU daily which can cause issues with breastfeeding. When a baby is born prematurely, it has a great negative impact on the family's psychological and financial status (WHO, 2018). Therefore, we need to mention that South African policies emphasize the importance of nutrition in the first 1000 days, however, we can't ignore the social aspect that can affect growth and development during this critical time (Bust, 2020). The Global Strategy for women's, children, and adolescent health states that 43% of children globally under the age of five are at risk of poor development, poverty being the main cause (WHO, 2018). It has been more than two decades since South Africa was declared a democratic state however most of the population still lives in poverty together with social problems such as unemployment, mental illness, substance abuse, and exposure to violence and crime. (Suchman et al., 2019). Poverty increases the stress on parents which in turn decreases their ability to provide adequate care for healthy development (Suchman et al., 2019). Poverty results in a decreased ability to protect your child and causes inconsistent, emotional, and harsh parenting (Suchman et al., 2019). Low-income south Africans endure chronic stress in their everyday lives which causes poor physical and mental health (Suchman et al., 2019). Due to poverty, South Africans are challenged with mental illness, substance abuse, malnutrition, foetal alcohol syndrome, and HIV/AIDS (Suchman et al., 2019). Exposure to these levels of chronic stress affects the

cognitive, emotional, and physical development of the child (Suchman et al., 2019). Maternal health issues are a cause of disease-related disability which leads to poverty, social grant reliance, and unemployment (Freed et al., 2012). Maternal mental illness is high in developing countries as parenting is done under socioeconomic hardship and high rates of depression and substance abuse (Suchman et al., 2019). This decreases maternal sensitivity to her baby (Suchman et al., 2019). Supportive services would require collaboration among various sectors (WHO, 2018). These sectors include health, nutrition, education, child protection, social protection, labour, and finance (WHO, 2018). The reality in South Africa is that services are increasing in the public healthcare sector however staff is not properly trained (Chopra et al., 2009). There is a need for increased health education for mothers (Chopra et al., 2009). When a mother is supported in this way, the bond between her and her baby will strengthen (WHO, 2018). She will eventually start to feel confident and hopeful (Veronez et al., 2017). Intervention for both mother and baby simultaneously will have a positive effect on infant health (WHO, 2018).

5.2.2.3. Sub-theme: resources

Early detection of a mental health disorder in a mother will positively affect the physical and emotional development of her baby which will ultimately lead to a healthy family environment (Freed et al., 2012). However, accessibility to adequate resources to these resources is currently a challenge (Biddle et al., 2007). The investigator asked whether the mothers were aware of any resources available to assist her. All of them expressed that they were unaware of any resources in the hospital that is available to assist them in any way.

'I don't know of any resources.' (Mother 3)

Alternatively, the nurses were aware of resources available to the mother if she requires any assistance. They highlighted various resources available to assist the mother with breastfeeding issues, social issues as well as emotional support.

'The moms have access to breastfeeding consultants, social worker for any social issues, eye clinic for premature babies.' (Nurse 2)

'Nurses can assist them. We are the patients advocate. If they have any emotional trauma, we have social workers to assist. We can assist with breastfeeding issues.' (Nurse 4)

'We give them health education. In the breastfeeding room, there are apps they can download. If the mother feels she can't cope, we have social workers to assist. If they have no money for transport, there is petty cash available from the social worker.' (Nurse 5)

The Health Belief model aimed to explore reasons why patients refused to partake in any disease prevention and treatment if it was free or at a minimal cost. In this study, it is evident that the mothers can't access any resources if they are unaware of what is available to them. However, we need to understand also that even if the awareness was present, it is unlikely that these mothers would partake in any post-natal programmes offered to them (Henderson et al., 2016). This is due to her baby being in the hospital and her spending all her time in NICU focusing on bonding (Henderson et al., 2016). The healthcare workers however are aware of the resources available to both mother and baby. These resources include breastfeeding support, an eye clinic for her baby, and a social worker for emotional and social support. Various barriers are linked to accessing resources in the public healthcare system (Agapidaki et al., 2015). These barriers include sparse services, lack of team-based care, perceived poor quality and availability of community mental health services (Agapidaki et al., 2015). The awareness of these resources should be done throughout her pregnancy (Fonseca et al., 2015).

Regular screenings should be done as many individuals find it challenging to engage with a healthcare worker (Fonseca et al., 2015). Unfortunately, healthcare workers are not adequately trained to manage emotional distress (Freed et al., 2012). Healthcare workers are only focused on risk factors rather than screening tools (Freed et al., 2012). If they were adequately trained, they would be able to provide adequate support and education to mothers of premature babies (Mahwasane et al., 2020). South Africa is a developing country with limited health resources and high patient numbers which makes it impossible to provide full tertiary support (Ballot et al., 2010). Throughout history in South Africa, the public healthcare system has been flawed (Coovadia et al., 2009). Since 1994, there has been an uneven distribution of healthcare workers that are poorly skilled (Coovadia et al., 2009). This impacts not only the healthcare system but the interventions for patients, especially in mental health (Coovadia et al., 2009). The results of the findings indicate that the healthcare workers are aware of the mothers' emotional state. This is indicative that there is a lack of education and awareness being done on available resources in the hospital.

5.2.3. Theme 3: Journey through a neonatal intensive care unit

Neonates in hospitals require care twenty-four hours a day, seven days a week (WHO, 2019). This type of care requires a multidisciplinary team of healthcare workers which is done in a hospital setting (WHO, 2019). Spending time in a neonatal intensive care unit daily is an experience for both groups of participants. Both are immersed in caring for this baby. Both groups of participants were asked to describe a typical day in the NICU. Besides caring for their baby, these mothers were focused on bonding. Due to the separation from her baby, one of the most important objectives for the mother was to bond with her baby when she came to the hospital. This routine was repetitive.

'Very quiet, very peaceful. I come in the morning and spend the whole day with her. I hold her most of the time.' (Mother 2)

'Feed, sleep and focus on the baby all day.' (Mother 4)

Aside from bonding with her baby, the emotions that's attached to spending the days and weeks in the NICU was challenging for the mother. The length of a NICU stay can depend on the progress of your baby. It could be days, weeks and even months. During this time mother and baby were separated.

'It's emotional seeing my baby in this state. I just come in, make sure his ok then leave. I just gave birth.' (Mother 7)

Leaving NICU every day, you leave your baby in the constant care of a healthcare. When you walk through those doors in NICU, your only focus was your child.

'To be honest, I come in every morning. I sit here all day. I take a break to eat. I just spend time with her and bond all day. The time goes so quick here then I need to leave. It is so hard to leave. I always wonder if they (nurses) are caring for her properly.' (Mother 1)

The mothers have an expectation from the healthcare workers to provide updates of their baby when they come to see their babies in NICU. This alludes to the healthcare workers being responsible for the care in hospital when the mother is absent. They have expressed feeling that they didn't willingly get these updates. This added to her emotions and made the process difficult.

'Very difficult when you come in the nurses doesn't talk to you. They don't explain to you what is happening with my child. I need to ask. They will never tell me anything on their own.'
(Mother 3)

The nurses are responsible for this care in the absence of the mother. NICU is very busy. As a nurse the minute you step through those doors your busy days starts.

'Very busy. You are busy all day with feeds and observations. It is hard work, and the doctors are not always present.' (Nurse 6)

'Days are so busy; we stand all day. The only break we get is lunchtime. Days are very unpredictable, depends on role and responsibilities.' (Nurse 5)

Aside from being busy the role comes with emotional challenges. Caring for a premature baby is not easy. Some of the babies are sick which makes their days very unpredictable.

'Unpredictable with the sick babies. We need to make sure that these babies are safe so that is hectic.' (Nurse 2)

'The days are very hectic especially with the sick babies. Emotionally it makes you feel bad.'
(Nurse 4)

Besides busy days, there is the challenge of the ratio of babies to nurses. There is a shortage of nurses which can make the days busier and stressful.

'We start very early, and we are very busy with the small babies. It can be stressful; we don't have a lot nurses.' (Nurse 3)

Mothers spending time in the NICU has the assumption that it's governed by various restrictions while their babies are in the constant care of healthcare workers (van Schalkwyk et al., 2020). This assumption and environment only heighten her emotions of anxiety and insecurities around caring for her baby (van Schalkwyk et al., 2020). Healthcare workers should keep the line of communication open (van Schalkwyk et al., 2020). Instead of focusing on medical challenges, they should focus on basic routines of care such as bathing, feeding,

and managing these small babies (van Schalkwyk et al., 2020) This will also decrease the mother insecurity as these tasks are part of daily living once, they are home (van Schalkwyk et al., 2020). Making these routines of care inclusive and hands on in NICU allows the mother to build her confidence to care for her baby once they are back home (van Schalkwyk et al., 2020). However, the study depicts that there is no active communication between mother and healthcare worker which makes the journey through NICU even more challenging. Lack of adequate staff to provide essential care in NICU can lead to further complications, even death (Mahwasane et al., 2020). Neonatal nurses form an integral part of the team responsible to care for premature babies, however some countries have shortages of nurses which poses a great challenge (WHO, 2019). The training of these nurses is so important and should be focused on family centred care as this gives the families the confidence to care for these babies once they are discharged (WHO, 2018). In South Africa, there is currently a shortage of nurses as many nursing colleges closed in the 1990's (Chopra et al., 2009; Coovadia et al., 2009; Naicker et al., 2009). The amount of healthcare workers that do exist are not adequately trained to meet the needs of the country (Naicker et al., 2009). In line with that, nurses migrate from the public healthcare system due poor salaries and being overworked (Naicker et al., 2009). Within the African continent, majority of healthcare workers emigrating to other countries are from South Africa (Naicker et al., 2009). Currently there is 2.3 healthcare workers per 1000 people (Naicker et al., 2009). 84 % of women in South Africa give birth in the public healthcare sector (Chopra et al., 2009). Added to this is the shortage of beds across all tertiary hospitals and a shortage of healthcare workers (Chopra et al., 2009). This place a strain on healthcare workers in the maternal setting as the shortage of staff and beds results in them being overworked (Chopra et al., 2009). Healthcare workers in NICU has expressed frustration with this shortage and lack of resources to adequately care for preterm babies (Mahwasane et al., 2020). Nursing staff in South Africa remains a red flag for government as they still work under very poor

conditions (Naicker et al., 2009). The Nurturing Care Framework is a clear depiction that focusing on early childhood development is the best investment a country can make to boost economic growth (WHO, 2019).

5.2.4. Theme 4: Role of a healthcare worker

The role of a healthcare worker in the NICU is to provide support, information, and advice to the mother (WHO, 2018). Healthcare workers in NICU highlighted that the main reason they entered the profession was due to a passion to help people.

'I became a nurse because I always wanted to help people. I have been a nurse since 1991.'

