



**UNIVERSITY of the  
WESTERN CAPE**

**“EXPLORING THE SUBJECTIVE MEANING-MAKING AND PERCEPTIONS OF  
THE IMPACT OF THEIR HIGH- RISK PREGNANCIES IN A SAMPLE OF  
WOMEN FROM RESOURCE-CONSTRAINED AREAS”**

*A mini thesis submitted in partial fulfilment of requirements for the degree of  
Master of Arts (Research Psychology) at the University of the Western Cape*

**2023**

**By**

***Gugulethu Cebekhulu***

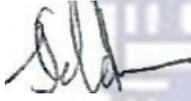
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***Key words: high- risk pregnancy, qualitative, motherhood, trauma, distress,  
subjective experiences, existential, post-natal, resource constrained, Western  
Cape***

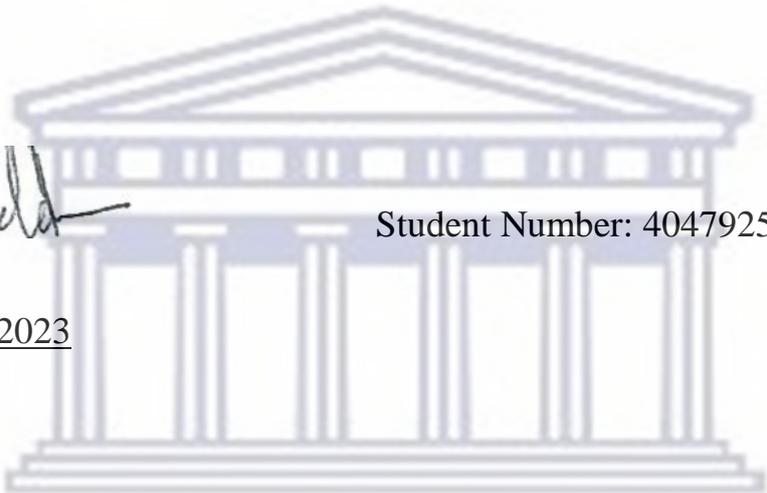
## DECLARATION

I, Gugulethu Cebekhulu hereby declare that the present mini thesis titled “*Exploring the subjective meaning making and perceptions of the impact of their high-risk pregnancies in a sample of women from resource constrained areas*”. This work has not been submitted for any other degree, examination, or professional qualification. I, therefore, confirm that this research is my own composition except for the work that was sourced from other researchers and authors as indicated by the APA (American Psychological Association) referencing style.

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## ACKNOWLEDGEMENTS

I extend my gratitude to God, who carried me throughout this entire research project. I have experienced his grace through the love and support of my family and friends.

Thank you to my little brother, Sfiso Cebekhulu and my mom, Fundisiwe Lucia Cebekhulu for their unwavering love, support and patience throughout the entire long journey. I also acknowledge my sister, Linda Cebekhulu and my cousin, Dumsile Mgaga for all the financial contributions. Thank you to my two dearest friends, my little sisters, Ramona Barclay and Hlumela Dyantyi. They have both been my pillar of strength and I would not have been able to continue on this journey without them by my side. I am very grateful for the amount of support that I received from my friend, Kimberly Fowler through not only proofreading my work but for the gentle pushes and the genuine love and support that she showed me.

I would like to thank my supervisor, Prof Michelle Andipatin for her guidance and for expecting nothing but excellence from me. Thank you to the National Research Foundation (NFR), for financing my studies. To all the mothers who took their time to share their very personal and intimate stories and without whom this paper would not be possible, I am grateful.

Lastly, I dedicate this thesis to my 3 children, Thando, Fundisiwe and Lwazi Dlamini, who have been very brave children, I honour them. Although I had to complete this journey alone in the end, I would not have embarked on it without the unconditional love and support of my late husband, “Mkhi’ Nhlanhla Dlamini. Although he is now in another dimension, I know that he is still very proud of me.

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## Abstract

**Background and Aim:** Health problems that occur before or during pregnancy may increase the likelihood of a high-risk pregnancy. While PTSD has been previously believed to occur following events such as war, sexual assault and violence, recent evidence suggests that it may occur after childbirth. The aim of this study was to explore the ways in which women from resource-constrained areas who experienced high-risk pregnancies made sense of their experiences and how those experiences impacted their postpartum mental health.

**Methodology:** The study utilised an existential theoretical framework which is located within a qualitative explorative enquiry. Women who were formally diagnosed with a high-risk pregnancy and had given birth within the last two years were purposively selected by utilising the WhatsApp platform. The study consisted of a total of 9 participants who were between the ages of 30 to 40 years old, the mean age being 36 years old. Ethics approval was obtained from the University of Western Cape Biomedical Research Ethics Committee (BMREC).

**Results:** The study revealed that a high-risk pregnancy is a difficult and traumatic experience that has a negative impact on postpartum mental health of mothers from resource-constrained areas of Cape Town. Consequently, finding spiritual meaning played a crucial role for all participants to cope and to make sense of their pregnancies.

**Conclusion:** Eight out of nine participants reported at least one PTSD symptom. Avoidance and vigilance were two dominant symptoms that were reported. Based on these findings, it is imperative that more efforts be directed towards primary prevention such as screening women during pregnancy in order to identify vulnerability to PTSD. In addition, mothers should receive extended support by healthcare professionals in the postpartum period. The use of spirituality as a coping mechanism came out quite strongly in the study. Hence, women's religious beliefs should be both respected and encouraged by clinicians.

# Chapter 1

## 1. Introduction

### 1.1. Background

Although in many cases pregnancy is a special and natural event, it may place a heavy burden on women's health by adding physical and emotional stress (Abdelhady et al., 2015; Petit et al., 2016). Health problems that occur before or during pregnancy may increase the likelihood of a high-risk pregnancy, of which 15% of all women develop a potentially life-threatening complication (Majella et al., 2019).

High-risk pregnancy is when either the mother or the developing foetus, or both, are at risk of complications during pregnancy, delivery or postpartum (Soh & Nelson-Piercy, 2015). Mothers who are considered to have high-risk pregnancies include those who have a history of chronic disease (diabetes, heart disease, etc.), those who have a history of previous pregnancy problems (abortion and stillbirth), multiple pregnancies, gestational age under 18 years or over 35 years and being previously pregnant more than 4 times (Hafez et al., 2014). Diabetes, preeclampsia and premature birth are some of the common conditions which may increase risk in pregnancy (Lee & Holden, 2012).

According to Hafez et al. (2014), about 529 000 women die globally due to pregnancy-related causes annually, of which complications in pregnancy and labour are the main causes of maternal mortality. 99% of these mortalities occur in developing countries, with sub-Saharan Africa accounting for two thirds of these mortalities (Merdad & Ali, 2018). Research additionally suggests that women who reside in resource-constrained neighbourhoods are more likely to experience adverse reproductive outcomes through healthcare, environmental exposure, and lifestyle pathways. (Agyemang et al., 2009; Vinikoor-Imler et al., 2011). It has been observed that when women have complicated

pregnancies, they experience intense stress that may lead to a decrease in mental functioning, which may potentially lead to post-traumatic stress disorder (Aftyka et al., 2020).

“Post-traumatic stress disorder (PTSD) is characterised by persistent re-experiencing of the traumatic event, persistent avoidance of stimuli associated with the event, numbing of general responsiveness and symptoms of increased arousal. Symptoms of PTSD include re-experiencing (e.g. intrusive images of witnessing one's own severe blood loss or being rushed to hospital in an emergency situation), avoidance of reminders of the traumatic event (e.g. avoiding hospital appointments), negative mood and cognitions (e.g. ‘It's my fault that the birth didn't go according to plan’) and hyperarousal (e.g. hypervigilance with regards to her baby).” (Soderquist et al., 2009, p. 627).

In the past, PTSD has been believed to occur following events such as war, sexual assault, violence and disasters (Ayers, 2016). However, recent evidence suggests that PTSD may also occur after childbirth (Coates et al., 2014). This is due to childbirth having characteristics that could be traumatic (Cook et al., 2018). Additionally, it has been observed that during childbirth many women fulfil the PTSD criteria while experiencing real threats regarding physical harm or death to themselves or their baby (Polachek et al., 2016).

It is important to acknowledge that the biomedical model has contributed significantly to reproductive health which has resulted in successfully reducing foetal, neonatal and maternal morbidity and mortality in most countries (Oliviera & Mandu, 2015). However, alongside the reduction in maternal-child mortality rates was an increase in personal trauma among labouring women as a result of being disconnected from their social and spiritual selves (George & Ellison, 2015). Thus, the biomedical approach has to be critically examined for being one-sided, often prioritising the physical aspects of a person to the exclusion of health, social, emotional, educational and spiritual needs (Pentecost et al., 2018).

Additionally, the victim-blaming tendency and a failure to recognise a person as a unique individual have been the model's greatest limitations as it has serious implications for birthing women, especially those with high-risk pregnancies (Groleau et al., 2019; Valles, 2020).

For most women, pregnancy may be a stressful period, eliciting feelings of incompetence, interpersonal loneliness and anxiety (Ben-Ari et al., 2009; Larsson et al., 2016). This may be even more relevant for women with high-risk pregnancies as the relationship with their unborn child is threatened (Badakhsh et al., 2020). As a result, high-risk pregnancy is often a time of turmoil which is characterised by uncertainty, fear and nervousness (O'Brien, 2010).

Moreover, women from low socioeconomic backgrounds experience motherhood in the context of poor emotional and structural support along with financial constraints which is over and above the psychological distress that characterises a high-risk pregnancy (Bloom et al., 2013). In many instances, this is a significant life transition which results in a strong sense of powerlessness and stress for many mothers (Larsson et al., 2016; McCoyd et al., 2020).

As women struggle to cope with the stress of pregnancy complications, the desire or attempt to create meaning in their experiences is often intensified (Park, 2010; Price et al., 2007). It is therefore common for mothers to ask existential questions beyond medical science when they are faced with a high-risk pregnancy diagnosis (Mueller, 2001). Price and colleagues (2007) report that women describe a search for meaning and a need to feel connected with whatever higher power they subscribe to.

According to the existential theory, suffering is an essential and inescapable aspect of human existence, and finding meaning in it makes pain more bearable and provides reasons for living (Wong, 2012). Existentialists believe that questions about the meaning of life and

suffering are powerful motivational forces (Esping, 2011). As a result, the discovery of meaning can result in profound healing, especially in challenging circumstances which involve unavoidable suffering and loss (Esping, 2011).

## **1.2. Rationale**

The impact of maternal PTSD following a high-risk pregnancy is great and far-reaching which can have a negative impact on women and their relationships, as well as influencing future reproductive choices (Polachek et al., 2016). Approximately 3.1% of women are affected by PTSD, of which 15.7% are considered to have high-risk pregnancies (Garthus-Niegel et al., 2016). While extensive research has been conducted on postpartum depression (Melville et al., 2010; Tsai & Tomlinson, 2012; Pearson et al., 2013; Shivalli & Gururaj, 2015), few studies focused on PTSD following a high-risk pregnancy. Moreover, studies (Andipatin, 2012; Isaacs, 2018; Roomaney et al., 2014) that have been conducted in the South African context that explore the subjective experiences of women following a high-risk pregnancy are scant. Despite the wide recognition that pregnancy affects a woman's overall state of health and emotional wellbeing (Abrar et al., 2020; Cole-Lewis et al., 2014; Deshpande et al., 2013), pregnancy is still considered a techno-medical event, often ignoring the spiritual distress that mothers face (Carver & Ward, 2007; Molony, 2007). Researchers continue to focus on mothers' physical states during pregnancy and postpartum (Nagar et al., 2015; Torabi et al., 2012), while overlooking their emotional and psychological wellbeing. Given the fact that postnatal mental disorders are more prevalent in developing countries, not much is known about how women make sense of and attach meaning to their experiences of high-risk pregnancy in South Africa. This study therefore aims to close this gap by exploring a sample of women from resource-constrained community's subjective feelings and trauma experienced as a consequence of high-risk pregnancy.