(Nurse 2)

Similarly, it was narrated that entering the profession of being a healthcare worker meant treating people with respect and dignity.

'We need to respect and treat our patients with dignity.' (Nurse 1)

A healthcare worker in NICU has a long day filled with roles and responsibilities that they all emphasized they enjoy.

'I enjoy my responsibilities and I am confident in my role.' (Nurse 6)

Besides caring for the babies, they have responsibilities to the mothers which included supporting her through this journey.

'I feel like I need to support these mothers. Give them emotional support. Giving birth to a premature baby is very hard for them and they need the support.' (Nurse 3)

'We play every role here. We clean, we are the mothers to these babies when the mothers are not here, we comforters to the mothers as well as their support system, we counsellors. We carry a huge load.' (Nurse 4)

However, these roles and responsibilities come with emotions that are both good and bad. Emotions of sadness are linked to a mother's loss of her baby and joy when she successfully breastfeeds and gets discharged.

'Sometimes I feel like it's too much. It's not nice seeing a mother losing her baby. There are also joys like her breastfeeding well and being discharged with her baby.' (Nurse 5)

However, the role of a NICU nurse doesn't only translate to caring for these small babies but also providing support to the mothers which can also be emotionally taxing for the healthcare worker. Healthcare workers have an important role in fostering and supporting nurturing care (Richter, 2019). This can be done by implementing simple measures like observing the mother's interaction with her baby, guiding her, and praising her so that she can build her confidence to care (WHO, 2018). Encourage her to talk to her baby by providing age-appropriate recommendations on how to communicate with her baby and encourage her to spend an adequate amount of time with her baby (WHO, 2018). However, governments are challenged with a lack of skilled healthcare workers in obstetric and neonatal care which translates to healthcare workers not being adequately trained to manage mothers in lower-income groups and the emotional distress they present with (C. M. Anderson et al., 2006).

5.2.4.1. Sub-theme: relationship with mothers of premature babies

Premature babies can spend an inevitable amount of time in NICU. Besides the relationship with her baby, the one with her healthcare worker is vital during this challenging time. The mother is in a very volatile state that requires support, education, and reassurance from healthcare workers in NICU tending to her baby through the challenging time she is faced with. The study explored this relationship, and the following was highlighted.

'Good. Some mothers are very difficult and aggressive, but we understand why. We try to keep a good relationship with them. We need to encourage them. We try and be open with them so they can confide in us. When we friendly with them, they open up to us.' (Nurse 4)

'We (nurse) support her (mother). We (nurse) give health education on how to manage her baby and constantly reassure her (mother).' (Nurse 6)

'Mothers are angry, lack of understanding on why her baby needs to stay here and she gets discharged.' (Nurse 2)

A nurse highlighted that the way the nurse spoke to the mother influenced her relationship with the nurse. This was evident that she understood her emotional state and needed to approach it with respect.

'I have a good relationship with the mummies because of my personality. It is because of the way I speak to them. I am nice to them friendly and respect them. If you speak to them like that, they will speak the same way back to you.' (Nurse 3)

Similarly, the length of the baby's NICU stay played a role in the relationship with the nurses. A lengthy stay allowed the mother to familiarise herself with the nurses and build a relationship with them.

'It depends. When the baby has been here for a while, you have a good relationship with them.' (Nurse 5)

Other factors like social issues can affect the mother's relationship with the nurses.

'The nurses get along well with the mothers. The social issues does make it challenging sometimes.' (Nurse 1)

Similarly, many of the mothers reported having good relationships with the nurses in the unit. They expressed that the nurses were helpful whenever they needed assistance.

'There service is good, I have a good relationship with the nurses.' (Mother 2)

'Very good. They were very encouraging me not to lose hope.' (Mother 9)

Similarly, some mothers highlighted a comparison. They expressed that some nurses were helpful, and some were not.

'Some nurses are not helpful. Other nurses are really helpful and assists me when I need.'
(Mother 5)

'Some nurses are helpful, some of them are lazy.' (Mother 7)

Some mothers observed nurses' behaviour that was unappealing in NICU. This observation could result in being tolerant of fear of neglect of their baby when they left the hospital for the day.

'Honestly when you here for a long period of time you see things that no-one does. Some of them are nice. I just try and be nice because I need to leave, and they will be here taking care of my baby.' (Mother 1)

'Some nurses are friendly and nice. Some shout, they would gossip about me. I don't answer and keep quiet because they look after my baby when I leave.' (Mother 12)

It's a common ideology to associate nurses with being cruel (Coovadia et al., 2009; Hastings-Tolsma et al., 2018). This ideology stems from how nurses were trained (Coovadia et al., 2009). They were trained to moralise and save as opposed to nurturing the sick (Coovadia et al., 2009). This has transcended and remains a current obstacle in the public healthcare sector as the relationship between patients and healthcare workers (Chopra et al., 2009; Coovadia et al., 2009; Hastings-Tolsma et al., 2018). Nurses have been linked to rudeness, physical assault, and neglect commonly found in sexual and reproductive health services (Chopra et al., 2009; Coovadia et al., 2009). Women who report birth trauma, express a huge amount of trauma to interactions with healthcare workers (Simpson & Catling, 2016). They expressed emotions of feeling ignored, disrespected, and unsupported (Hastings-Tolsma et al., 2018; Simpson & Catling, 2016). A preterm birth is traumatic (C. Anderson & Cacola, 2017). The event around her preterm birth consumes her with emotions that make it difficult for her to communicate (Steyn et al., 2017). Emotions, that healthcare workers find difficult to manage (Suchman et al., 2019). Research suggests that healthcare workers in obstetrics should undergo training to support and assist mothers as there is a link between birth trauma and unsupportive care by healthcare workers (Simpson & Catling, n.d.). We can't deny that there are policies and theories in place to assist on how to nurture this relationship, however, these policies have remained just that, policies that are struggling to align with the South African belief system (Bust, 2020). Within South Africa, healthcare workers are not only challenged with the current emotional distress of the mother but also the social aspect that contributes to her mental health. This aligns with the Health Belief model that states it was the personal circumstances of the individual, not the environment, that will influence the individual's behaviour however his environment will be represented or portrayed during his reaction (Rosenstock, 2016). There has been a major shift in the healthcare system but common problems like health equity remain which is linked to apartheid (Gilson et al., 2017).

5.3 Summary of Data analysis

Thematic analysis was used, and four major themes emerged. These themes were generated via codes that were created from the data collected and transcribed. These four major themes highlighted help-seeking behaviour in mothers of premature babies in public sector hospitals. The findings of the study indicated that these mothers were not prepared for the emotional distress of having a premature baby. Emotions that didn't make sense to her however all she was focused on was the bonding and care of her baby. Time spent with her baby in NICU could result in unfavourable interactions with healthcare workers. These interactions hindered her ability to seek help. However, added to this is the healthcare workers who expressed the challenge of managing the emotions in this group of mothers.

The findings also indicated that healthcare workers in NICU worked long and tiring days. Added to this was the challenge of the shortage of staff. Besides caring for these small and sick babies they were also required to support and guide the mother all while working under these conditions which is a huge role to fill. However, this role could be made lighter as there are resources in the hospital to assist with emotional and social support to the mother healthcare workers were aware. These resources alluded to the social worker and were resources that the mothers were not made aware of by healthcare workers. This unawareness led to the mothers having expectations from healthcare workers to assist them with everything including emotional and social support as they were not aware of any resources available to them. The literature review supported these findings as well as the application of The Health Belief Model and The Nurturing Care Framework.

CHAPTER SIX

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

6.1 Introduction

This is the final chapter of the study. The study is summarised and concluded. Recommendations for future research is discussed as well as limitations of the study that the researcher experienced. The current study was to explore help-seeking behaviour in mothers of premature babies in public sector hospitals. The results of the study were presented and discussed in the previous chapter. This chapter will focus on summarising the discussion based on the objectives of the study. A qualitative approach was used incorporating interview schedules to answer the research questions presented in the introductory chapter of the study.

The aim of the study was to explore study the help-seeking behaviour of mothers who had premature babies in public sector hospitals.

The objectives of the study were to:

- (1) Explore the perceptions, experiences, beliefs, and attitudes of mothers who had premature babies in a public sector hospital.
- (2) Explore the kind of help mothers need from a healthcare worker following the birth of their premature baby.
- (3) Identify and explore the resources to assist mothers who had premature babies in a public sector hospital.

(4) Explore how healthcare workers assist mothers who birthed premature babies.

(5) Explore how mothers seek help in a public sector hospital after they had given birth to a premature baby

6.2 Summary of research findings

Help-seeking behaviour is a pathway to care that starts with oneself and ends with a healthcare worker. The participants in this group were mothers of premature babies as well as nurses in the NICU. A premature baby enters this world spontaneously or due to a high-risk pregnancy which placed the mother in a seat of overwhelming emotions linked to the birth. The participants reported that having a baby born too soon was filled with so many emotions of anxiety, fear, and overall shock at the fragility and size of their baby. Participants highlighted caring for a premature baby required a lot of care, attention, and patience as their needs are different. Added to these emotions was the immediate separation not only after birth but the separation when the mother was discharged, and her baby remained in the NICU. For some mothers, this separation created an urgency and resulted in an instant bond and a heightened attachment to their baby. As expressed by other mothers, bonding was slow and took time to develop. The participants were required to travel to see their babies in NICU. As expressed by the participant, hours spent in the NICU were repetitive and focused on bonding with your baby.

Aside from the mothers of premature babies, the study also focused on healthcare workers caring for these babies in NICU every day. This group of participants highlighted that the time spent in NICU was tiring as they worked long hours. Their days were unpredictable with all the sick babies and their objective was to keep the babies safe and healthy yet challenged with a shortage of nurses.

Another important aspect of the study was the relationship between both groups of participants The mother of premature babies as well as healthcare workers and how this relationship influenced the mother's ability to seek help. The results from the group of mothers reflected different views regarding healthcare workers. Some expressed no issues with healthcare workers in NICU and went further to emphasize the willingness to help them while other mothers argued that healthcare workers were lazy and temperamental. Similarly, the mothers in the study highlighted tolerance to unfavourable conditions in NICU in fear of neglect of their baby when they were absent. The results from the group of healthcare workers also reflected different views regarding their relationship with the mothers in the group. Some highlighted that the mothers were emotional, and some were aggressive and lacked understanding. The healthcare workers added that the mothers required support and guidance on how to manage their babies. Additionally, a healthcare worker added that the way mothers are addressed influenced her reaction. The healthcare workers further mentioned that she spoke to them with respect and kindness which sparked the same reaction from the mother. The findings also reflected that the mothers had an expectation from healthcare workers to assist them and similarly this was highlighted by the healthcare workers also however they found this expectation unrealistic.

Additionally, the study also set out to explore the ability of these mothers to seek help from healthcare workers. Both groups of participants highlighted that these mothers required help with breastfeeding and how to manage and care for their premature babies. The findings reflected an additional factor that the mothers required help with only mentioned by the group of healthcare workers, which was transport fare to travel to and from the NICU. The challenge of transport fare influenced how often she came to NICU to bond with her baby. Daily visits were not a reality for some mothers. Observations in NICU influenced the mother's decision to seek the help she needs from a healthcare worker. Some mothers highlighted that they would

vocally warrant help and received it while others refused to seek help based on the reactions from healthcare workers. Different views were expressed by healthcare workers on how these mothers would seek help. A long time spent in NICU allowed a mother to trust the healthcare worker which positively influenced her ability to seek help. Her emotional state also affected her ability to seek help as some mothers struggled to manage emotions.

Lastly, the study explored whether there were any available resources in the hospital to assist the mother and her well-being. The findings of the study reflected that all the mothers in the group were not aware of any resources available to assist them however the group of healthcare workers was aware of resources available to assist both mother and baby. These resources included a social worker for emotional social issues, breastfeeding assistance, and guidance and health education done by nurses and doctors. The chapter proceeds to explore whether any of the objectives were achieved with the findings of the study.

6.2.1 Perceptions, experiences, beliefs, and attitudes of mothers

Birth perception is a subjective judgment of a women's global birth experience indicating personal satisfaction with the birth process and outcome (Simpson & Catling, 2015). The study revealed that a mother is never prepared for the birth of premature birth. The birth is a traumatic experience that is detrimental to her physical and psychological health (Simpson & Catling, 2015). The fragility of her baby together with the negative emotions associated with her birth placed the mother in distress. Immediate separation from her baby after birth added to her emotional distress with added worry as to whether bonding will be possible. The worry disappeared and bonding was instant when she was reunited with her baby. However, bonding was delayed for some mothers caused of the separation from their children. The separation caused by hospitalisation makes it a challenge when communicating with her baby (van

Schalkwyk et al., 2020). Added to this separation was her being discharged while her baby remained behind in the hospital which required her to commute to visit and bond with her baby. Additionally, these small babies required extra care and attention which resulted in these mothers being very protective and patient. 20-40% of women experience birth trauma which includes mothers of premature babies (Simpson & Catling, 2015). The Nurturing Care Framework highlights that the care and support a mother need starts at conception (WHO, 2018). This theme answered the first objective which explored the perceptions, experiences, beliefs, and attitudes of mothers who had premature babies in a public sector hospital.

6.2.2 Helping mothers as healthcare workers' post-birth

Participants highlighted that mothers needed help with breastfeeding and managing their babies. Additionally, healthcare workers mentioned that mothers also needed financial assistance with transport fares to travel to and from NICU. None of the mothers in the group mentioned this. This challenge influenced how often a mother visited her baby. 43% of children under the age of five globally are at risk of poor development, poverty being the main cause (WHO, 2018). Poverty increases the stress on parents which decreases their ability to provide adequate care needed for healthy development (Suchman et al., 2019). This theme answered the second objective which was to explore the kind of help mothers needed from a healthcare worker following the birth of her premature baby.

6.2.3 Resources to assist mothers in public sector hospitals

The mothers in the study revealed that they were unaware of any resources available to assist them in any way. However, the group of healthcare workers revealed that they were aware of resources available to both mother and baby. Resources for the mother included a social worker

who can assist with both emotional and social support. Healthcare workers also highlighted that they could support and guide these mothers. According to the Health Belief Model, various factors hinder utilisation of mental health services which include sociocultural (stigma), navigating the system (finding a provider), and lack of education on mental health, race, ethnicity, and religion (Maykrantz et al., 2017). This theme answered the third objective which identified and explored the resources that assisted mothers who had premature babies in a public sector hospital.

6.2.4 Methods healthcare workers utilise to help mothers

The group of healthcare workers expressed that their role was to provide the mother with emotional support and health education. They added that they tried to maintain a friendly and respectful relationship with the mother to gain their trust to provide the support she required. However, the emotional state of the mother was challenging at times when offering support and help due to her lack of understanding. Healthcare workers highlight that the emotional distress in this group of mothers is challenging to manage (Suchman et al., 2019). The mothers in the study argued that not all healthcare workers are willing to help or offer support. Laziness and unfavourable behaviour such as rudeness were expressed. However, not all mothers expressed these sentiments. Some mothers added that healthcare workers were helpful and provided the emotional support they needed. This theme answered the fourth objective which explored how healthcare workers assisted mothers who birthed premature babies.

6.2.5 Help-seeking behaviour in mothers

The study reflected that the mothers would vocally warrant help when needed. Some received the help needed while others were met with resistance from healthcare workers. The healthcare workers however reflected a different narrative. They expressed the emotional state of these mothers resulted in rude behaviour and aggression towards healthcare workers when warranting any assistance. They also added that these mothers needed to build a sense of trust to seek any help. This trust developed when they spent enough time in NICU. The time spent in NICU allowed both groups of participants to develop a relationship that positively affected help-seeking behaviour. Women who suffer birth trauma report a huge amount of trauma that links to interactions with healthcare workers (Simpson & Catling, 2015). They expressed emotions of feeling ignored, disrespected, and unsupported (Hastings-Tolsma et al., 2018; Simpson & Catling, 2015). Research suggests that healthcare workers in obstetrics should undergo training to assist and support mothers during birth and the postpartum period (Simpson & Catling, 2015). Giving voice to women's experiences is key to the creation of care that embodies humanistic, family-centred service (Hastings-Tolsma et al., 2018). This theme answered the fifth objective which explored how mothers would seek help in a public sector hospital after they had given birth to a premature baby.

The Health Belief Model states that there is a hinderance in individuals to utilise resources that were either free or of minimal cost (Rosenstock, 2016). The results from the study exploring help-seeking behaviour in mothers of premature babies in public hospitals indicated that various factors influenced her ability to seek help. The Nurturing Care Framework highlights that the health of the mother impacts not only the healthy development of the child but the maternal mental state of the mother (Black et al., 2021). Her health relies on the bond with her

baby and breastfeeding (Black et al., 2021). Giving birth to a premature baby caused emotional distress to the mother that she was unable to manage, however her primary focus was caring and bonding with her small child. Her emotions were placed on hold while she tried to manage her baby. Emotions that she didn't understand. Lack of understanding can be alluded to mentalising which is a process where she struggles to recognise, make sense, and process emotions (Suchman et al., 2019). Emotions around her birth are filled with shock and fear of the unknown as to whether her baby will survive (Veronez et al., 2017). She placed the care of her baby in the hands of healthcare workers with the expectation of receiving guidance from them through such a difficult time. Shifting the baton of care to a healthcare worker makes her feel helpless (Veronez et al., 2017). However, this expectation was not met as healthcare workers are strained and were unable to manage her and her emotions. According to the Global Strategy for Women's, Children and Adolescent health, lack of skilled healthcare workers in both obstetric and neonatal care is a current obstacle that needs attention (WHO, 2018). This is an obstacle that extends in South Africa as healthcare workers emphasized that the emotions in this group of mothers are not easy to manage (Suchman et al., 2019). Added to this challenge is the shortage of healthcare workers that currently work under poor conditions (Coovadia et al., 2009; Naicker et al., 2009). These mothers were also unaware of any resources that might have been available to assist them and therefore assumed it non-existent. Any help she requires in NICU is sought only for her baby and not for herself. South African policies on maternal care are guided by international policies however there is a disparity that is conflicting with the South African belief system as well as the social aspects that affect maternal care and early childhood development. (Bust, 2020; Pentecost & Ross, 2019).

6.3 Application of the Health Belief Model and the Nurturing Care Framework

Two theories were applied to the study namely the Health Belief Model and the Nurturing Care Framework. Both theories are discussed in depth in chapter two of the study. The Health Belief Model was applied to explain help-seeking behaviour. This model was created by a group of researchers to understand underutilisation of resources offered free of charge or at a minimal cost to prevent disease (Rosenstock, 2016). This model was applied to assess whether any barriers hindered the help-seeking behaviour of mothers of premature babies. During the early stages of the model, it is stated that for an individual to prevent disease, the individual needs to believe that they were susceptible to the disease, severity of the disease is mild and that it will not largely affect their life, action will reduce severity, belief that the individual is asymptomatic with a current illness. These factors make up the four components of the Health Belief Model namely perceived susceptibility, perceived seriousness, perceived benefits of acting, and barriers to taking action as well as a cue to action (Maiman & Becker, 2016; Rosenstock, 2016). Mothers experiencing emotional distress refrain from seeking help due to the perception that it's not linked to a psychological condition that requires treatment (Freed et al., 2012). In the context of the study, the emotions surrounding the birth of her baby were emotions that were too overwhelming for these mothers to understand or process as a possible predisposition to a mental health disorder or a reason to seek help. Seeking help for a mental health disorder can also be hindered by emotions of fear and shame (Smith, 2009). The barrier of emotions should be an extension of the Health Belief Model (Smith, 2009). The study did deduce that these mothers were also unaware of any resources that are available to them in the public healthcare setting. Resources that were highlighted by healthcare workers. The lack of education explains the barrier to utilising any resources available to her. Mothers in lower-income groups perceive that certain risk factors result in issues with mental health that prevents them from seeking help (Anderson et al., 2006). These factors include poverty, domestic violence, or a child that is

challenged both emotionally and physically (Anderson et al., 2006). Social issues were highlighted however these factors were not explored in this study. Interactions with healthcare workers were another factor that influenced help-seeking behaviour.

The Nurturing Care Framework was applied to explore both the needs of the mother and the needs of premature babies. The Nurturing Care Framework is a set of policies and services to help parents and caregivers provide nurturing care for babies with primary care at the core (WHO, 2018). The Nurturing care framework emphasizes that the health and development of a baby are dependent on the mental and physical health of the caregiver which is the mother. The important of the framework is to be implemented during the first 1000 days which is a critical time in the healthy development of a child. In the context of the study, this nurturing environment needed to be created by healthcare workers in the public healthcare sector. The South African public healthcare sector is challenged with a shortage of adequately trained healthcare workers. This challenge negatively affects interactions between healthcare workers and patients. Additionally, it negatively affects the nurturing environment needed for caregivers to adequately care for their babies. This has a domino effect on the mother's mental health and her ability to seek help. Policies in South Africa are guided by international policies however it doesn't align with the South African belief system and social factors that affect nurturing care and the implementation of the framework.

6.4 Limitations of the study

Limitations of the study were identified as:

- The study intended to use three NICUs across three public sector hospitals however approval was only granted from one hospital. Additional NICU allows the investigator to increase the sample size within both groups and would allow a comparison of

findings across different public sector hospitals and whether there were similarities in findings.