### **1.3. Problem statement**

Despite the fact that South Africa has a high prevalence of mental health disorders, with PTSD rates among women of reproductive age being high, mental disorders are often under-diagnosed and untreated in South Africa (Sikkema et al., 2011). According to Vignato et al. (2017), the 2012 Bulletin of the World Health Organization (WHO) identifies maternal mental health as a global health priority. In addition, the WHO (2014) recognises postnatal mental health problems as having an adverse impact on mothers, their children and their relationships. Moreover, the WHO (2014) has identified psychological illness as a significant indirect cause of maternal death in the first year after birth. Despite this, mental health care in South Africa continues to be under-funded and under-resourced in comparison with other health priorities in the country (National Mental Health Policy Framework and Strategic Plan 2012-2013, 2013). Additionally, women of reproductive age from low-income areas are the most affected as a result of inequity in the distribution of mental health resources. Moreover, the overlooking of links between mental health challenges and poverty further exacerbates the problem (Peterson et al., 2010).

### **1.4. Research question**

What ways have women from resource-constrained areas experienced and made sense of their high-risk pregnancies and how have those experiences impacted their postpartum mental health?

### **1.5. Aims and objectives**

**Aim:** Exploring the ways in which women from resource-constrained communities who experienced high-risk pregnancies make sense of their experiences and how those

experiences have impacted their postpartum mental health. The following objectives have therefore been developed:

- a) To explore a sample of women from a resource-constrained area in Cape Town's perceptions of their trauma and distress experienced as a result of their high-risk pregnancies
- b) To understand the ways in which these participants made sense of their high-risk pregnancies
- c) To explore the participants' perceptions of how their high-risk pregnancies impacted their mental health

## **1.6. Thesis outline**

This research project is outlined in six chapters which include the introduction, literature review, methodology, results, discussion and recommendations.

### **Chapter 2 - Theoretical framework**

This chapter outlines the theoretical framework of the study. An existential theoretical framework is utilised in order to demonstrate that pregnancy is not a pathology, but is rather a unique and special experience for each mother. This ties in with the focus of the proposed research as its purpose is to recognise each woman as a unique being with an experience that has a meaning which can be understood.

### **Chapter 3 - Literature review**

This chapter presents a detailed account of the literature that is relevant to the topic of this study. It will review empirical studies on high-risk pregnancy and the psychological distress and trauma that surrounds it. In addition, a detailed account of contributing factors to

poor maternal outcomes in South Africa will be unpacked. Furthermore, the biomedical model and its problematic way of framing pregnancy will be explored.

#### **Chapter 4 - Methodology**

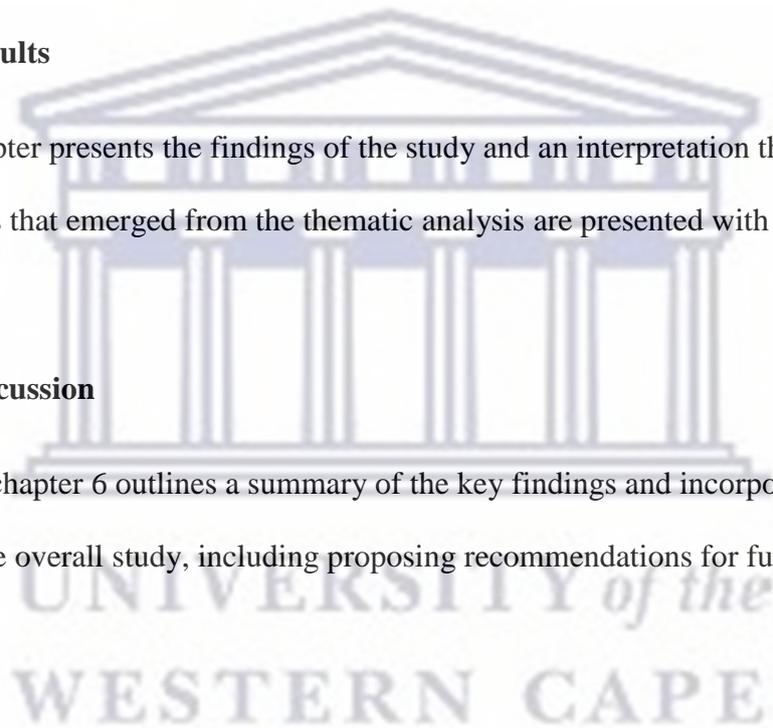
The aim of this chapter is to report on the methodological procedures that were employed to conduct this study, and how rigour was established throughout the research process. The chapter comprises the research design, participants, data collection, data analysis technique, procedures, trustworthiness, reflexivity and ethical considerations.

#### **Chapter 5 - Results**

This chapter presents the findings of the study and an interpretation thereof. The recurring themes that emerged from the thematic analysis are presented with illustrative extracts.

#### **Chapter 6 - Discussion**

Finally, chapter 6 outlines a summary of the key findings and incorporates a discussion on the overall study, including proposing recommendations for future research.



## Chapter 2

### 2. Theoretical framework

#### 2.1. Introduction

This chapter provides a broad idea of what existentialism is, by identifying some of the historical contributors of existential thinking. Although there are many different facets of varying importance within the existential philosophy, this paper seeks to draw out applications through which existential thought can be used to understand the experiences of women from resource-constrained communities who have been diagnosed with high-risk pregnancy.

The underpinnings of this framework will be influenced by the work of Søren Kierkegaard and Viktor Frankl. Kierkegaard took an interest in both religion and the pursuit of man's relationship with God (Bartin, 2001). He believed that failed attempts to connect with God caused individuals to experience anguish that is expressed in loneliness, anxiety, fear, and dread (Barton, 2001). Through his work as a psychiatrist and his experience as a Holocaust survivor, Viktor Frankl's central theme is that man's primary reason for living is to find meaning in all circumstances including death (Nigesh & Saranya, 2017).

Although existential issues are generally not given much attention under normal circumstances, they become prominent concerns in times of difficulties. It is usually during challenging times of pain and anxiety that individuals experience their existence and question their meaning within.

Existentialism derives from ordinary, everyday human experiences and simply seeks to explore "fundamental dilemmas that human beings face during the course of their lives" (Vieth, 2013, p. 1). Making existential meaning is a fundamental aspect of motherhood

transition, as it is understood as an existentially transformative process relating to the importance of fundamental life questions and their importance in mothers' lives (Prinds, 2014). Therefore, existentialism has always been interested in the lived experiences of human beings, thus making it a fitting theoretical framework to understand the experiences of women who have experienced high-risk pregnancy.

## **2.2. Historical context of existential philosophy**

Like most philosophical movements, existentialism was a reflection of and response to its larger cultural context, which was the Western Industrial Era (Dung & Suong, 2019). A distinct feature of this period was a major shift from individual apprenticeship and craftsmanship towards mechanised production (Allen, 2009). One of the major consequences of this organised labour was the loss of a sense of significance of being an individual (Dung & Suong, 2019).

In addition, the industrial age also offered a new kind of ethic for people's lives, which promoted practical rationality in order to help people be better adapted to the demands of an automated age (Allen, 2009). Furthermore, a third factor was that empirical scientific enquiry began to challenge the traditional Christian view (Sherrard, 1976; Petrović, 2020). As a result, God and religion became a less important way of organising and making sense of life, and other forces began to take precedence in cultural practices (Sherrard, 1976). Hence, this eroded the central narrative that made sense of life for many centuries in the entire Western world (Sherrard, 1976).

As a result of this, the world lacked a powerful and compelling framework that orientated people meaningfully to reality, and the industrial era provided little sense of transcendence (Dung & Suong, 2019). This left the world in an increasing state of what Viktor Frankl called the 'existential vacuum', a state that represents spiritual distress

(Pattakos & Dundon, 2017). Hence, Frankl considers life to be more than the gratification and satisfaction of drives and instincts (Pattakos & Dundon, 2017).

### **2.3. Existential meaning and spirituality**

Meaning-making is a general life orientation, creating personal significance and serving as a coping mechanism (Breitbart et al., 2017). Existential meaning refers to attempts to understand how events in life fit into a broader context, which includes the meaning-making process through which individuals facilitate a sense of order in the world (Nahlbom, 2018).

The previous belief system provided meaning through the view that regardless of the amount of suffering one endures, it will be rewarded in an afterlife through death if one lived by God's will. Consequently, this gives suffering meaning. Hence historically, there was little need to question the meaning of life as most people felt that they already knew the answer to life's suffering. However, science brought a new way of understanding the world including man's position in it. Unlike in previous times of religious dominance where most individuals believed in an existence of an afterlife, the scientific view is sceptical of a two-world theory (Dawes, 2016; Northbourne, 1969).

However, Viktor Frankl believed that science failed to grasp the uniqueness of being human, by describing human beings as mere machines as opposed to possessing the ability to transcend beyond their unique physicality (Bushkin et al., 2021). Frankl, a psychiatrist who suffered through imprisonment in Nazi concentration camps during World War II, found meaning because of, and in spite of, the suffering all around him. One of the conclusions that he came to was that man strives to fulfil as much meaning in his existence and to realise as much value in his life as possible (Wong, 2015). Frankl regarded the search for meaning as

both a universal primary motivation and a unique human capacity in which to make sense of the world including creating a value or belief system (Wong, 2015).

When Frankl observed prisoners in the Nazi concentration camp where he was also imprisoned, he realised that finding meaning in suffering was a significant protective factor against emotional, psychological, and spiritual suffering (Costanza et al., 2020). He also noticed that individuals possess transformative power in seemingly hopeless situations when they choose to ascribe meaning to their painful experiences (Shapiro, 2013). Hence, "to search for meaning is to seek self-transcendence, which means to step out of ourselves and serve someone or something bigger than oneself" (Wong, 2015, p. 155). Therefore, for Frankl, the will to find meaning is situated in the spiritual core of human nature (Joshi et al., 2014).

Mothers interpret giving birth as being one with the new-born baby and as a spiritually transcendent experience which connects them to a higher self (Wojtkowiak & Crowther, 2018). Like spirituality, childbirth is linked to a mysterious, unexplainable and extraordinary experience (Crowther & Hall, 2015). These are both beautiful experiences which have a sense of wonder in them (Crowther & Hall, 2015; Crowther et al., 2020). Hence, birth can be interpreted as something that is sacred and worthy of being safeguarded (Crowther, 2014; Hall, 2010). Even when birth is experienced in the context of dread due to something that has gone wrong as in the case of a high-risk pregnancy, the joy may be delayed but the mystery of birth does not diminish (Crowther, 2014).