- The study used purposeful sampling limited to mothers of premature babies in a NICU setting. The study should have included mothers of premature babies outside of a NICU setting. Mothers in NICU are still very emotional as their babies are currently in the hospital. Including mothers of premature babies that have already been discharged will create a better understanding of the care and needs of these babies and the emotional impact it has on the family dynamic.

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6.5 Recommendations

These recommendations were based on the outcomes of the research findings. The use of the Bronfenbrenner approach will work well in support of the mother, healthcare workers, and policymakers. This theory explains the impact of a social environment on human development (Evans, 2020).

6.5.1. Recommendations for mothers of premature babies

- Mothers should hone in on an individual that they can trust. This person can translate to another mother in NICU as there is a sense of relatability and the likelihood of her communicating her emotions is high.
- A social worker who is a mother of a premature baby can be present in NICU to serve as a confidant in communicating her emotions while still being guided professionally on her to manage and deal with them accordingly. Having a healthcare worker that is a mother of a premature baby also creates that sense of relatability for the mother to communicate her emotions easier. Communicating emotions this way forms a method

of processing which is also a pathway to seeking help. This is important to prevent a prolonged state of emotional distress so that it doesn't complicate something worse both physically and mentally.

- In the case that she seeks help from a healthcare worker and receives unfavourable treatment, due process needs to be followed where she can lay a complaint regarding the conduct the healthcare worker displayed. This can be done with the unit manager who is present in the unit.

6.5.2. Recommendations for healthcare workers

- This could include simple measures on how to keep the conversation open around her mental health during antenatal visits. These measures can be informal ways of checking on the mother like enquiring about her wellbeing with a simple question of 'How are you doing?'. This conversation could increase awareness and make her feel heard. Making her feel this way creates a sense of relatability which will likely increase the chances of her attending all her antenatal check-ups which are currently poorly attended nationwide.
- The public healthcare sector is used by the majority of the population. There is a current challenge of a shortage of healthcare workers that are overworked A NICU nurse has the responsibility of caring for premature babies as well as guiding and supporting the mother during this difficult time. A ward filled with babies and a shortage of staff can be a tumultuous task for these healthcare workers. The hospital is an academic hospital which translates to medical students spending time in NICU assessing these babies. Allow these medical students the task of providing emotional support and guidance to the mother as well. This gives her access to emotional support daily and provides

training to these students on how to manage the emotional distress in this group of mothers.

- Education doesn't only involve mental health but also the reality of having a premature baby. Most of these mothers are so unprepared and shocked when they deliver these small babies and the procedure of what happens after birth. This education should be an integration of healthcare based at the hospital. Social workers provide emotional support immediately after the separation from her baby. A dietitian to educate her about the importance of eating and hydrating as a breastfeeding mother and the impact on milk supply. Medical students to be present always to check on her and assist if she might have any enquiries as well as assist her on how to manage and care for her baby. This will lessen the strain on healthcare workers in NICU.
- The daily commute to NICU is long and tiring as the mother spends long hours a day bonding and breastfeeding. Providing basic snacks for her in NICU such as sandwiches and water so she stays hydrated. Nutrition is vital for breastfeeding as it assists with milk supply. Breastfeeding further assists with the bonding process between mother and baby. if
- Social workers can arrange support groups in NICU to navigate through the mother's emotions around her journey with her premature baby. These focus groups should also be done separately with healthcare workers to assess their challenges and outline possible ways to manage the mothers and their emotions.

6.5.3 Recommendations for policy makers/government

- Create policies catering only to maternal mental health and how it can be managed. Policies are focused on her physical health, which is undoubtedly important, and so is her mental health. It not only affects the development of her baby but also the healthy functioning of her family dynamic. These policies should also focus on mothers of premature as their mental health takes extra strain with the circumstances around their birth with their baby being born too soon.
- Social grants should be made easily accessible in terms of application. Premature babies require extra care and attention upon discharge. This results in the mother not being able to work hence relying on social grants to financially manage her child as she might not have access to childcare.
- Extending maternity leave for a mother of a premature baby. Her baby can spend an inevitable amount of time which feeds into her maternity leave. Her maternity leave could be ending while her baby is still hospitalised.
- Create awareness in the communities about the reality of the risk of having a premature baby and the importance of attending antenatal check-ups regularly to manage and possibly prevent preterm birth.
- Activating community healthcare workers to do home visits to provide support and guidance as well as direct the mothers towards any resources she requires if need be. These community health workers could also set up points of contact between these mothers for them to support each other so she doesn't feel isolated.

6.6 Area for future research

There is a need for research on the help-seeking behaviour of mothers with premature babies. A more extensive study can be conducted taking into account all the social aspects that affect help-seeking behaviour in mothers of premature babies. Additionally, more research is required on the management of mothers of premature babies by healthcare workers. This study only included public sector hospitals. Private hospitals can be included in future research to provide a comparison in care and management of mothers of premature babies and whether it also affects her help-seeking behaviour.

6.7 Conclusion

The study explored help-seeking behaviour in mothers of premature babies in public sector hospitals. The findings of the study concluded that the emotions around the birth of a premature baby are overwhelming for a mother to understand and process. The emotions affect her ability to care for and manage her baby. Additionally, she ignores her emotions to focus on her baby as these babies need more care and attention. The role of the healthcare worker is to support, guide, and educate her through emotional distress. However, the shortage of healthcare workers results in long and tiring days in NICU caring for these babies could contribute to the lack of empathy, support, and guidance from some healthcare workers. The mothers' emotional distress combined with strained healthcare workers resulted in unfavourable reactions between mothers and healthcare workers. These reactions make the feeling mother feel ignored and unsupported which hinders her ability to seek help. The findings indicated that there was a lack of unawareness of available resources in the hospital to assist the mother. South African policies focus mostly on the physical health of the mother to aid the development of the child. Her mental health is ignored. This is concerning as it plays a vital role in how she manages and

cares for her child. These policies also can't ignore the plight of healthcare workers. The shortage of healthcare workers combined with being unable to manage emotional distress adequately poses a red flag. They play a vital role in supporting, guiding, and creating awareness around mental health and how understands and translates her emotions to seek help.

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APPENDIX 1

INFORMATION SHEET - MOTHER

Project Title:

Exploring the help-seeking behaviour of mothers with premature babies in public sector hospitals.

What is this study about?

This is a research project being conducted by Nazeefah Safi in fulfilment of a master's in social work at the University of the Western Cape. We are inviting you to participate in this research project because you are a mother of a premature baby. The purpose of this research project is to explore the help-seeking behaviour of mothers with premature babies in public sector hospitals.

What will I be asked to do if I agree to participate?

You will be asked to fill in the agreement form for the interview. A Qualitative research method will be followed, which means that you will be interviewed. You will be asked to answer specific questions which may bear relevance to the topic. It can be answered in English or Afrikaans. The questions will revolve around your emotions as a parent and your relationship with the baby. The interview will be audio-recorded if you consent to it. You may respond to interview questions in the way that you understand them. The interview will take about 60-90 minutes. The interview will take place in a



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suitable space in the neonatal intensive care unit agreed upon by both parties at a local public sector hospital.

Would my participation in this study be kept confidential?

The researcher undertakes to protect your identity and the nature of your contribution. *To ensure your anonymity:* - Your name will not be included for any purpose in this research project.

- The interviews are anonymous and will not contain information that may personally identify you.
- A code will be used to differentiate between different transcriptions of participants.
- Only the researcher will be able to link your identity and will have access to the identification key for verification purposes.

To ensure your confidentiality, the interviews will be copied to a computer as soon as possible and deleted from the audiotape. It will be kept in a protected folder which will be known by the researcher only. The transcriptions will be identified with codes and stored in a lockable filing cabinet/safe. If a report or article is written about this research, your identity will not be disclosed.



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Following legal requirements and/or professional standards, we will disclose to the appropriate individuals and/or authorities' information that comes to our attention concerning neglect or potential harm to you or others. *In this event, we will inform you that we have to break confidentiality to fulfil our legal responsibility to report to the designated authorities.*

What are the benefits of this research?

The research will provide useful insight into help-seeking behaviour of mothers of premature babies in public sector hospitals. The results may help the researcher understand whether there may be any barriers in accessing any help to these mothers in public sector hospitals. We hope that, in the future, other people might benefit from this study through an improved understanding of help-seeking behaviour and what it entails.

What are the risks of this research?

All human interactions and talking about self or others carry some number of risks which are minimal. Participants might find themselves challenged by questions or ideas they have not considered. We will nevertheless minimise such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention.



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Do I have to be in this research, and may I stop participating at any time?

Your participation in this research is entirely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

What if I have questions?

This research is being conducted by Nazeefah Safi from the Child and Family Studies at the University of the Western Cape. If you have any questions about the research study itself, please contact me at 073 119 5887 or e-mail at nazeefahs@gmail.com.

Should you have any questions regarding this study and your rights as a research participant, or if you wish to report any problems you have experienced related to the study, please contact:

Dean of the Faculty of Community and Health Sciences:

Prof A Rhoda

University of the Western Cape

chs-deanoffice@uwc.ac.za

Professor Nicolette Roman



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APPENDIX TWO

INLIGTINGSBLAD – MOEDER

Projek Titel:

Verken hulpsoekende gedrag van moeders met voortydige babas in hospitale in die openbare sektor.

Waaroor gaan hierdie studie?

Dit is 'n navorsingsprojek wat deur Nazeefah Safi gedoen word ter vervulling van 'n meestersgraad in maatskaplike werk aan die Universiteit van Wes-Kaapland. Ons nooi jou uit om aan hierdie navorsingsprojek deel te neem omdat jy 'n ma van 'n voortydige baba is. Die doel of hierdie navorsingsprojek is om die hulpsoekende gedrag van moeders met voortydige babas in hospitale in die openbare sektor te ondersoek.

Wat sal ek gevra word om te doen as ek instem om deel te neem?

U sal gevra word om die ooreenkomsvorm vir die onderhoud in te vul. 'n Kwalitatiewe navorsingsmetode sal gevolg word, wat beteken dat jy ondervra sal word. U sal gevra word om



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spesifieke vrae te beantwoord wat relevansie vir die onderwerp kan dra. Dit kan in Engels of Afrikaans beantwoord word. Die vrae sal wentel om jou emosies as 'n ouer en jou verhouding met die baba. Die onderhoud sal audio-opgeneem word as jy toestemming daartoe gee. U kan reageer op onderhoudsvrae in die manier waarop u dit verstaan. Die onderhoud sal ongeveer 60-90 minute duur. Die onderhoud sal

plaasvind in 'n geskikte ruimte in die neonatale intensiewesorgeenheid waarop albei partye by 'n plaaslike openbare sektor hospitaal ooreengekom is.

Sou my deelname aan hierdie studie vertroulik gehou word?

Die navorser onderneem om jou identiteit en die aard van jou bydrae te beskerm. *Om jou anonimiteit te verseker:* - Jou naam sal nie vir enige doel in hierdie navorsingsprojek ingesluit word nie.