In addition to the joy and happiness which is felt at birth, giving birth is also related to suffering in the form of physical pain during labour and emotional pain when there is a high-risk pregnancy diagnosis (Baltaci, 2019; Hall, 2010). However, most women tend to deal with this pain by giving it meaning (Hall, 2010). Even during intense labour pains, it has been

found that women accept the pain as a natural part of childbirth, thus continuing to describe the experience as extraordinary (Rudrum, 2013). For most mothers, labour pain is not just a transition to a new developmental stage, but also a time of spiritual and psychological growth (Taghizdeh et al., 2017; Yadollahi et al., 2018).

Like with most people whose health is threatened, women with high-risk pregnancies often rely upon spiritual beliefs and values to make sense of their pregnancies (Price et al., 2007; Mutmainnah & Afiyanti, 2019). Their spiritual beliefs and practices aid them in their search for meaning, while at the same time they calm their fears and anxieties as they move through the experience of a high-risk pregnancy (Akbarzadeh & Ahmadinezhad, 2019; Mutmainnah & Afiyanti, 2019).

The most widely-used techniques by women in stressful periods of their pregnancies are prayer, reading the bible and performing religious rituals (Akbarzadeh & Ahmadinezhad, 2019). It has been found that women's spiritual beliefs and practices do not only buffer the effects of stress and assist in coping, but often lead to hope, optimism and positive expectations during a high-risk pregnancy (Cheadle et al., 2015; Price et al., 2007).

#### **2.4. Subjective truth**

The core concept of Søren Kierkegaard's philosophy is subjective truth. Kierkegaard distinguished between two types of truths: subjective truth and objective truth (Holmer, 2012). For Kierkegaard, objective truth is truth as we usually think about it, which is a product of empirical observation such as in the case of Natural Sciences or Mathematics (Astley, 2019; Lakoff & Núñez, 2000). Kierkegaard noted that objective truth is usually governed by consensus (Whittaker, 1999; Astley, 2019). For instance, it is commonly regarded that  $(E=mc^2)$  is true due to the fact that many expert scientists have agreed that it is

so, and consequently this was propagated across the social domain to a larger cultural consensus about this truth (Whittaker, 1999).

Accordingly, the mechanism of the application of biomedical science, which is largely male-dominated, is a form of social control which is often exerted under the guise of benevolent help (Cahill, 2001). It was previously pointed out that modern medicine developed into a major institution of social control while incorporating the more traditional institutions of religion and law (Zola, 1977, as cited in Cahill, 2001). This was accomplished by 'medicalising' most of daily living, by making medicine and labels such as 'healthy' and 'ill' become increasingly relevant to our human existence (Zola, 1977, as cited in Cahill, 2001).

The physiological event of childbirth has changed into a medical procedure which often prevents women from experiencing pregnancy in their own way (Pazandeh et al., 2017). Reports of physical symptoms from women such as a headache or epigastric pain may be identified as an obstetric complication (e.g. preeclampsia) which can be managed according to recognised clinical guidelines (Warland et al., 2018). However, when women report symptoms that seem vague, it becomes difficult for clinicians to understand or value. One such example is when a pregnant woman expresses intuitive feelings or hunches about her pregnancy. It can be difficult to define or diagnose because intuition encompasses the ability to understand something instinctively, without conscious reasoning (Gore & Sadler-Smith, 2011).

Consequently, intuition has the potential to be easily discounted and devalued in the current biomedical model of illness because there may be nothing objective by which to measure it (Warland et al., 2018). Women therefore feel that they have to suppress their own feelings in favour of the received medical view. The disregard of the opinions and feelings of

women is a consequence of the belief that medicine as a science is ‘the only truth’. In this way, the understanding of women’s own bodies is not considered important (Andipatin, 2012; Cupido, 2017).

## **2.5. Existential isolation**

According to Helm and colleagues (2014), feeling existentially isolated is the feeling that a person is alone in their experiences, and that others cannot understand their perspective. Pregnancy, particularly high-risk pregnancy, can be an isolating and alienating experience for most women (Isaacs, 2018). High-risk pregnancy often leaves women feeling disconnected from other pregnant women in various ways. We can therefore infer that these women are not able to express their truth because they are often not as happy as others might expect them to be. As a result, what is experienced on the inside does not match up to others' expectations.

The medicalisation of pregnancy has been identified as a major contributing factor to the feelings of isolation in women (Prosen & Tavčar, 2013). This is due to the mechanistic way of viewing pregnancy, which subjects pregnant women to be labelled as ‘high risk’ based on statistics rather than individual considerations (van Teijlingen, 2005). Additionally, by removing female midwives from childbirth, obstetrics and gynaecology has been transformed into a technological, powerful, male-dominated profession (Al-Gailani & Davis, 2014; Prosen & Tavčar, 2013).

## **2.6. Conclusion**

Existentialism is renowned for the critique of rationalism from the standpoint of individualism. Kierkegaard is well known for rejecting the philosophical belief that one gains an objective understanding of the whole of existence by having a perfect understanding and a comprehensive system of logic and reasoning (Szemerda, 2013). Instead, Kierkegaard

believed that a person must choose and take responsibility without the help of laws, ethnic rules or traditions. This should entail humanising birth, which means understanding that women giving birth are individual and unique human beings.



## Chapter 3

### 3. Literature Review

#### 3.1. Introduction

This section will draw on some of the literature that has links with this thesis. Appropriate topics which describe factors that contribute to poor pregnancy outcomes and the interplay among the environmental and socioeconomic factors that influence adverse pregnancy outcomes will be explicitly explained. The literature will focus on various topics organised into different themes which include: roots of healthcare challenges in South Africa, an overview of the country's healthcare system, maternity care and its challenges, the biomedical model framework, contextualising high-risk pregnancy, risk factors of PTSD and an exploration of the postnatal period.

#### 3.2. Impact of the apartheid system on healthcare

Understanding the concept of apartheid is imperative for the context of this study as it continues to have negative ramifications for maternal and child health in South Africa (Coovadia et al., 2009). South African healthcare challenges are rooted in the country's long history of race-based oppression, discrimination and exploitation which can be traced back beyond the apartheid era to the arrival of the Dutch settlers in 1652 (Maphumulo & Bhengu, 2019; Strauss, 2019). These unjust practices were later formalised and legalised by creating a system called 'apartheid' in 1948 (Adonis, 2020; Delobelle, 2013). The apartheid system was characterised by various modes of social, economic and political oppression which were brutally enforced (Adonis, 2020).

This system was made up of policies that structured society according to race, thus determining where people could live and work, and the resources allocated to their education

and healthcare (Conmy, 2018). The Black majority were allocated inadequate resources, including basic services such as clean water and basic sanitation (Conmy, 2018)<sup>1</sup>. Consequently, when the first democratic government was elected in South Africa, the country's health sector was extremely fragmented and poorly coordinated (Delobelle, 2013).

Disparities still persist nearly three decades after the apartheid regime was officially abolished (Benatar, 2013; Coovadia et al., 2009; Mbali & Mthembu, 2016). As a result, the majority of the South African population (Black women and children being particularly affected) continue to live in poor conditions (Coovadia et al., 2009). More specifically, the historical context of apartheid has severely affected the health outcomes of most South Africans (Coovadia et al., 2009).

### **3.3. Links between social determinants and access to healthcare in South Africa**

According to Wickham and colleagues (2016), social determinants greatly impact a nation's health status, more so than the availability of curative healthcare services. Among social factors, poor living conditions are strongly associated with morbidity and mortality across a wide range of health problems (Ngoma & Mayimbo, 2017; Wickham et al., 2016).

People who live in poorer communities in South Africa often experience structural constraints whereby economic, social and political factors influence their behaviour (Harris et al., 2011). For example, people from resource-constrained backgrounds are more inclined to eat unhealthy food as a result of having no healthy alternatives available for grocery shopping besides convenient stores, liquor stores or fast food restaurants that sell foods that are high in fat, sugar and salt (Frederick et al., 2014).

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<sup>1</sup>The racialised terms "Black" and "White" were used and popularised by the Population Registration Act of 1950, but this was repealed in 1991. However, the operational use of these terms for the purpose of this study is to demonstrate the historical significance of how it was and still is used to classify people into abstract categories on the basis of skin colour (Mosavel et al., 2011).

High consumption of such food predisposes many women to serious health problems such as gestational diabetes, hypertension and obesity, which may threaten their lives and that of their unborn babies (Procter & Campbell, 2014). Benatar (2013) observed that social circumstances that influence health begin with the physical, mental and nutritional state of women during pregnancy and childbirth and continue throughout life. Women are particularly at risk for preterm delivery, perinatal mortality and congenital malformation (Mathiesen et al., 2011), thus making them vulnerable to a traumatic birth (Henriques et al., 2009; Lev-Wiesel et al., 2009).

Inequalities in perinatal and maternal outcomes dominate in women of lower socioeconomic status and specific ethnic groups (Lam et al., 2012). Health inequalities manifest in different forms of perinatal morbidity which play a role in adult health (de Graaf, 2013). Two South African studies that were conducted by Coetzee and Kagee (2013) and Silal et al., (2012) investigated structural barriers to accessing health facilities in resource-constrained areas. Themes in these studies included difficulty in accessing transport or transport money, pregnant women being turned away at clinics because they were either full, or women coming on the wrong day for antenatal healthcare.

The postnatal period for women from low socio-economic backgrounds is deeply embedded in a background of financial hardships (Abraham & Curran, 2009). Previous research suggests a link between maternal distress and potentially more serious psychological problems including trauma (Emmanuel & St John, 2010). Poor living conditions is a vulnerability factor, of which its interaction with high-risk pregnancy may result in PTSD (Ayers et al., 2016). Moreover, vulnerability factors may impact on whether or not women with initial PTSD develop chronic PTSD or resolve their symptoms (Ayers et al., 2016).

### **3.4. An overview of the healthcare system in South Africa**

Although great efforts have been made to improve the South African healthcare system, significant challenges still remain. While the country's health system was previously divided along racial lines, in contemporary South Africa it reflects the country's social divide (Young, 2016). To date, the country has two healthcare systems: private and public. The public healthcare system services the majority (84%) of the population, most of whom are Black and poor (Naidoo, 2012). This is in stark contrast to the private healthcare sector which services less than 20% of the population, the majority being White and of high socioeconomic status (Maphumulo & Bhengu, 2019). Out of 48 developed and developing countries, the quality of care in the South African public healthcare sector is ranked eighth last, while the private healthcare sector is in sixth place, which is on par with Switzerland and Sweden (Burger & Christian, 2020).

#### **3.4.1. Maternity care in South Africa**

South Africa's dual healthcare system (private healthcare and public healthcare) is divided along socioeconomic lines (Young, 2016). The public healthcare system is offered free of charge to South African citizens and is often utilised by those individuals who reside in low socioeconomic areas.

The public healthcare system is based on the primary care model. Women who are considered low risk deliver in clinics, community health centres and district hospitals (Wium et al., 2019). Those who have been diagnosed with high-risk pregnancies deliver in secondary hospitals, or may be referred to tertiary hospitals where there is specialised care by trained obstetricians (Mgudlwa et al., 2017). The majority (60%) of pregnant women are serviced by midwives at primary level Community Health Centres and District Hospitals, while 25%

receive care at regional hospitals, with a further 15% being admitted to tertiary hospitals (Wium et al., 2019).

In an attempt to improve the country's healthcare services and to address inequalities in the healthcare system, there is a provision of free healthcare, particularly to pregnant women and children under the age of six years (Zar et al., 2015). In addition, physical availability of public healthcare has been expanded, with more than 1300 primary healthcare centres having been constructed in previously disadvantaged areas (Chopra et al., 2009).