1. Thy onderhoude is anoniem en sal nie inligting bevat wat jou persoonlik kan identifiseer.
2. 'N Kode sal gebruik word om te onderskei tussen verskillende transkripsies van deelnemers.
3. Slegs die navorser sal jou identiteit kan koppel en sal toegang hê tot die identifikasiesleutel vir verifikasiedoeleindes.

Om jou vertroulikheid te verseker, sal die onderhoude so gou as moontlik na 'n rekenaar gekopieer word en uit die oudiotape geskrap word. Dit sal in 'n beskermde vouer gehou word wat slegs deur die navorser bekend sal wees. Die transkripsies sal met kodes geïdentifiseer word en in 'n sluitbare



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liasseringkabinet/kluis gestoor word. Indien 'n verslag of artikel oor hierdie navorsing geskryf is, sal jou identiteit nie bekend gemaak word nie.

Na aanleiding van wetlike vereistes en / of professionele standaarde, sal ons openbaar aan die toepaslike individue en / of owerhede inligting wat onder ons aandag kom met betrekking tot verwaarlosing of potensiële skade aan jou of ander. *In hierdie geval sal ons u inlig dat ons vertroulikheid moet verbreek om ons regsverantwoordelikheid na te kom om aan die aangewese owerhede verslag te doen.*

Wat is die voordele van hierdie navorsing?

Die navorsing sal nuttige insig gee in hulpsoekende gedrag van moeders van voortydige babas in hospitale in die openbare sektor. Die resultate kan die navorser help om te verstaan of daar enige hindernisse kan wees om toegang tot enige hulp aan hierdie moeders in openbare sektor hospitale te verkry. Ons hoop dat ander mense in die toekoms voordeel kan trek uit hierdie studie deur 'n verbeterde begrip van hulpsoekende gedrag en wat dit behels.

Wat is die risiko's van hierdie navorsing?

Alle menslike interaksies en praat oor self of ander dra 'n paar hoeveelheid risiko's wat minimaal is. Deelnemers kan hulself uitgedaag deur vrae of idees wat hulle nie oorweeg het nie. Ons sal nietemin sulke risiko's verminder en dadelik optree om u te help as u enige ongemak, sielkundig of andersins



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tydens die proses van u deelname aan hierdie studie ervaar. Waar nodig, sal 'n toepaslike verwysing aan 'n geskikte professionele persoon gemaak word vir verdere hulp of intervensie.

Moet ek in hierdie navorsing wees , en may ek ophou deelneem te eniger tyd?

Jou deelname aan hierdie navorsing is heeltemal vrywillig. Jy kan kies om glad nie deel te neem nie.

As jy besluit om aan hierdie navorsing deel te neem, kan jy te eniger tyd ophou deelneem. As jy besluit

om nie aan hierdie studie deel te neem nie of as jy te eniger tyd ophou deelneem, sal jy nie gepeenaliseer word of enige voordele verloor waaraan jy andersins kwalifiseer nie.

Wat as ek vrae het?

Hierdie navorsing word gedoen deur Nazeefah Safi van die Kinder- en Gesinstudies aan die Universiteit van Wes-Kaapland. As u enige vrae het oor die navorsingstudie ditself, kontak my asseblief by 073 119 5887 of e-pos by nazeefahs@gmail.com.

Indien u enige vrae het oor hierdie studie en u regte as 'n navorsingsdeelnemer, of as u probleme wat u met die studie ondervind het, wil aanmeld, kontak asseblief:

Dekaan van die Fakulteit Gemeenskaps- en Gesondheidswetenskappe: Prof A Rhoda



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APPENDIX 3

IPHEPHA LOLWAZI-UMAMA

Isihloko seProjekthi:

Ukuphonononga indlela yokuziphatha yokufuna uncedo koomama abaneentsana ezizelwe ngaphambi kwexesha kwizibhedlele zikarhulumente.

Singantoni esi sifundo?

Le yiprojekthi yophando eqhutywa nguNazeefah Safi ukuzalisekisa i-master's kwezentlalo ntle kwiYunivesithi yaseNtshona Koloni. Siyakumema ukuba uthathe inxaxheba kule projekthi yophando kuba ungumama wosana olungekazalwa. Injongo yale projekthi yophando kukujonga indlela yokuziphatha yokufuna uncedo koomama abaneentsana ezizelwe ngaphambi kwexesha kwizibhedlele zikarhulumente.

Yintoni endiza kucelwa ukuba ndiyenze ukuba ndiyavuma ukuthatha inxaxheba?

Uya kucelwa ukuba ugcwalise ifom yesivumelwano yodliwanondlebe. Inkqubo yophando esemgangathweni iya kulandelwa, oko kuthetha ukuba uza kudliwanondlebe. Uya kucelwa ukuba



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uphendule imibuzo ethile enokubaluleka kwesihloko. Inokuphendulwa ngesiNgesi okanye ngesiBhulu. Imibuzo iya kujikeleza kwiimvakalelo zakho njengomzali kunye nolwalamano lwakho nosana. Udliwanondlebe liza kurekhodwa ngerekhodi ukuba uyavuma. Ungaphendula kwimibuzo yodliwanondlebe ngendlela oyiqonda ngayo. Udliwanondlebe luza kuthatha malunga nemizuzu

engama-60-90. Udliwanondlebe luya kwenzeka kwindawo efanelekileyo kwicandelo lokhathalelo lwempilo ebandayo ekuvunyelwene ngalo ngamacala omabini kwisibhedlele secandelo likarhulumente.

Ngaba inxaxheba kwam kwesi sifundo zigcinwe ziyimfihlo?

Umphandi uthembisa ukukhusela isazisi sakho kunye nohlobo lwegalelo lakho. Ukuqinisekisa ukuba awuchazwanga: -Igama lakho aliyi kubandakanywa kuyo nayiphi na injongo yale projekthi yophando.

Udliwanondlebe aluchazwanga kwaye alunakuqulatha ulwazi olunokukuchonga.

- Ikhawudi iya kusetyenziswa ukwahlula phakathi kokukhutshelwa kwabathathi-nxaxheba.

-Umphandi kuphela oya kuba nakho ukudibanisa isazisi sakho kwaye uya kuba nakho ukufikelela kwisitshixo sokuchonga ngeenjongo zokuqinisekisa.

Ukuqinisekisa ukuba yimfihlo kwakho, udliwanondlebe luya kukhutshelwa kwikhompyuter ngokukhawuleza kwaye lucinywe kwi-audiotape. Iya kugcinwa kwifolda ekhuselekileyo eya kwaziwa



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ngumphandi kuphela. Imibhalo ekhutshelweyo iya kuchongwa ngeekhowudi kwaye igcinwe kwikhabhathi egcinayo / ekhuselekileyo. Ukuba ingxelo okanye inqaku libhaliwe malunga nolu phando, isazisi sakho asizukuxelwa.

Ukulandela iimfuno zomthetho kunye / okanye imigangatho yobungcali, siya kuchaza kubantu abafanelekileyo kunye / okanye nabasemagunyeni ulwazi oluza kuthi malunga nokungahoywa okanye ukwenzakala okunokubakho kuwe okanye kwabanye. Kule meko, siya kukwazisa ukuba kufuneka sophule imfihlo ukuze sizalisekise uxanduva lwethu olusemthethweni lokunika ingxelo kwabasemagunyeni.

Zithini izibonelelo zolu phando?

Uphando iza kubonelela siqonde luncedo ukuba uncedo-efuna ukuziphatha koomama iintsana ngaphambi kwexesha kwizibhedlele kwicandelo likarhulumente. Iziphumo zinokunceda umphandi aqonde ukuba ingaba ikhona na imiqobo ekufikeleleni kulo naluphi na uncedo kwaba mama kwizibhedlele zecandelo likarhulumente. Siyathemba ukuba, kwixa elizayo, abanye abantu banokuxhamla kolu phanonongo ngokuqonda okuphuculweyo kokuziphatha okufuna uncedo kunye nokuba kubandakanya ntoni.



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Buphi ubungozi kolu phando?

Lonke unxibelelwano lomntu kunye nokuthetha ngesiqu sakho okanye abanye bathwele umngcipheko othile ubuncinci. Abathathi-nxaxheba banokuzifumana becelomngeni ngemibuzo okanye izimvo abangakhange baziqwalasele. Siza kubunciphisa obo bungozi kwaye sisebenze ngokukhawuleza ukukunceda ukuba uhlangabezana nokungaphatheki kakuhle, nasengqondweni okanye ngenye indlela ngexesha lokuthatha kwakho inxaxheba kolu phando. Apho kufanelekileyo, ukuthunyelwa ngokufanelekileyo kuya kuthunyelwa kwingcali efanelekileyo ukufumana uncedo olungaphezulu okanye ungenelelo.

Ngaba kufuneka ndibekho kolu phando, kwaye ndingayeka ukuthatha inxaxheba nangaliphi na ixesha?

Ukuthatha kwakho inxaxheba kolu phando kungokuzithandela. Unokukhetha ukungathathi nxaxheba kwaphela. Ukuba uthatha isigqibo sokuthatha inxaxheba kolu phando, unokuyeka ukuthatha

inxaxheba nangaliphi na ixesha. Ukuba uthatha isigqibo sokungathathi nxaxheba kolu phonoongo okanye uyeka ukuthatha inxaxheba nangaliphi na ixesha, awuyi kohlwaywa okanye uphulukane naziphi na izibonelelo ofaneleke ngazo.



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Kuthekani ukuba ndinemibuzo?

Olu phando lwenziwa nguNazeefah Safi ovela kwiZifundo zaBantwana nezoSapho kwiDyunivesithi yaseNtshona Koloni. Ukuba unemibuzo malunga nophando ngokwalo, nceda unxibelelane nam kule nombolo: 073 119 5887 okanye nge-imeyile apha nazeefahs@gmail.com.

Ukuba unayo nayiphi imibuzo malunga nolu phando kunye namalungelo akho njengomthathi-nxaxheba wophando, okanye ukuba unqwenela ukuxela naziphi na iingxaki ozifumeneyo ezinxulumene nophando, nceda unxibelelane:

UMlawuli weCandelo loLuntu kunye neNzululwazi yezeMpilo:

UNjingalwazi A Rhoda

KwiYunivesithi yaseNtshona Koloni

chs-deanoffice@uwc.ac.za

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APPENDIX 4

INFORMATION SHEET – HEALTHCARE WORKER

Project Title:

Exploring the help-seeking behaviour of mothers with premature babies in public sector hospitals.

What is this study about?

This is a research project being conducted by Nazeefah Safi in fulfilment of a master's in social work at the University of the Western Cape. We are inviting you to participate in this research project because you are a healthcare worker that works in a neonatal intensive care unit that cares for premature babies. The purpose of this research project is to explore the help-seeking behaviour of mothers with premature babies in public sector hospitals.

What will I be asked to do if I agree to participate?

You will be asked to fill in the agreement form for the interview. A Qualitative research method will be followed, which means that you will be interviewed. You will be asked to answer specific questions which may bear relevance to the topic. It can be answered in English or Afrikaans. The questions will



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revolve around your emotions as a parent and your relationship with the baby. The interview will be audio-recorded if you consent to it. You may respond to interview questions in the way that you understand them. The interview will take about 60-90 minutes. The interview will take place in a

suitable space in the neonatal intensive care unit agreed upon by both parties at a local public sector hospital.

Would my participation in this study be kept confidential?

The researcher undertakes to protect your identity and the nature of your contribution. *To ensure your anonymity:* - Your name will not be included for any purpose in this research project.

- The interviews are anonymous and will not contain information that may personally identify you.
- A code will be used to differentiate between different transcriptions of participants.
- Only the researcher will be able to link your identity and will have access to the identification key for verification purposes.



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To ensure your confidentiality, the interviews will be copied to a computer as soon as possible and deleted from the audiotape. It will be kept in a protected folder which will be known by the researcher only. The transcriptions will be identified with codes and stored in a lockable filing cabinet/safe. If a report or article is written about this research, your identity will not be disclosed.

Following legal requirements and/or professional standards, we will disclose to the appropriate individuals and/or authorities' information that comes to our attention concerning neglect or potential

harm to you or others. *In this event, we will inform you that we have to break confidentiality to fulfil our legal responsibility to report to the designated authorities.*

What are the benefits of this research?

The research will provide useful insight into help-seeking behaviour of mothers of premature babies in public sector hospitals. The results may help the researcher understand whether there may be any barriers in accessing any help to these mothers in public sector hospitals. We hope that, in the future, other people might benefit from this study through an improved understanding of help-seeking behaviour and what it entails.

What are the risks of this research?



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All human interactions and talking about self or others carry some number of risks which are minimal. Participants might find themselves challenged by questions or ideas they have not considered. We will nevertheless minimise such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention.

Do I have to be in this research, and may I stop participating at any time?

Your participation in this research is entirely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to

participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

What if I have questions?

This research is being conducted by Nazeefah Safi from the Child and Family Studies at the University of the Western Cape. If you have any questions about the research study itself, please contact me at 073 119 5887 or e-mail at nazeefahs@gmail.com.

Should you have any questions regarding this study and your rights as a research participant, or if you wish to report any problems you have experienced related to the study, please contact:



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APPENDIX 5

INLIGTINGSTUK – GESONDHEIDSORGWERKER

Projek Titel:

Verken hulpsoekende gedrag van moeders met voortydige babas in hospitale in die openbare sektor.

Waaroor gaan hierdie studie?

Dit is 'n navorsingsprojek wat deur Nazeefah Safi gedoen word ter vervulling van 'n meestersgraad in maatskaplike werk aan die Universiteit van Wes-Kaapland. Ons nooi u uit om aan hierdie navorsingsprojek deel te neem omdat u 'n gesondheidsorgwerker is wat in 'n neonatale intensiewe sorgeenheid werk wat na vroeggebore babas omsien. Die doel van hierdie navorsingsprojek is om die hulpsoekende gedrag van moeders met vroeggebore babas in openbare sektorhospitale te ondersoek.

Wat sal ek gevra word om te doen as ek instem om deel te neem?

U sal gevra word om die ooreenkomsvorm vir die onderhoud in te vul. 'n Kwalitatiewe navorsingsmetode sal gevolg word, wat beteken dat jy ondervra sal word. U sal gevra word om



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spesifieke vrae te beantwoord wat relevansie vir die onderwerp kan dra. Dit kan in Engels of Afrikaans beantwoord word. Die vrae sal wentel om jou emosies as 'n ouer en jou verhouding met die baba. Die onderhoud sal audio-opgeneem word as jy toestemming daartoe gee. U kan reageer op onderhoudsvrae in die manier waarop u dit verstaan. Die onderhoud sal ongeveer 60-90 minute duur. Die onderhoud sal

plaasvind in 'n geskikte ruimte in die neonatale intensiewesorgeenheid waarop albei partye by 'n plaaslike openbare sektor hospitaal ooreengekom is.

Sou my deelname aan hierdie studie vertroulik gehou word?

Die navorser onderneem om jou identiteit en die aard van jou bydrae te beskerm. *Om jou anonimiteit te verseker:* - Jou naam sal nie vir enige doel in hierdie navorsingsprojek ingesluit word nie.

1. Thy onderhoude is anoniem en sal nie inligting bevat wat jou persoonlik kan identifiseer.
2. 'N Kode sal gebruik word om te onderskei tussen verskillende transkripsies van deelnemers.
3. Slegs die navorser sal jou identiteit kan koppel en sal toegang hê tot die identifikasiesleutel vir verifikasiedoeleindes.

Om jou vertroulikheid te verseker, sal die onderhoude so gou as moontlik na 'n rekenaar gekopieer word en uit die oudiotape geskrap word. Dit sal in 'n beskermde vouer gehou word wat slegs deur die navorser bekend sal wees. Die transkripsies sal met kodes geïdentifiseer word en in 'n sluitbare liasseringkabinet/kluis gestoor word. Indien 'n verslag of artikel oor hierdie navorsing geskryf is, sal jou identiteit nie bekend gemaak word nie.



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Na aanleiding van wetlike vereistes en / of professionele standaarde, sal ons openbaar aan die toepaslike individue en / of owerhede inligting wat onder ons aandag kom met betrekking tot verwaarlosing of potensiële skade aan jou of ander. *In hierdie geval sal ons u inlig dat ons vertroulikheid moet verbreek om ons regsverantwoordelikheid na te kom om aan die aangewese owerhede verslag te doen.*

Wat is die voordele van hierdie navorsing?

Die navorsing sal nuttige insig gee in hulpsoekende gedrag van moeders van voortydige babas in hospitale in die openbare sektor. Die resultate kan die navorser help om te verstaan of daar enige hindernisse kan wees om toegang tot enige hulp aan hierdie moeders in openbare sektor hospitale te verkry. Ons hoop dat ander mense in die toekoms voordeel kan trek uit hierdie studie deur 'n verbeterde begrip van hulpsoekende gedrag en wat dit behels.

Wat is die risiko's van hierdie navorsing?

Alle menslike interaksies en praat oor self of ander dra 'n paar hoeveelheid risiko's wat minimaal is. Deelnemers kan hulself uitgedaag deur vrae of idees wat hulle nie oorweeg het nie. Ons sal nietemin sulke risiko's verminder en dadelik optree om u te help as u enige ongemak, sielkundig of andersins tydens die proses van u deelname aan hierdie studie ervaar. Waar nodig, sal 'n toepaslike verwysing aan 'n geskikte professionele persoon gemaak word vir verdere hulp of intervensie.



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Moet ek in hierdie navorsing wees , en may ek ophou deelneem te eniger tyd?

Jou deelname aan hierdie navorsing is heeltemal vrywillig. Jy kan kies om glad nie deel te neem nie. As jy besluit om aan hierdie navorsing deel te neem, kan jy te eniger tyd ophou deelneem. As jy besluit om nie aan hierdie studie deel te neem nie of as jy te eniger tyd ophou deelneem, sal jy nie geenaliseer word of enige voordele verloor waaraan jy andersins kwalifiseer nie.

Wat as ek vrae het?

Hierdie navorsing word gedoen deur Nazeefah Safi van die Kinder- en Gesinstudies aan die Universiteit van Wes-Kaapland. As u enige vrae het oor die navorsingstudie ditself, kontak my asseblief by 073 119 5887 of e-pos by nazeefahs@gmail.com.

Indien u enige vrae het oor hierdie studie en u regte as 'n navorsingsdeelnemer, of as u probleme wat u met die studie ondervind het, wil aanmeld, kontak asseblief:

Dekaan van die Fakulteit Gemeenskaps- en Gesondheidswetenskappe:

Prof A Rhoda

Universiteit van Wes-Kaapland

chs-deanoffice@uwc.ac.za



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APPENDIX 6

IPHEPHA LOLWAZI-UMSEBENZI WENKONZO YEMPILO

Isihloko seProjekthi:

Ukuphonononga indlela yokuziphatha yokufuna uncedo koomama abaneentsana ezizelwe ngaphambi kwexesha kwizibhedlele zikarhulumente.

Singantoni esi sifundo?

Le yiprojekthi yophando eqhutywa nguNazeefah Safi ukuzalisekisa i-master's kwezentlalo ntle kwiYunivesithi yaseNtshona Koloni. Sikumema ukuba uthathe inxaxheba kule projekthi yophando kuba ungumsebenzi wokhathalelo lwempilo osebenza kwicandelo lokhathalelo lweentsana olunonophelo lweentsana olukhathalela iintsana ezizelwe ngaphambi kwexesha. Injongo yale projekthi yophando kukujonga indlela yokuziphatha yokufuna uncedo koomama abaneentsana ezizelwe ngaphambi kwexesha kwizibhedlele zikarhulumente.

Yintoni endiza kucelwa ukuba ndiyenze ukuba ndiyavuma ukuthatha inxaxheba?



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Uya kucelwa ukuba ugcwalise le fomu yesivumelwano ukuze ndlebe. Inkqubo yophando esemgangathweni iya kulandelwa, oko kuthetha ukuba uza kudliwanondlebe. Uya kucelwa ukuba uphendule imibuzo ethile enokubaluleka kwesihloko. Inokuphendulwa ngesiNgesi okanye ngesiBhulu. Imibuzo iya kujikeleza kwiimvakalelo zakho njengomzali kunye nolwalamano lwakho nosana. Udliwanondlebe liza kurekhodwa ngerekhodi ukuba uyavuma. Ungaphendula kwimibuzo

yodliwanondlebe ngendlela oyiqonda ngayo. Udliwanondlebe luza kuthatha malunga nemizuzu engama-60-90. Udliwanondlebe luya kwenzeka kwindawo efanelekileyo kwicandelo lokhathalelo lwempilo ebandayo ekuvunyelwene ngalo ngamacala omabini kwisibhedlele secandelo likarhulumente.

Ngaba inxaxheba kwam kwesi sifundo zigcinwe ziyimfihlo?

Umphandi uthembisa ukukhusela isazisi sakho kunye nohlobo lwegalelo lakho. Ukuqinisekisa ukuba awuchazwanga: -Igama lakho aliyi kubandakanywa kuyo nayiphi na injongo yale projekthi yophando.

Udliwanondlebe aluchazwanga kwaye alunakuqulatha ulwazi olunokukuchonga.

- Ikhawudi iya kusetyenziswa ukwahlula phakathi kokukhutshelwa kwabathathi-nxaxheba.