### **3.5. Challenges in maternity care in South Africa**

Despite the South African government's attempt to improve care for pregnant women and children, and to address causes of maternal and perinatal death, pregnancy-related conditions continue to make up 66.7% of preventable deaths (Malherbe et al., 2016). In fact, maternal mortality has increased from 150/100 000 pregnancies in 1998 to 650/100 000 in 2007 (National Department of Health, Republic of South Africa, 2015). For example, obstetric haemorrhage and complications of hypertension in pregnancy continue to rise (Malherbe et al., 2016).

Although contributing factors are multifaceted, some identified factors have been HIV, haemorrhage, hypertension, inadequate training for healthcare workers and the weak healthcare system (National Department of Health, Republic of South Africa, 2015). Moreover, the disparities in wealth and health in South Africa have significantly contributed to the country's poor maternity health outcomes (Benatar, 2013; Naidoo, 2012). Although the public healthcare sector services the majority of South Africans, it is grossly under-resourced (Maphumulo & Bhengu, 2019). As a result, most public healthcare facilities in many parts of the country are understaffed, which often leaves health professionals highly stressed and overworked (Crush & Tawodzera, 2014).

### **3.5.1. Quality of care**

### **3.5.2. Unequal access to healthcare**

Silal and colleagues (2012) define access as “the degree of fit between the needs of pregnant women during labour and delivery and health system responses”. In South Africa, the unequal distribution of healthcare within the population still continues to be a major challenge (Silal et al., 2012). Availability is only one way of improving healthcare, and has not been sufficient to improve the quality of care in South Africa. As a result, maternal and child mortality still remains a major weakness in the healthcare system due to inequities in accessing maternal health (Chetty et al., 2012). Therefore, while more women are accessing services, they are still receiving poor quality of care, as the South African healthcare system continues to face many challenges (Koblinsky et al., 2016).

Quality is intangible and subjective in nature, thus making it difficult to define, particularly within a healthcare setting. This often causes confusion about what is meant by quality. Despite this challenge however, the South African Medical Association asserts that quality needs to be defined, pursued, measured and ultimately improved upon (Burger et al., 2016).

The World Health Organization (WHO) states that a health system should aspire to make improvements in six dimensions which require that healthcare be:

**Effective:** Responds to the needs of the individuals and their communities and should result in improved health outcomes.

**Efficient:** Care should be delivered in a non-wasteful way which maximises resources.

**Accessible:** Healthcare should be within reach of those that need it, be delivered timeously and should be provided in a setting where skills and resources are appropriate to medical need.

Acceptable / Patient-Centred: Healthcare needs to consider the needs of individuals, including their cultures and the communities from which they come.

Equitable: There should be no variance in quality due to personal characteristics such as gender, race, ethnicity, geographical location or socioeconomic status.

Safe: Delivering in a manner which minimises risks and harm to service users.

Based on these six dimensions which have been laid out for achieving equity and quality in healthcare, we can infer that there are healthcare facilities that would be rendered inadequate in South Africa. In fact, overall, sub-Saharan Africa has been reported as falling short in achieving satisfactory maternity health outcomes, with poor healthcare systems having been identified as a fundamental reason for this shortfall (Thomas et al., 2007).

The quality of healthcare in South Africa has been compromised by various challenges, some of which include: high maternal and child mortality, dysfunctional management and support systems, lack of resources, variability of quality care across public / private sectors and variability of quality care across provinces (Coovadia et al., 2009; Maphumulo & Bhengu, 2019; Tsawe & Susuman, 2014).

An important aspect of service coverage is not only the availability of a range of healthcare facilities but also the quality of the care received. For example, a study that was conducted by Wabiri and colleagues (2016) investigating inequities in maternal health in South Africa revealed that despite some improvement in access to services, inequities have generally worsened.

Wabiri and colleagues (2016) observed an increase in haemorrhage among women who gave birth via Caesarean Section, which was attributed to poor quality of care in maternal services. This particularly reflected unequal access to healthcare according to the different provinces. Additionally, the study also discovered that poorer socio-economic

groups disproportionately experienced deficiencies in access to services. On further analysis, it was found that in comparison to other race groups, Black women still continued to have poorer access to services which, among others, include lack of skilled birth attendance.

### **3.5.3. Inaccessible quality care**

According to the World Health Organisation's definition of quality, 'access' in itself is a critical element of quality. Therefore, this implies that the South African private healthcare system does not meet the criteria for quality care because it is inaccessible to a large percentage (84%) of the population due to exorbitant fees that are being charged (Ramjee et al., 2013). In fact, South Africa has been found to have an extraordinarily high for-profit private healthcare sector; with one of the highest percentages of total health expenditure in for-profit private healthcare in the world (Drechsler & Jutting, 2005; Ramjee et al., 2013).

Although the private sector services less than 20% of the population, it takes up 60% of the total health expenditure, leaving only 40% of the total expenditure to public healthcare that services the majority of the population (Maphumulo & Bhengu, 2018; Pillay, 2009). Additionally, 70% of the country's medical specialists are engaged by the private healthcare sector, leaving a mere 30% in the public healthcare sector (de Beer et al., 2011).

Consequently, the government healthcare facilities are often characterised by challenges such as long waiting periods and limited resources, while private health facilities are well-resourced with a wide range of diagnostic and therapeutic options (Wium et al., 2019). Thus, concentrating such a huge proportion of the country's resources (including its high-quality capacity) in the private sector which only services a fraction of the population is problematic, both in terms of equity and efficiency (Ramjee et al., 2013).

The reality is that the private healthcare sector is profit-driven and shows no concern for social justice and the provision of healthcare to all citizens (Choonara & Eyles, 2015). On the contrary, the sector's materialism which considers health as a commodity that can be bought with money, is in direct contradiction with the South African constitution which states that 'everyone' has the right to access healthcare services including reproductive healthcare (Alfaro-Velcamp, 2017; Omotoso & Koch, 2018).

Furthermore, the private healthcare sector is notorious for performing treatments that are deemed unnecessary and inappropriate (Choonara & Eyles, 2015). Notable is the high rate of Caesarean Sections performed, which is reported to be the highest in the world (Govender et al., 2019). Caesarean Section rates in the South African private healthcare sector have risen from 67% between 2011 and 2013, to more than 75% in 2018 (Solanki et al., 2020).

Although Caesarean Sections are regarded as effective, quick and harmless by many pregnant women and medical practitioners, evidence suggests that morbidity and mortality for mother and foetus/neonate resulting from a Caesarean Section are higher in comparison to vaginal deliveries (Naidoo & Moodley, 2009). In sub-Saharan Africa, the highest rates of neonatal morbidity and mortality have been seen in elective Caesarean Sections (Villar et al., 2007). Therefore, unnecessary Caesarean Sections do not only increase costs, but are detrimental to both mothers and their children, and can even affect future pregnancies (Neuman et al., 2014; Edmeston & Francis, 2012).

#### **3.5.4. Negative staff attitudes and low morale among public healthcare workers**

Lack of commitment and low staff morale among healthcare workers in the public health sector is a big concern in South Africa. This can often be observed in the healthcare staff's attitudes, which have been consistently reported as cold and hostile. Attesting to this is

a study that was conducted by Chadwick and colleagues (2014) which revealed four themes of distress among women who had given birth at public healthcare facilities. Women's narratives in the study were characterised by shouting and lack of care from staff, lack of information about the labour and birth process, neglect and abandonment.

Consequently, pregnant women have been reported to initiate antenatal care much later than the recommended time, owing to the perceived bad quality of service in public healthcare facilities (Ali et al., 2018). Studies found that most women who attend antenatal care do so mostly to avoid reprimands from healthcare staff when they attend a health facility for delivery, more specifically, they attend out of fear of the refusal of care during labour (Okedo-Alex et al., 2019). This is of great concern as the relationship between nurse and patient has been found to play a crucial role in how expectant mothers perceive their quality of care, which subsequently influences their decisions to make use of antenatal healthcare facilities (Ngomane & Mulaudzi, (2012).

Sharma and colleagues (2019) who investigated the phenomenon of patient perception of nursing staff, emphasise the importance of the patient's perceptions in the quality of care. According to these authors, the manner in which patients perceive quality of care is not only a crucial indicator of the effectiveness of care, but it is also an important determinant of adherence to treatment.

When women do not attend antenatal care, they miss opportunities for a variety of services, such as education about birth, danger signs, nutrition, exclusive breastfeeding and family planning (Gitonga et al., 2022). Hence, antenatal attendance has been identified as one of the main indicators of safe motherhood (Gitonga et al., 2022). Maternal deaths have therefore to some extent been linked to poor antenatal attendance (Gumede et al., 2017; Kaswa et al., 2018). Gumede and colleagues (2017) have found that not accessing antenatal

care is associated with adverse maternal outcomes, especially in the case of women who present with high-risk pregnancies as they cannot be timeously treated.

### **3.6. Biomedical model framework as expressive of Western culture values**

#### **3.6.1. The body as a machine**

South African medical care is based on the biomedical model. Philosophical underpinnings of the biomedical model “cast the body as a mechanical, universal object, which is ahistorical and without culture or politics” (Pentecost et al., 2018, p. 221). The mechanistic view of the human body was brought about by the belief that illnesses are a result of the failure of mechanical functions of various parts of the human body and that medicine is a science that has concrete answers to fixing pathologies in the body (Rocca & Anjum, 2020). This idea was further strengthened by the successful medical achievements in the eighteenth century (Rocca & Anjum, 2020).

The biomedical model has been accused of being a Western product and of drawing some of its philosophical traditions from the Western culture (Atkinson et al., 2015; Valles, 2020). It is further believed that this model cannot be solely explained by scientific advancement, but rather it is underscored by social, cultural, economic and political conditions (Atkinson et al., 2015). In addition, the system is believed to put male bodies on a pedestal while female bodies are viewed as dysfunctional as a result of biological processes such as menstruation, pregnancy, childbirth and menopause, which are pathologised and subjected to technological interventions (Ganes & Davis-Floyd, 2004).

As this system focuses on bodies, disease and technology, we can infer that showing empathy may be viewed as ineffective. This way of thinking presumes that pregnancy can only be understood as strictly physical, while undermining the role that culture and experience play in the meaning-making of pregnant women (Matambanadzo, 2016). As a

result, there is a loss of respect, empathy and integrity in the clinician-patient relationship (Pentecost et al., 2018). Therefore, women do not receive the required emotional and psychological satisfaction from encounters with clinical staff.

Moreover, the biomedical model stands in stark contrast to African traditions and values, which advocate wholeness whereby healing takes the whole person, including their social environment, into account (Botha, 2004). Instead, this system undermines the traditional, moral and spiritual values of South African society. Millum and Ezekiel (2012) have gone on to suggest that the biomedical model framework has been used to prolong colonial power dynamics between Western institutions and non-Western people.

### **3.6.2. Review of biomedical language**

Language, which is largely informed by the medical discourses around childbirth, plays a pivotal role in the manner in which women are treated at healthcare facilities (Minnaar, 2020). Although compassion is considered to be an essential element of quality healthcare (Minnaar, 2020), within the biomedical framework, talking with patients is carried out in a downgrading and dehumanising manner in clinical settings (Khan, 2019).