-Umphandi kuphela oya kuba nakho ukudibanisa isazisi sakho kwaye uya kuba nakho ukufikelela kwisitshixo sokuchonga ngeenjongo zokuqinisekisa.



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Ukuqinisekisa ukuba yimfihlo kwakho, udliwanondlebe luya kukhutshelwa kwikhompyuter ngokukhawuleza kwaye lucinywe kwi-audiotape. Iya kugcinwa kwifolda ekhuselekileyo eya kwaziwa ngumphandi kuphela. Imibhalo ekhutshelweyo iya kuchongwa ngeekhowudi kwaye igcinwe

kwikhabhathi egcinayo / ekhuselekileyo. Ukuba ingxelo okanye inqaku libhaliwe malunga nolu phando, isazisi sakho asizukuxelwa.

Ukulandela iimfuno zomthetho kunye / okanye imigangatho yobungcali, siya kuchaza kubantu abafanelekileyo kunye / okanye nabasemagunyeni ulwazi oluza kuthi malunga nokungahoywa okanye ukwenzakala okunokubakho kuwe okanye kwabanye. Kule meko, siya kukwazisa ukuba kufuneka sophule imfihlo ukuze sizalisekise uxanduva lwethu olusemthethweni lokunika ingxelo kwabasemagunyeni.

Zithini izibonelelo zolu phando?

Olu phando luza kubonelela ngendlela efanelekileyo yokufuna uncedo koomama beentsana ezizelwe ngaphambi kwexesha kwizibhedlele zikarhulumente. Iziphumo zinokunceda umphandi aqonde ukuba ingaba ikhona na imiqobo ekufikeleleni kulo naluphi na uncedo kwaba mama kwizibhedlele zecandelo likarhulumente. Siyathemba ukuba, kwixa elizayo, abanye abantu banokuxhamla kolu phononongo ngokuqonda okuphuculweyo kokuziphatha okufuna uncedo kunye nokuba kubandakanya ntoni.



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Buphi ubungozi kolu phando?

Lonke unxibelelwano lomntu kunye nokuthetha ngesiqu sakho okanye abanye bathwele umngcipheko othile ubuncinci. Abathathi-nxaxheba banokuzifumana becelomngeni ngemibuzo okanye izimvo

abangakhange baziqwalasele. Siza kubunciphisa obo bungozi kwaye sisebenze ngokukhawuleza ukukunceda ukuba uhlangebazana nokungaphatheki kakuhle, nasengqondweni okanye ngenye indlela ngexesha lokuthatha kwakho inxaxheba kolu phando. Apho kufanelekileyo, ukuthunyelwa ngokufanelekileyo kuya kuthunyelwa kwingcali efanelekileyo ukufumana uncedo olungaphezulu okanye ungenelelo.

Ngaba kufuneka ndibekho kolu phando, kwaye ndingayeka ukuthatha inxaxheba nangaliphi na ixesha?

Ukuthatha kwakho inxaxheba kolu phando kungokuzithandela. Unokukhetha ukungathathi nxaxheba kwaphela. Ukuba uthatha isigqibo sokuthatha inxaxheba kolu phando, unokuyeka ukuthatha inxaxheba nangaliphi na ixesha. Ukuba uthatha isigqibo sokungathathi nxaxheba kolu phonoongo okanye uyeka ukuthatha inxaxheba nangaliphi na ixesha, awuyi kohlwaywa okanye uphulukane naziphi na izibonelelo ofaneleke ngazo.

Kuthekani ukuba ndinemibuzo?

Olu phando lwenziwa nguNazeefah Safi ovela kwiZifundo zaBantwana nezoSapho kwiDyunivesithi yaseNtshona Koloni. Ukuba unemibuzo malunga nophando ngokwalo, nceda unxibelelane nam kule nombolo: 073 119 5887



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okanye nge-imeyile apha nazeefahs@gmail.com.

Ukuba unayo nayiphi na imibuzo malunga nale sifundo kunye namalungelo akho njenge nxaxheba uphando, okanye ukuba ufuna ukuxela naziphi na iingxaki othe wagagana enxulumene sifundo, nceda qhagamshelana:

Umlawuli weCandelo loLuntu kunye neNzululwazi yezeMpilo:

UNjingalwazi A Rhoda

KwiYunivesithi yaseNtshona Koloni

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APPENDIX 7

CONSENT FORM – Mother

Title of Research Project: Exploring the help-seeking behaviour of mothers with premature babies in public sector hospitals.

I agree with the following statements:

The study has been described to me in a language that I understand. The questions that will be asked has been explained. I understand that my participation is voluntary. This means that I can withdraw from the study at any time or refrain from answering any questions that I am not comfortable with. My identity will always be kept anonymous. There are no known risks involved in this study. If I choose not to participate there will be no penalty or loss of benefits, *I consent to participate in this research programme.*

_____ I agree to be audio-taped during my participation in the study.

_____ I do not agree to be audiotaped during my participation in this study.

Participant's name:

Participant's signature:

Date:



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APPENDIX 8

TOESTEMMINGSVORM – Moeder

Titel van Navorsingsprojek: **Verkenning van die hulpsoekende gedrag van moeders met voortydige babas in hospitale in die openbare sektor.**

Ek stem saam met die volgende stellings:

Die studie is aan my beskryf in 'n taal wat ek verstaan. Die vrae wat gevra sal word, is verduidelik. Ek verstaan dat my deelname vrywillig is. Dit beteken dat ek te eniger tyd aan die studie kan onttrek of my daarvan weerhou om enige vrae waarmee ek nie gemaklik is nie, te beantwoord. My identiteit sal altyd anoniem gehou word. Daar is geen bekende risiko's by hierdie studie betrokke nie. As ek kies om nie deel te neem nie, sal daar geen boete of verlies aan voordele wees nie, stem *ek in om aan hierdie navorsingsprogram deel te neem.*

_____ Ek stem in om oudio-getik te word tydens my deelname aan die studie.

_____ Ek stem nie in om tydens my deelname aan hierdie studie oudiotaped te word nie.

Deelnemer se naam:.....

Deelnemer se handtekening:.....

Datum:



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APPENDIX 9

IFOMU YEMVUMELWANO - umama

Isihloko seProjekthi yoPhando: Ukuphonononga indlela yokuziphatha yokufuna uncedo koomama abaneentsana ezizelwe ngaphambi kwexesha kwizibhedlele zikarhulumente.

Ndiyavumelana nezi ngxelo zilandelayo:

Isifundo sichazwe kum ngolwimi endiliqondayo. Imibuzo eza kubuzwa icacisiwe. Ndiyaqonda ukuba ukuthatha inxaxheba kwam kungokuzithandela. Oku kuthetha ukuba ndinokurhoxa esifundweni ngalo naliphi na ixesha okanye ndiyeke ukuphendula nayiphi na imibuzo endingonwabanga ngayo. Isazisi sam siya kuhlala singaziwa. Akukho bungozi baziwayo obubandakanyekayo kolu phando. Ukuba ndikhetha ukungathathi nxaxheba akuyi kubakho isohlwayo okanye ilahleko yezibonelelo, *Ndiyavuma ukuthatha inxaxheba kule nkqubo yophando.*

_____ Ndiyavuma ukuthathwa ngomsindo ngexesha lokuthatha inxaxheba kolu phando.

_____ Andivumi ukuba ndicuthwe ngevidiyo xa ndithatha inxaxheba kwesi sifundo

Igama lomthathi-nxaxheba:.....

Utyikityo lwabathathi-nxaxheba:.....

Umhla:.....



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APPENDIX 10

CONSENT FORM – Healthcare worker

Title of Research Project: Exploring the help-seeking behaviour of mothers with premature babies in public sector hospitals.

I agree with the following statements:

The study has been described to me in a language that I understand. The questions that will be asked has been explained. I understand that my participation is voluntary. This means that I can withdraw from the study at any time or refrain from answering any questions that I am not comfortable with. My identity will always be kept anonymous. There are no known risks involved in this study. If I choose not to participate there will be no penalty or loss of benefits, *I consent to participate in this research programme.*

_____ I agree to be audio-taped during my participation in the study.

_____ I do not agree to be audiotaped during my participation in this study.

Participant's name:

Participant's signature:

Date:



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APPENDIX 11

TOESTEMMINGSVORM – Gesondheidsorgwerker

Titel van Navorsingsprojek: Verkenning van die hulpsoekende gedrag van moeders met voortydige babas in hospitale in die openbare sektor.

Ek stem saam met die volgende stellings:

Die studie is aan my beskryf in 'n taal wat ek verstaan. Die vrae wat gevra sal word, is verduidelik. Ek verstaan dat my deelname vrywillig is. Dit beteken dat ek te eniger tyd aan die studie kan onttrek of my daarvan weerhou om enige vrae waarmee ek nie gemaklik is nie, te beantwoord. My identiteit sal altyd anoniem gehou word. Daar is geen bekende risiko's by hierdie studie betrokke nie. As ek kies om nie deel te neem nie, sal daar geen boete of verlies aan voordele wees nie, stem *ek in om aan hierdie navorsingsprogram deel te neem.*

_____ Ek stem in om oudio-getik te word tydens my deelname aan die studie.

_____ Ek stem nie in om tydens my deelname aan hierdie studie oudiotaped te word nie.

Deelnemer se naam:.....

Deelnemer se handtekening:.....

Datum:



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APPENDIX 12

IFOMU YEMVUMELWANO - Umsebenzi wezempilo

Isihloko seProjekthi yoPhando: Ukuphonononga indlela yokuziphatha yokufuna uncedo koomama abaneentsana ezizelwe ngaphambi kwexesha kwizibhedlele zikarhulumente.

Ndiyavumelana nezi ngxelo zilandelayo:

Isifundo sichazwe kum ngolwimi endiliqondayo. Imibuzo eza kubuzwa icacisiwe. Ndiyaqonda ukuba ukuthatha inxaxheba kwam kungokuzithandela. Oku kuthetha ukuba ndinokurhoxa esifundweni ngalo naliphi na ixesha okanye ndiyeke ukuphendula nayiphi na imibuzo endingonwabanga ngayo. Isazisi sam siya kuhlala singaziwa. Akukho bungozi baziwayo obubandakanyekayo kolu phando. Ukuba ndikhetha ukungathathi nxaxheba akuyi kubakho isohlwayo okanye ilahleko yezibonelelo, *Ndiyavuma ukuthatha inxaxheba kule nkqubo yophando.*

_____ Ndiyavuma ukuthathwa ngomsindo ngexesha lokuthatha inxaxheba kolu phando.

_____ Andivumi ukuba ndicuthwe ngevidiyo xa ndithatha inxaxheba kwesi Sifundo

Igama lomthathi-nxaxheba:.....



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Utyikityo lwabathathi-nxaxheba:.....

Umhla:.....