Treatment is administered through the use of technical language, which excludes patients from its processes (Sherlmerdine, 2011). In addition to clinician discourse constructing women as body parts, they also construct them in terms of social identity (e.g. implicative age, gender, race, or gender categories) (Ganes & Davis-Floyd, 2004). Khan (2019) conducted a systematic review that investigated studies which critically analysed the language of medical case presentations and their social consequences. The study found that the day-to-day practice teaches trainee doctors to declare patients as ‘complainers, male and female, non-compliant’. Other ways of referring to patients include excessive use of passive

voice, such as, “Patient ‘states’, ‘reports’, ‘claims’, ‘complains of’, ‘admits’ and ‘denies’”. Such constructions have strong consequences for treatment.

### **3.6.3. Framing of pregnancy as risky**

From the biomedical model’s perspective, a woman is considered to be at risk by virtue of being pregnant, which is then classified as either low risk or high risk (Majella et al., 2019; Evans & O’Brien, 2005; Jadhao et al., 2017). The notion is that regardless of its risk status, pregnancy has to be medically controlled in order to intervene early in case of any pathology. This has led to the claim that birth is only safe if it takes place in a hospital, overseen by medical professionals (Yuill et al., 2020). Consequently, healthcare professionals have been assigned by law the right to act as gatekeepers, largely depriving women of the right to self-determination (Farsaci, 2022).

The perception is that risk is an objective phenomenon which can be predicted and controlled through science and expert knowledge (Chadwick & Foster, 2013). This puts women under constant surveillance which subjects them to reproductive technologies that are sanctioned against them in order to identify any perceived risk (Majella et al., 2019; Jadhao et al., 2017; Evans & O’Brien, 2005). Hence pregnancy has become techno-medical in nature, as healthcare professionals treat it as a pathology rather than something that is natural and normal (van Teijlingen, 2017).

Women are under a great deal of pressure to act in a manner that reduces these perceived risks (Lennon, 2016). In addition, labelling pregnancy as low or high risk has successfully strengthened the power base of obstetricians (Cahill, 2001). It is therefore argued that the risk perception of pregnancy is the exertion of power over women by healthcare professionals (Bradley et al., 2019; Cahill, 2001), achieved by making women believe that their babies will only be safe if they comply (Brailey et al., 2017; Valadares et al., 2020).

### 3.7. High-risk pregnancy

There is no definite cause for a high-risk pregnancy, although a number of factors have been identified. These include risks that were present before the pregnancy and those that occurred as a result of pregnancy (Hafez & Dorgham, 2014; Lev-Wiese et al., 2009; Ayers et al., 2015). According to Tomlinson et al. (2014), 66% of pregnant women in Cape Town, South Africa experience at least one risk factor including depression, HIV, alcohol abuse or a previous low birth-weight child.

Globally, gestational diabetes, preeclampsia and postpartum haemorrhage have dominated maternal health over the past two decades (Wendland et al., 2012; Callaghan et al., 2010). Common problems in pregnancy in South Africa include intrauterine growth restriction, antepartum haemorrhage, multiple pregnancies, breech presentation and transverse lie, preterm labour, pre-labour rupture of the membranes, prolonged pregnancy, vaginal birth after previous Caesarean Section (VBAC), rhesus incompatibility and poor obstetric history (National Department of Health, Republic of South Africa, 2015).

A 'high risk' label consequently shifts patient management from a primary healthcare provider to an obstetrician which subsequently leads to increased visits and intense monitoring for women, thus increasing the subjective nature of the pregnancy (Simmons & Goldberg, 2011). This label, according to Bayrampour et al. (2012) usually impacts women negatively by eliciting high levels of stress.

Hospitalisation during a high-risk pregnancy is a common feature that brings its own set of unique challenges. Women usually report feelings of depression, boredom, loneliness and anxiety after overcoming the initial shock (Kent et al., 2015). The effects of hospitalisation resulting from a high-risk pregnancy are profound as women are further challenged in a variety of ways including family and relational disruptions, according to

Richter et al. (2007). Family responsibilities are usually the main source of concern for women as they are unable to contribute to housework, often resulting in feelings of guilt (Isaacs & Andipatin, 2020).

Themes that emerged from a study by Meaney and colleagues (2016) that explored women's experiences of high-risk pregnancy were that women felt unprepared for the high-risk diagnosis; they did not clearly understand their treatment and management of their conditions and they were concerned about the impact of the pregnancy on their families. These concerns elicited feelings of powerlessness which contributed to high levels of frustration, anxiety and fear. Women from the study of Ayers and colleagues (2015) also expressed similar emotions, such as fear and hopelessness. As a result, women diagnosed with a high-risk pregnancy often spend lots of time worrying about their pregnancies, which according to Souza et al. (2020) takes away from the special experience and existential meaning of the woman's pregnancy.

### **3.7.1. Making meaning of the 'high risk' label**

The 'high risk' label elicits inherent fear for women, many of whom become unsure about their abilities to birth naturally (Minnaar, 2020). Additionally, for some women, their pregnancy is the first time that they are confronted with an immediate personal risk which threatens their lives as well as that of their baby (Lee, 2014). Therefore, the inflated perception of risk during pregnancy has consequences such as stress, anxiety and depression (Jordan & Murphy, 2009).

Women often find themselves having to contend with complex emotions, especially when they have to quickly make sense of the situation in order to make decisions about their care (Lee, 2014). As a result, women with a high-risk pregnancy experience the pregnancy

process with a particular meaning attached to it. These meanings, depending on their nature, can generate vulnerabilities to mental health (do Carmo Oliveira & Mandi, 2015).

The magnitude of the psychological distress is usually determined by the woman's perception of the total risk to herself and her infant. Thus, the higher the perception of the risk, the more likely she is to experience increased stress, irrespective of whether the risk is real or perceived (Rodrigues et al., 2016). As a result, a woman's perception of her pregnancy has a significant impact on the well-being of both mother and baby (Lee et al., 2012).

Risk perception has both an objective and subjective element; the objective element being the medically, quantifiable approach while the subjective is how women perceive and make sense of the risk, usually drawing from their own experiences to make sense of it (Lee et al., 2012). A study conducted by Bayrampour and colleagues (2012) analysed women who were labelled high risk as a result of their advanced age (35 years and above), and three themes emerged. Firstly, women admitted to dismissing statistics given to them by medical staff and thought that the 'risk label' was an 'overreaction'. Secondly, women were not in agreement with the biomedical model and rather perceived pregnancy as a societal issue. Lastly, women believed that personal circumstances such as being in an abusive relationship or having no financial means to support the baby was more risky than their physical health. This low perception of the medical risk in high-risk pregnancies was also observed by Lee and colleagues (2012) in the analyses of four qualitative studies that investigated the risk perception of women.

### **3.8. Defining PTSD/PTSS in high-risk pregnancy**

According to Abrahams et al. (2013), traumatic experiences for women take many forms and have serious implications on reproductive health. A high-risk pregnancy is regarded as an extremely stressful event which may often lead to clinical levels of

posttraumatic stress symptoms (PTSS) or might act as a risk factor for the development of Posttraumatic Stress Disorder (PTSD) (Dikmen-Yildiz et al., 2018). According to Dikmen-Yildiz et al. (2017), around 4% of women meet the diagnostic criteria for PTSD after a traumatic birth, and the rates of both traumatic birth experiences and PTSD is believed to be higher in low and middle-income countries (Fisher et al., 2012).

“PTSS as a response to a traumatic event can manifest in 4 main clusters (a) intrusion of unwanted trauma-related memories, (b) avoidance of trauma-related thoughts or external reminders, (c) negative alterations in cognitions and mood, and (d) alterations in hyperarousal and altered reactivity. The diagnostic criteria for a PTSD are fulfilled, if symptoms from each of these clusters are reported and persist for at least 1 month.” (Barthel et al., 2020, p. 2). Symptoms should cause discomfort and severe impairment in the mothers’ functioning (Khoramroudi, 2018). Although this disorder can occur during pregnancy or at birth, it usually worsens after the birth of the child (Di Blasio et al., 2015). This has been linked to mothers being worried and anxious about the health of their babies after they are born (Khoramroudi, 2018).

### **3.8.1. Risk factors of trauma and PTSD in pregnancy**

### **3.8.2. Childbirth as a perceived traumatic event**

Pregnancy and childbirth are different from other traumatic events in that they are positively viewed by society, are often entered into voluntarily and events are in many cases predictable (Ayers et al., 2016). Although the normality of pregnancy and childbirth makes it difficult to understand as a trauma, the reality is that around one third of women relate to their maternal experience as traumatic (Ford & Ayers, 2011).

According to Gelaye et al. (2017), women are at greater risk of PTSD during their reproductive years, especially during pregnancy and postpartum, of which PTSD symptoms

are likely to reach severity closer to delivery. The spike in symptoms, according to Onoye and colleagues (2013) may be related to the upcoming delivery and the birth process being perceived as traumatic. This perception may be as a result of childbirth possessing traumatic elements such as the threat to life and possible physical danger to mother and baby (Lev-Wiesel et al., 2009). Pregnancy and childbirth may therefore contribute to PTSD symptoms by increasing the frequency and intensity of traumatic memories (Vignato, 2017).

According to Seng et al. (2010), physical changes of pregnancy such as cardiovascular, respiratory and renal system alterations affect the experience of PTSD symptoms in some women. Furthermore, increased heart and respiratory rates, shortness of breath and nausea may possibly be misattributed physical sensations to PTSD hyperarousal because these somatic changes resemble a physical sensation that is associated with anxiety (Seng et al., 2010).

A study conducted by Greken & O'Hara (2014) revealed two groups of women who experienced PTSD postpartum. One group of women developed PTSD as a result of experiencing childbirth as traumatic, while the other group developed PTSD as a result of unexpected interventions during labour and delivery such as emergency Caesarean Sections or vacuum-assisted vaginal deliveries. Apart from the infant being likely to develop a host of medical complications such as convulsions and facial palsy (Thies Lagergren et al., 2011), interventions during labour may be a traumatic experience to some women (Walker et al., 2015).

### **3.8.3. Subjective experience of childbirth**

Among other factors, women's subjective birth experiences are the most important factor for developing PTSD symptoms after childbirth (Garthus-Nigel, 2013). According to Dikmen-Yildiz (2018), maternal PTSD may result from some women's perceptions of a

seemingly normal birth as traumatic due to loss of control. When healthcare professionals fail to recognise the importance of women's needs to be involved in decision-making and to be fully informed about all aspects of their labour and birth, it decreases their sense of control (Vedam et al., 2019). This perception of loss of control has the danger of mothers perceiving the birth as traumatic and this leading to PTSD symptoms in some women (Reed et al., 2017).

Perceptions of traumatic birth experiences can also be strongly linked to unsupportive, disrespectful and dehumanising care by medical staff, which have far-reaching consequences (Elmir et al., 2010). In addition to decreased postnatal health and well-being, emotional detachment from partners and babies and fear of future pregnancies, there is agreement that a traumatic birth experience also produces clinical levels of psychological distress (Vossbeck-Elsebusch et al., 2014; Dikmen-Yildiz, 2018; Elmir et al., 2010). The prevalence of women experiencing trauma and developing PTSD and PTSS has been estimated to have risen from 19.7% to 45.5% (Maju et al., 2022).

### **3.9. Risk factors for maternal PTSD / trauma and high-risk pregnancy**

#### **3.9.1. Race**

Although psychological trauma is likely to affect all people to some extent, research suggests that Black individuals are exposed to more traumatic events in comparison to White groups (Ghafoori et al., 2012). Hence, Black women have the highest prevalence of PTSD symptoms in comparison to Caucasian women (Vesel & Nickash, 2015).