APPENDIX 13

INTERVIEW SCHEDULE: MOTHER

Title: Exploring the help-seeking behaviour of mothers with premature babies in public sector hospitals

Date:

Time:

Place:

Interviewer:

Interviewee:

- 1) Tell me about your journey to become a mother? (Prompts: bonding, life changing)
- 2) What is a typical day like in the neonatal intensive care unit? (Prompts: Tiring, overwhelming)
- 3) How do you feel about your baby being born too soon? (Prompts: Feelings of sadness, helplessness)
- 4) How is the relationship with your baby? (Prompt: Check for any feelings of detachment)
- 5) What is your relationship like with the healthcare workers in neonatal intensive care unit? (Prompt: intimidation)
- 6) How would you ask for help from a healthcare worker? (Prompt: being evasive, fear)
- 7) What kind of help do you need from a healthcare worker? (Prompt: information, guidance, support)
- 8) What resources are available in the hospital to assist you in anyway after you gave birth to your baby? (Prompt: confusion, lack of awareness)

- 9) What do you understand by help-seeking behaviour? (Prompt: check for hesitancy, confusion)
- 10) What does being a mother to a premature baby mean to you? (Prompt: scared, fear of the unknown)

APPENDIX 14

ONDERHOUDSKEDULE: MOEDER

Titel: Verken die hulpsoekende gedrag van moeders met vroeggebore babas

Datum:

Tyd:

Plek:

Onderhoudvoerder:

Ondervra:

1. Vertel my van jou reis om 'n ma te word? (Aanwysings: binding, lewensveranderende)
2. Wat is 'n tipiese dag soos in die neonatale intensiewesorgeenheid? (Aanwysings: Uitputtend, oorweldigend)
3. Hoe voel jy oor jou baba wat te gou gebore word? (Por aan: Gevoelens van hartseer, hulpeloosheid)
4. Hoe is die verhouding met jou baba? (Por aan: Kyk vir enige gevoelens van losmaking)
5. Hoe lyk jou verhouding met die gesondheidsorgwerkers in neonatale intensiewesorgeenheid? (Por aan: intimidasie)

6. Hoe sal jy hulp van 'n gesondheidsorgwerker vra? (Por aan: om ontduikend te wees, vrees)
7. Watter soort hulp het jy van 'n gesondheidsorgwerker nodig? (Por aan: inligting, leiding, ondersteuning)
8. Watter hulpbronne is in die hospitaal beskikbaar om jou in elk geval te help nadat jy geboorte gegee het aan jou baba? (Por aan: verwarring, gebrek aan bewustheid)
9. Wat verstaan jy deur hulpsoekende gedrag? (Vinnige: kyk vir huiwering, verwarring)
10. Wat beteken 'n ma vir 'n voortydige baba vir jou? (Por aan: bang, vrees vir die onbekende)

APPENDIX 15

ISHEDYULI YODLIWANO-NDLEBE: UMAMA

Isihloko: Ukuphonononga indlela yokuziphatha yokufuna uncedo koomama abaneentsana ngaphambi kwexesha

Umhla:

Ixesha:

Indawo:

Udliwanondlebe:

Udliwanondlebe:

- (1) Ndixelele ngohambo lwakho lokuba ngumama? (Kukhuthaza: ukudibanisa, ukutshintsha ubomi)
- (2) Lunjani usuku oluqhelekileyo kwicandelo lokhathalelo lweentsana olusandul'ukuzalwa? (Kuyakhathaza: Kuyadinisa, kuyothusa)
- (3) Uziva njani xa usana lwakho luzalwa kungekudala? (Yazisa: Iimvakalelo zosizi, ukungabi nakuzinceda)
- (4) Bunjani ubudlelwane nomntwana wakho? (Khawulezisa: Jonga naziphi na iimvakalelo zediski)
- (5) Bunjani ubudlelwane bakho nabasebenzi bokhathalelo lwempilo kwicandelo lokhathalelo lwempilo lwabazalwayo? (Yazisa: ukoyikisa)
- (6) Ungalucela njani uncedo kumsebenzi wezempilo? (Khuthaza: ukubaleka, uloyiko)
- (7) Loluphi uhlobo loncedo olufunayo kumongi? (Yazisa: ulwazi, isikhokelo, inkxaso)

- (8) Zeziphi izibonelelo ezikhoyo esibhedlele zokukunceda nakanjani na emva kokuba ubelekile umntwana wakho? (Yazisa ngokukhawuleza: ukudideka, ukunqongophala kokuqonda)
- (9) Uqonda ntoni ngokuziphatha okufuna uncedo? (Yazisa: jonga ukuthandabuza, ukudideka)
- (10) Kuthetha ntoni ukuba ngumama kusana ngaphambi kwexesha kuwe? (Yazisa: woyika, woyike into engaziwayo)

APPENDIX 16

INTERVIEW SCHEDULE: HEALTHCARE WORKER

Title: Exploring the help-seeking behaviour of mothers with premature babies

Date:

Time:

Place:

Interviewer:

Interviewee:

- 1) Tell me about your journey to become a healthcare worker? (Prompts: helping people, community outreach)
- 2) What is a typical day like as a healthcare worker in the neonatal intensive care unit? (Prompt: busy, tiring)
- 3) Do you enjoy these roles and responsibilities? (Prompts: overworked, long working days)
- 4) Have these mothers been informed why their babies were born too soon? (Prompts: lack of education, lack of time)
- 5) What resources are available in the hospital to help these mothers after they give birth to a premature baby? (Prompt: confusion, hesitancy)
- 6) What is your relationship like with the mothers in neonatal intensive care unit? (Prompt: hierarchy, lack of bonding)
- 7) How would these mothers ask for help from a healthcare worker? (Prompt : lack of enquiry, lack of interest)

- 8) What kind of help do these mothers need from a healthcare worker? (Prompt: support, guidance, and education)
- 9) What do you understand by help-seeking behaviour? (Prompt: reference to healthcare worker)
- 10) What does being a healthcare worker mean to you? (Prompt: helping people, awareness, upliftment)

APPENDIX 17

ONDERHOUDSKEDULE: GESONDHEIDSORGWERKER

Titel: Verken die hulpsoekende gedrag van moeders met voortydige babas

Datum:

Tyd:

Plek:

Onderhoudvoerder:

Ondervra:

- 1) Vertel my van jou reis om 'n gesondheidsorgwerker te word? (Aanwysings: help mense, gemeenskapsuitreik)
- 2) Wat is 'n tipiese dag soos 'n gesondheidsorgwerker in die neonatale intensiewesorgeenheid? (Por aan: besig, uitputtend)
- 3) Geniet jy hierdie rolle en verantwoordelikhede? (Aanwysings: oorwerkte, lang werksdae)
- 4) Is hierdie moeders ingelig waarom hul babas te gou gebore is? (Aanwysings: gebrek aan onderwys, gebrek aan tyd)
- 5) Watter hulpbronne is in die hospitaal beskikbaar om hierdie moeders te help nadat hulle geboorte gegee het aan 'n voortydige baba? (Vinnige: verwarring, huiwering)
- 6) Hoe lyk jou verhouding met die moeders in neonatale intensiewesorgeenheid? (Prompt: hiërargie, gebrek aan binding)
- 7) Hoe sal hierdie moeders hulp van 'n gesondheidsorgwerker vra? (Vinnige : gebrek aan navraag, gebrek aan belangstelling)

- 8) Watter soort hulp het hierdie moeders van 'n gesondheidsorgwerker nodig? (Vinnige: ondersteuning, leiding en opvoeding)
- 9) Wat verstaan jy deur hulpsoekende gedrag? (Prompt: verwysing na gesondheidsorgwerker)
- 10) Wat beteken om 'n gesondheidsorgwerker vir jou te wees? (Por aan: help mense, bewustheid, opheffing)

APPENDIX 18

ISHEDYULI YODLIWANO-NDLEBE: UMSEBENZI WEZEMPILO

Isihloko: Ukuphonononga indlela yokuziphatha yokufuna uncedo koomama abaneentsana ngaphambi kwexesha

Umhla:

Ixesha:

Indawo:

Udliwanondlebe:

Udliwanondlebe:

- 1) Ndixelele ngohambo lwakho lokuba ngumsebenzi wokhathalelo lwempilo? (Yazisa: ukunceda abantu, ukufikelela eluntwini)
- 2) Yintoni Ngosuku ngathi njengomsebenzi lwempilo kwiyunithi lweentsana labagula kakhulu? (Khawuleza: uxakekile, uyadinwa)
- 3) Uyazivuyela ezi ndima noxanduva? (Ukunyusa: ukusebenza ngaphezulu, iintsuku ezinde zokusebenza)
- 4) Ngaba aba mama baye baziswa ukuba kutheni iintsana zabo zizalwa ngokukhawuleza? (Ukunyusa: ukunqongophala kwemfundo, ukunqongophala kwexesha)
- 5) Ziziphi izibonelelo ezifumanekayo esibhedlele ukunceda ezi oomama emva kokuba azale umntwana ngaphambi kwexesha? (Ukukhawuleza: ukudideka, ukuthandabuza)

- 6) Bunjani ubudlelwane bakho noomama abakwiiyunithi zononophelo lweentsana ezisandul 'ukuzalwa? (Yazisa ngokukhawuleza: ulawulo oluphezulu, ukusilela kokubopha)
- 7) Oomama bangalucela njani uncedo kumongi? (Ukukhawuleza: ukungabikho kophando, ukungabikho komdla)
- 8) Loluphi uncedo abalufunayo aba mama koonompilo? (Yazisa: inkxaso, isikhokelo kunye nemfundo)
- 9) Yintoni na kakuhle ukuziphatha uncedo-efuna? (Yazisa: kubhekiswa kunompilo)
- 10) Kuthetha ntoni ukuba ngumsebenzi wezempilo kuwe? (ngokukhawuleza: ukunceda abantu, ukuqonda, ukuphakamisa)



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19 November 2021

Dr N Safi
Centre for Interdisciplinary Studies of Children, Families and Society
Faculty of Community and Health Sciences

Ethics Reference Number: BM21/8/15

Project Title: Exploring the help-seeking behaviour of mothers with premature babies in public sector hospitals

Approval Period: 19 November 2021 – 19 November 2024

I hereby certify that the Biomedical Science Research Ethics Committee of the University of the Western Cape approved the scientific methodology and ethics of the above mentioned research project and the requested amendment to the project.

Any further amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

Please remember to submit a progress report annually by 30 November for the duration of the project.

For permission to conduct research using student and/or staff data or to distribute research surveys/questionnaires please apply via:

<https://sites.google.com/uwc.ac.za/permissionresearch/home>

The permission letter must then be submitted to BMREC for record keeping purposes.

The Committee must be informed of any serious adverse event and/or termination of the study.

Ms Patricia Josias
Research Ethics Committee Officer
University of the Western Cape