There is little evidence to suggest that these differences are attributed to racial differences, but environmental factors are believed to play a role (Thayer & Kuzawa, 2015). According to Roberts and colleagues (2011), racial and ethnic differences in PTSD may originate from different rates of exposure to potentially traumatic events or by specific types

of events. For example, Black people are usually exposed to more assaultive trauma in the form of childhood maltreatment, sexual assault and intimate partner violence, which is believed to hold the greatest risk for developing PTSD (Lipsky et al., 2016).

In addition, Black people often live in unsafe environments that are characterised by high levels of violence and crime (Brown-Luthango et al., 2017). A study conducted by Dailey and colleagues (2011) revealed that 87% of pregnant African American women reported at least one traumatic event while being relatively young. In their adult lives, crime-related activities which include serious injury to oneself or witnessing serious injury of a significant other were among the highest incidents reported.

Likewise, a South African study that was conducted in Cape Town Black communities revealed that 95% of Xhosa speaking adolescents had witnessed violence, with 56% of them having been victims (Bach & Louw, 2010). These findings were later corroborated by another Cape Town study which found 84.1% of the adolescent Black sample to be exposed to violence in their communities (Stansfeld et al., 2017). In addition to the exposure to high levels of violence, Black people's social contexts are often characterised by high levels of daily stressors in the form of perceived discrimination, race-related verbal assault and racial stigmatisation, all of which increase the risk of PTSD symptoms (Roberts et al., 2011; Childs, 2021).

Moreover, the sexual violence which is specifically directed at teenage girls in South African Black communities is outrageously high (Otwombe et al., 2015). Such communities are not conducive to the sexual and reproductive health of adolescents and often expose girls to trauma which often leads to unhealthy coping mechanisms such as experimentation with drugs and alcohol (Svanemyr et al., 2015). PTSD in women generally occurs during peak

incidence of trauma exposure between ages 16 and 20, which for many Black girls coincides with the average age for falling pregnant for the first time (Seng et al., 2011).

Additionally, despite a high prevalence of PTSD among Black females, many women respond to trauma by avoidance and passive coping strategies and are less inclined to use mental health services (Carpenter-Song et al., 2010). These coping strategies, according to Stevens-Watkins and colleagues (2014), may further increase their risk for psychological distress, thus leaving them more susceptible to PTSD.

### **3.9.2. Intimate partner violence**

Intimate partner violence is a pattern of assaultive and coercive behaviours which include threats or acts of physical or sexual violence, aimed at controlling a partner or former partner (Zacher et al., 2018). South Africa has one of the highest levels of interpersonal violence, with particularly women of child-bearing age being most affected (Atwoli et al., 2013). A South African study revealed that 20% of women attending antenatal care reported having experienced sexual violence by their intimate partners (Closson et al., 2016).

According to Habib and colleagues (2018), partner violence constitutes a large percentage of the overall disease burden among women of reproductive age and it accounts for 20% of all violent crimes.

Women who are in long-term abusive relationships are often traumatised and are likely to develop mental disorders such as PTSD, depression and alcohol abuse. These women often have no autonomy in sexual and reproductive health decisions including contraceptive use, which can affect the lives of their children even as adults (Amin, 2015).

Women who are physically or sexually abused by their partners have a greater likelihood of having a high-risk pregnancy, which includes a low birth-weight baby, an abortion or

contraction of HIV, and they are more likely to develop depression and PTSD (Taft et al., 2015).

### **3.10. Impact of high-risk pregnancy in the postpartum period**

Childbirth is a critical period in a woman's life which involves major physiological and psychological changes. Thus, it was previously understood that new mothers needed time for maternal recuperation after giving birth. Both within the family setting and in hospital, a new mother was freed from childcare responsibilities apart from breastfeeding (Kurth et al., 2010). However, the paradigm for postnatal care provision has changed, leaving the mother with the main responsibility of caring for her own newborn (Kurth et al., 2010). Although this way of thinking has produced positive results in relation to mother-child bonding, it challenges mothers with a previous high-risk pregnancy.

In addition to the normal anxiety of motherhood, high-risk pregnancy mothers are confronted with unique challenges which include poor health, complications with baby, interpersonal relationships and self-sufficiency. (Mirzakhani et al., 2020; Badakhsh et al., 2020). For example, mothers with sick infants experience stress and anxiety as they are often separated from their babies in order for them to receive care (Edell-Gustafsson et al., 2014).

It has been observed that lack of participation in infants' care decreases confidence in the parent's ability to be an effective parent which subsequently increases anxiety (Teng et al., 2018; Premji et al., 2018). All of this has a negative impact on the mother's pattern of sleep (Kurth et al., 2010; Valadares et al., 2020). These women often experience elevated levels of maternal psychological distress which may continue for months after the baby has been born (Holditch-Davis et al., 2015).

Furthermore, women from low socioeconomic groups are further challenged by poor living conditions and financial constraints which both play a vital role in women's distress

(Isaacs et al., 2018). Moreover, studies have consistently reported an association between a low socioeconomic status and lack of social support (Mirzakhani et al., 2020; Garfield et al., 2015). Poor social support has been largely reported as a strong predictor of distress in high-risk pregnancies (Goyal et al., 2010; Tyrlik et al., 2013).

Postpartum distress can have a negative impact on the quality of life, often leaving women with a general feeling of dissatisfaction in all areas of life including physical and psychosocial health and family relationships (Emmanuel et al., 2011). These feelings, according to Emmanuel and St John (2010), lead to a host of psychological problems and difficulty in adapting to the mothering role or changed social circumstances. Illness and birth complications resulting from high-risk pregnancy can be very overwhelming for mothers and often lead to the internalisation of motherhood as failure (Abraham & Curran, 2011).

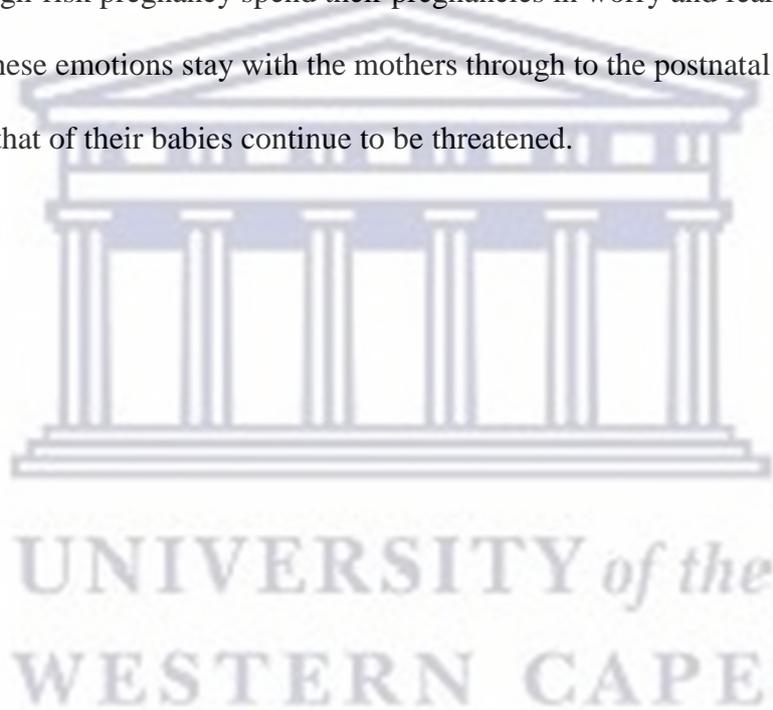
### **3.11. Conclusion**

The above literature highlights prominent factors facing the South African healthcare system and consequently, maternal health. Inequity in the distribution of healthcare among the population has been identified as a key challenge, resulting in lack of access to good quality maternal healthcare for most women. Therefore, despite good intentions of the South African government to reform the public healthcare system, the country has not yet caught up with the health needs of the population. Instead, the health outcomes of most South Africans have become progressively worse.

Literature additionally revealed that routine antenatal practices and discourses reflect the wider historical, political, structural and cultural power-relations and social processes in South Africa. Despite this evidence, however, the medical model views pregnancy as independent of wider sociocultural, physical, or political environments of mothers.

Furthermore, medicine and obstetrics have aligned themselves with science, of which knowledge produced within these fields is considered to be authoritative and truthful. Evidence suggests that categorising pregnancy as low or high risk has important consequences for the way in which pregnancy is managed, thus increasing surveillance and medical intervention.

It was further discovered that a high-risk pregnancy does not follow a usual pregnancy trajectory, which is characterised by joy for the mother and her family. Instead women with a high-risk pregnancy spend their pregnancies in worry and fear. Literature concluded that these emotions stay with the mothers through to the postnatal period, whereby their health and that of their babies continue to be threatened.



## Chapter 4

### 4. Methodology

#### 4.1. Introduction

The goal of this chapter is to describe the methodological process of the study. I presented a discussion on the research design, research context, sampling, data collection methods and procedures, data analysis, reflexivity, trustworthiness and ethics statement. The study sought to understand how women from resource-constrained areas made sense of their high-risk pregnancy diagnosis and how these inner mental cognitions have impacted them in the postnatal period.

#### 4.2. Research design

The current study utilised a qualitative research design which focuses on how people make sense of their experiences to gain a better understanding of their social reality (Mohajan, 2018). As a result, this design was fitting as it allowed for an in-depth understanding of the unique meaning that mothers in the study have attached to their high-risk pregnancy diagnosis. In order to fully achieve its objectives, the study made use of an existential theoretical framework which is located within a qualitative exploratory inquiry. The qualitative methodology complemented the existential theoretical framework in understanding how mothers made sense of their high-risk pregnancies. A major goal of existentialism is to emphasise human freedom as it views humans to be free to make choices (Flynn, 2009).

Smith and colleagues (2011) note that a theoretically-based qualitative design positively influences how evidence is collected, analysed and understood (Smith et al., 2011).

Moreover, this research design, according to Meyer and Ward (2014) has the ability to move beyond a description and potentially translate health research into practice and policy.

### **4.3. Research setting**

A research setting is defined as the physical, social and cultural site where a researcher conducts their study (Given, 2008). The present study was conducted by means of the Zoom digital platform and the telephone. At the time of the study, all the participants were residents of Cape Town, in the Western Cape Province of South Africa. Cape Town is one of the world's most multicultural cities, with a population of over 4.4 million people (City of Cape Town, 2020). Mothers who participated in the study lived in Gugulethu, Mandalay, Mitchells Plain, Philippi and Nyanga which are neighbourhoods that are traditionally known as townships. Cape Town townships are the direct consequence of racism, whereby the apartheid system under the Group Areas Act segregated all South Africans according to race. As a result, non-white South Africans live in high-density, low income townships. These neighbourhoods often have unfavourable living conditions such as poverty, extremely high unemployment rates and lack of reasonable infrastructure (adequate educational facilities, health, housing, recreational and transport facilities) (Jürgens et al., 2013).

### **4.4. Sampling and participant recruitment**

Women who were older than 18 years old, formally diagnosed with having had a high-risk pregnancy and had given birth within a two-year time frame were purposively recruited. I chose women who had given birth within a two-year frame because the experiences of both their pregnancies and the postnatal period would still be fairly reasonable to remember. Purposive sampling is a non-probability sampling technique that allows the

researcher to intentionally sample a group of people that will best inform the research problem of the study being conducted (Lopez & Whitehead, 2013). Purposive sampling methods place emphasis on obtaining a comprehensive understanding, rather than the number of participants (Etikan & Alkassim, 2016; Trotter, 2012). This technique is specifically used to aid the direction in which the sampling size is limited, but is still able to achieve information that is saturated with knowledge about a phenomenon. Thus, the purposive sampling technique was deemed most suited for the current study.

Participants were recruited on the WhatsApp platform whereby I sent out an advert of my study to my contacts list and asked people to share the advert with their contact lists. In the end, thirteen mothers approached me with an interest to participate in the study, all of whom were not known to me. Out of the thirteen mothers, two of them did not meet the criteria because their last high risk pregnancies were more than two years ago. After interviewing nine participants, no new data was emerging, therefore the number was deemed sufficient, as the aim of the interview process was to reach saturation. The nine participants presented similar themes and provided rich detail.

According to Morrow (2005), insights generated from qualitative inquiry have more to do with information that is rich, rather than the sample size. Purposive sampling was both appropriate and useful for this study as the research was directed at a specific sample, namely women from resource-constrained areas who were formerly diagnosed with a high-risk pregnancy.

#### 4. 4.1. Participant Demographics

Participant	Age	Language	Relationship Status	Place of Residency	Last High-Risk Pregnancy	High-Risk Diagnosis

Participant 1	40	isiXhosa	In a relationship	Mandalay	24 months ago	Hypertension
Participant 2	38	isiXhosa	In a relationship	Philippi	18 months ago	Appendicitis
Participant 3	40	isiZulu	In a relationship	Gugulethu	1 week ago	Hypertension, diabetes
Participant 4	34	isiXhosa	Married	Gugulethu	24 months ago	Hypertension, preeclampsia, diabetes
Participant 5	32	English	In a relationship	Mitchells Plain	20 months ago	Hypertension, pre-eclampsia
Participant 6	30	Afrikaans	Married	Mitchells Plain	4 months ago	Polycystic ovarian syndrome (PCOS)
Participant 7	40	isiXhosa	Single	Nyanga	23 months	Preeclampsia
Participant 8	32	isiXhosa	Married	Mandalay	6 months ago	Hypertension
Participant 9	35	isiXhosa	Married	Nyanga	24 months ago	Anaemia

In summary, nine participants who were all formally diagnosed with a high-risk pregnancy (hypertension, preeclampsia, diabetes, anaemia, Polycystic Ovarian Syndrome (PCOS), appendicitis) agreed to participate in my study. Only one participant had in the past suffered a miscarriage. Four participants in the sample were first-time mothers, three were having their third child and two participants were having their second child. Participants were between the

ages of thirty (30) and forty (40) years old, with a mean age of thirty six (36) years old. All participants reported living with a spouse or partner five (5) in a relationship, four (4) married). Seven (7) participants had completed high school education, one (1) participant completed grade ten (10), while the remaining three (3) participants possessed a National Diploma certificate. In terms of employment status, three (3) of the participants were unemployed and the other six (6) indicated that they were employed full time. None of the participants had medical aid and had therefore utilised public healthcare facilities for their antenatal care as well as the birth of their babies.

#### **4.5. Data collection and procedure**

Upon ethics clearance as approved by the University of Western Cape and the Biomedical Research Ethics Committee (BMREC), I commenced with the data collection process. A semi-structured interview guide (see Appendix A) was used for the interview process. A semi-structured interview guide is often used to guide interviews in an exploratory study (Hennink et al., 2011). Kallio and colleagues (2016) note that a semi-structured interview guide enhances the trustworthiness of qualitative research. Prior to the telephonic interview, the information sheet (see Appendix B) and the informed consent (see Appendix C) were sent to the participants via WhatsApp. This was followed by a WhatsApp message to schedule a meeting for a telephone call in order to explain the purpose of the study and to establish rapport. During this call, suitable appointment times for participants were scheduled.

One-on-one semi-structured interviews were conducted with mothers. Data was collected both telephonically and on the Zoom platform. Although the initial plan was to conduct all interviews telephonically, some participants indicated that they would be more

comfortable to be interviewed on Zoom. As a result, four participants were interviewed on Zoom and five were interviewed over the telephone.

I interviewed participants using open-ended questions. With this type of interview technique, all participants were asked identical questions in order to allow uniformity. After interviewing the first participant, I refined some of the questions before continuing with the rest of the interviews. This was after observing that some of the questions lacked clarity. Appointments for all participants were made via WhatsApp messaging. The interviews were conducted in English and isiXhosa and were recorded and later transcribed verbatim by myself. The interviews lasted between 22 and 42 minutes. Data was collected until data saturation was reached, meaning that no new information was emerging in the data. The recordings were securely stored with a secret password on my laptop. Overall, interviews went smoothly, although I experienced a connectivity challenge with one participant that was interviewed via Zoom and another participant's cell phone battery died in the middle of the interview. However, in both cases, we were able to successfully resume and complete the interviews.

#### **4.6. Data analysis technique**

Data was interpreted by using a theoretical thematic analysis, which means that it was driven by the existential framework theory. Despite this, I remained open to the possibilities of the emergence of new themes from the thematic analysis. A guideline provided by Percy and colleagues (2015) was followed to conduct the analysis. I began by familiarisation and immersion in each participant's data. Following this, each piece of data was coded while making use of the research question as a guide. This process involved searching and identifying distinct concepts and themes for categorisation (Williams & Moser, 2019). Data that was not related to the research question was separately stored for possible later use. All

related items were then grouped together to form a pattern. Patterns that were related to pre-existing themes were placed together with other thematically corresponding patterns, as well as direct quotes from the transcribed interviews. Patterns that did not relate to pre-existing themes were stored separately and revisited at a later stage to see if the meanings related to the overall topic. All the patterns were taken in order to identify any emergence of overarching themes. After analysing all the data, themes were arranged to correspond with the supporting patterns. Patterns that did not fit the pre-existing categories were then revisited. I then checked to see if there were any new patterns and themes that were related to the research topic which may have emerged from the data analysis. A detailed analysis of each theme was written. Lastly, all themes were synthesised together with their respective quotes and related to the research question and objective of the study.

#### **4.7. Trustworthiness**

According to Anney (2014) and Morrow (2005), in order to ensure trustworthiness of a research study, credibility, transferability, dependability and conformability has to be considered.

Credibility is the confidence that is placed in the research findings. In order to ensure credibility for this study, I strived to ensure that the participant's answers were accurately interpreted. In a qualitative study, credibility is established by the researcher's demonstration of prolonged engagement, methods of observation, triangulation, member-checking, peer debriefing, referential adequacy, negative case-analysis and by providing an audit trail (Anney, 2014).

For the current study, I paid attention to the emotions of participants during the interview process. Through member checking, participants were able to validate if I had interpreted the data accurately. To ensure dependability, I utilised the peer debriefing method

and member checking in order to determine whether or not findings are supported by data. To establish confirmability in this study, I reduced bias on the results and ensured that the data presented only the participant's responses.

Transferability is the degree to which results can be transferred to other contexts. In order to achieve this, extensive details concerning the methodology and context of the study have been provided in the current study.

Dependability is achieved by ensuring that the study is conducted in a consistent way across time, researchers, and analysis techniques. In this study, dependability has been ensured by detailing the data collection process. In addition, dependability has been achieved by peer debriefing method, whereby peers who are fellow Masters Research students and have been trained in the research process have evaluated whether or not the findings, interpretations and conclusions were supported by the data. In addition, I worked closely with my supervisor to explore various aspects of this research such as biases, understandings, interpretations as well as methodological and ethical processes. My supervisor also challenged some of my interpretations and provided alternative insight in terms of my analysis and write up of the final report.

Conformability is ensuring as far as possible that findings are based on the experiences and ideas of the participants, rather than the characteristics and preferences of the researcher. Thus, the researcher has to acknowledge any beliefs underpinning, decisions made and methods adopted within the research report. Reasons for favouring an existential theoretical framework which is located within a qualitative explorative has been explained in the research design section of the study.

#### **4.8. Reflexivity**

Reflexivity is the continuous internal dialogue and critical self-evaluation of the researcher's position within the research and the effect that it may have on the participants (Berger, 2015). Although as a Black woman who belongs to a marginalised group, I recognise the power that I hold within my professional capacity as a university student and as a researcher. Despite being a mother previously diagnosed with a high-risk pregnancy, I recognise the uniqueness of each experience and do not perceive myself as an expert in the subject. I also acknowledge that I may have preconceived ideas about high-risk pregnancy that have been shaped by my own experience along with the literature that I have immersed myself in while preparing for this paper. Therefore, it was imperative for me to put aside my feelings, personal beliefs, understanding and experiences of a high-risk pregnancy diagnosis during the interview process. I have been a counsellor for 13 years and have knowledge and training on separating my own experience from others. Drawing on this experience, reflexivity was maintained by continuous self-reflection and self-awareness and by keeping notes of any emotions, thoughts and discomfort that arose during this research process. In addition, I requested guidance from my supervisor when I was unsure.

#### **4.9. Ethics**

Ethics approval was obtained from the university ethics boards, the Biomedical Research Ethics Committee (BMREC), ethics reference number, BM21/5/16 (see appendix J). Requirements and the nature of the study were thoroughly explained to all parties involved. All participants were informed that they needed to consent and they provided verbal consent which was recorded as part of the interview process. According to a POPIA act seminar that I attended in 2021 which was hosted by the University of the Western Cape, verbal consent is deemed sufficient in a research study, and this was even more relevant

during the COVID-19 restrictions period. Participants were also informed that they could withdraw at any stage of the process without any prejudice. During the interview process, I was at all times aware of the sensitive nature of the study, and the potential for some participants to suffer psychological harm. Therefore, I assured all participants that they will be directed to free counselling services such as the South African Depression and Anxiety Group (SADAG), Life Line and the Counselling Hub should they require it. In addition, I debriefed participants after interviews and also had follow-up calls with them to ensure that they were still well. Privacy and confidentiality was kept by isolating myself while conducting interviews. This process involved booking a meeting room in the office with clear instructions not to be disturbed. All recordings were kept confidential and data was safely kept in a password-locked laptop. Participants were all given pseudonyms such as 'Participant 1'.

#### **4.10. Conclusion**

The present chapter provided a comprehensive overview of the methods employed in the study in order to deepen the understanding of the experiences and meaning-making of a high-risk pregnancy diagnosis as well as the impact in the postnatal period. Participants consisted of nine mothers who live in South Africa, in Cape Town's resource constrained communities. Interviews were conducted, recorded and transcribed by myself. A theoretical thematic analysis was employed to analyse the transcribed qualitative data and to provide a summarised and fully detailed account of the significant themes in the data. A detailed reflection on my role and involvement throughout the entire research process was concisely provided.

## Chapter 5

### 5. Results

#### 5.1. Introduction

This chapter reports the research findings which were conducted virtually and telephonically, in line with the COVID-19 protocols that were in place during the time of the interviews. The research findings were identified through a theoretically-based qualitative research design which involved closely examining the interview transcripts in order to identify, analyse and interpret prominent themes within the data. The findings were then reported according to the research questions as well as the aims and objectives which informed the study.

#### 5.2. Summative overview of the main themes and sub-themes

This study set out to understand the experiences of a group of participants from resource-constrained communities in Cape Town who were diagnosed with a high-risk pregnancy. The researcher sought to explore women from these areas' perceptions of their trauma and distress experienced as a result of their high-risk pregnancies. The following section will explore the findings of the study. Below is a summary of the main themes and sub-themes:

Themes	Sub-themes
1. Being labelled as 'high risk'	
2. Locus of control	<ul style="list-style-type: none"><li>● Mothers taking full control of birth outcomes: defying biomedical rules</li><li>● Loss of control: Releasing control to clinicians</li></ul>
3. Emotional experiences	<ul style="list-style-type: none"><li>● Fear</li></ul>

	<ul style="list-style-type: none"> <li>● Clinicians' focus on the pregnancy risks as fear-eliciting</li> <li>● Fear of losing the baby</li> <li>● Fear of losing one's own life</li> <li>● Anxiety</li> <li>● Hopelessness</li> </ul>
4. Hospitalisation	<ul style="list-style-type: none"> <li>● Sudden hospital admission</li> <li>● Prolonged waiting period for hospital admission</li> <li>● Lack of compassion from medical staff</li> <li>● Lack of support from medical staff</li> <li>● Support from hospital staff: showing compassion</li> </ul>
5. Coping mechanisms	<ul style="list-style-type: none"> <li>● Prayer</li> <li>● Placing trust in God</li> <li>● Family support</li> </ul>
6. Meaning-making / search for meaning	<ul style="list-style-type: none"> <li>● Renewed relationship with God</li> <li>● Gratitude</li> </ul>
7. PTSS / PTSD symptoms	<ul style="list-style-type: none"> <li>● Avoidance symptoms: Fear of having another baby</li> <li>● Increased arousal: being hypervigilant / overprotective</li> </ul>

### 5.3. Being labelled 'high risk'

This theme refers to the clinicians' portrayal of the potential negative outcome of pregnancy based on generic risk profiles rather than the participant's individual circumstances. The labelling of participants as 'high risk' was an important theme for the current study as it was what shaped participants' pregnancy journeys, which resulted in pregnancy being experienced in a particular way. According to Rajbanshi and colleagues (2021), risk perception is based on two elements: a statistical assessment of how likely an event is to occur; secondly, a psychological component, which includes how women feel about the risk. Despite this, however, clinicians tend to focus more on statistical assessment

and neglect the psychological component which include factors such as life experience, coping strategies and the context in which the risk occurs (Rajbanshi et al., 2021).

In their first encounters with clinicians, several participants were informed about the potential poor outcomes of their pregnancies, based only on statistical assessment. For example, Participant 1 and Participant 3 were labelled as ‘high risk’ based solely on their age, as seen in the extracts below:

*“When I went to book at the clinic, I was sent to the hospital. They said that I was high risk because of my age, because at that time, I was 39.”* **Participant 1**

*“...they said because of my age, because I’m 40, it’s possible for me to have a miscarriage, if not the baby won’t be normal. So they gave me a study about that 100 out of 500, something like that, mothers at my age...”* **Participant 3**

Participant 5 was a young mom who was diagnosed as ‘high risk’ in her second trimester after experiencing unusual symptoms. She was then examined and diagnosed with hypertension and preeclampsia. Following this diagnosis, she was informed that it was unlikely for her to have any further children in future. This was of course difficult for the young mom to hear, especially since it was her first pregnancy:

*“...the doctor told me that because of my first experience I might not be able to have children again, because I’ll always get sick. So it’s very traumatising and heart breaking.”*

#### **Participant 5**

It can be argued that the tendency of clinicians to focus on the negative aspect of pregnancy is often rooted in the best of intentions as they may be preparing mothers for the worst-case scenario (Behruzi et al., 2014). The challenge with this view however, is that once pregnancy is labelled as ‘high risk’ and a woman is categorised as such, it compels clinicians to focus their full attention on medications and tests, and the woman herself is subsequently

neglected (Rodrigues et al., 2016). This can unfortunately be construed as non-patient-centred (Lyerly et al., 2007).

#### **5.4. Locus of Control**

In the current study, the theme ‘locus of control’ denotes “the measure of the degree to which individuals believe their lives are controlled by themselves or external forces” (Eswi & Khalil, 2012, p. 463). The sub-themes under the main theme are ‘mothers taking full control of birth outcomes: defying biomedical rules’ and ‘loss of control: releasing control to clinicians’.

##### **5.4.1. Mothers taking full control of birth outcomes: defying biomedical rules**

The above-mentioned theme refers to participants who took full control of their pregnancies and birthing outcomes by refusing treatments and interventions which they perceived as unnecessary or a threat to themselves and their babies. These participants asserted themselves and ignored the statistics about the risks that were presented to them (Lee et al., 2014). Instead, participants relied on their own intuitive knowledge when they made decisions about themselves and their babies’ wellbeing.

For example, Participant 2 was diagnosed with appendicitis in the 7th month of her pregnancy. She was then informed by the medical team that continuing with the pregnancy posed a threat to her life, and that in a situation like that, the procedure was to first save the mother’s life. This translated to taking the baby out before full term, of which, the participant did not agree with clinicians. Below is her narrative:

*“So they performed the operation but also told me about the chances. But I also told them that you used to doing things a certain way to people, but my baby will be fine. Then they said that they would keep me for observation since they didn’t do things the way that they normally do it, but I kept saying to them, that no, I will give birth at 9 months.”* **Participant 2**

In addition, participants assessed the extent to which medical management was being beneficial to their pregnancy and childbirth (Lee et al., 2019). They also weighed up the effects of recommended treatments and made decisions according to what they believed to be best for their individual circumstances:

*“The test was to check if the baby had any disability, so what they told me was the test is risky, it can let you have a miscarriage or it may cause some kind of damage to the baby. So I said no...if my baby is not ok, then I’ll live with that when the time comes.”* **Participant 3**

Although participants were reluctant to comply due to perceiving the suggested medical interventions as posing an increased risk to their unborn babies, this did not mean that it was an easy decision to make. In fact, it resulted in considerable stress and anxiety for Participant 3:

*“I had mixed, mixed feelings which resulted to having a very low BP and the doctor said that it was anxiety, I can remember.”* **Participant 3**

Despite this however, participants were committed to the wellbeing of their babies and took whatever steps they believed would achieve this goal, an indication that women are trusting their own ‘embodied’ pregnancy experiences to tell them that their babies are fine (Markens et al., 2010):

*“They wanted to admit me now to induce labour, and I refused, I said no! I want a second opinion, I don’t believe you guys and whatever.”* **Participant 5**

These actions do not necessarily point to the participants’ lack of understanding of risks involved in their high-risk pregnancies, rather it indicates that they were not satisfied with the clinicians’ decisions about their pregnancies (Lee, 2014). Although women rejected many aspects of medicalised pregnancy, it is not to say that they fully rejected medical intervention, but instead objected to unnecessary interventions that they deemed as an

inflation of risk (Hammer & Burton-Jeangros, 2013). More important is the fact that participants in the current study took full responsibility for their birth outcomes which was a reflection of true control over decision-making.

#### **5.4.2. Loss of control: releasing control to clinicians**

While some participants took total control of their pregnancy and birthing outcomes, there were those who felt forced to surrender their control to clinicians, especially when there were unforeseen events in their pregnancies. Hence the theme ‘releasing control to clinicians’ describes participants who perceived their circumstances to be beyond their control. These participants described situations of having “no power and no control” in their birthing process and pregnancy outcomes, especially when their pregnancies took an unpredictable turn for the worse.

For example, one participant’s pregnancy shifted to high risk during labour. She was shocked and unprepared, especially since she had complied with all clinicians’ requests and suggestions from the beginning of her pregnancy. She reported that this was in the hope of being “guaranteed a healthy pregnancy outcome”. Hence, when the situation escalated, she felt let down by clinicians. She conveyed her feelings in the statement below:

*“I had no control, yes, I had no control because all my faith, I had given it to the doctors.”*

#### **Participant 7**

Similarly, another participant reported being in control at the beginning of her pregnancy:

*“I’m a planner. You know, I plan this whole experience, what it’s gonna be, all of that stuff.”*

#### **Participant 6**

However, when her pregnancy became high risk during labour, she felt powerless. She felt that her body had failed her and therefore had to release control to the clinicians:

*“I also released some control to them (clinicians), because I didn’t fight, I couldn’t really fight, I was too scared to, yeah.” Participant 6*

Because of the unpredictable nature of a high-risk pregnancy, lack of control was a common theme in previous studies that examined women’s experiences of high-risk pregnancy. For example, Andipatin (2012) found that participants in her study felt that they had no control over their pregnancy situations and circumstances. Similarly, participants in a study conducted by Roomaney and colleagues (2013) reported that a sense of not knowing as well as the rapid pace of events in their pregnancies resulted in feelings of loss of control.

## **5.5. Emotional experiences**

Emotional experiences refer to the feelings that dominated participants throughout their pregnancies. Eight of the nine participants described their overall pregnancy experiences using words that depict high levels of distress. They experienced a variety of often mixed and complex emotional responses (Price et al., 2007). Words such as ‘frightened’, ‘worry’, ‘tormenting’, ‘hopelessness’ were commonly used to describe feelings. Hence, what was expected to be a joyful experience for participants was subsequently affected by complications that are often associated with a high-risk pregnancy (Currie & Barber, 2016).

### **5.5.1. Fear**

“Fear is a normal reaction to a real or imagined threat, which is considered to be an integral and adaptive aspect of development” (Gullone, 2000, p. 429). All nine participants experienced some kind of fear during their pregnancies. Fear was therefore a central category that united all themes in this study. It manifested itself in different ways relating to different aspects (‘clinicians’ focus on the pregnancy risks as ‘fear-eliciting’, ‘fear of losing the baby’ and ‘fear of losing one’s own life’). These findings resonated with most South African

studies that examined women's emotions when in the midst of pregnancy complications (Andipatin, 2012; Isaacs, 2018; Isaacs & Andipatin, 2020).

### **5.5.2. Clinicians' focus on the pregnancy risks as fear-eliciting**

In the current study, 'clinicians' focus on the pregnancy risks as fear-eliciting' denotes the clinicians' sharing of information as being focused on worst-case scenarios regarding participants' diagnoses. For participants, this was frightening rather than educational. Below are some of the extracts of participants:

*"I was scared, I was traumatised because they told me, especially during that time of preeclampsia. They told me that it's 50/50 chance that the baby will not make it, so I was very scared."* **Participant 4**

*"What was on my mind was what he told me that if I happen to bleed, there's a 50/50 chance that I would not live. That frightened me."* **Participant 8**

For some participants, hearing the mention of 'high-risk pregnancy' among clinicians increased the degree of concern:

*"...that made me scared, when I kept hearing high risk, high risk, everywhere. It made me realise that I was in trouble. No, it was very difficult."* **Participant 2**

Findings of the current study resonate with previous studies. For example, in 2004, participants in Lashen and Sturdee's study reported mothers to be frightened by clinicians' sole focus on factual aspects of their high-risk pregnancies. These findings were later corroborated by Currie and Barber (2016) who reported that clinicians caused unnecessary fear in mothers by focusing solely on the risks of their pregnancies. Some studies have however found the contrary. For example, a study conducted by Lee (2014) revealed that clinicians' emphasis on the negative aspects of participants' pregnancies did not produce any

negative outcomes. These findings were later corroborated by Aldrighi and colleagues (2018). Despite these few cases, for the majority of women, the negative manner in which clinicians provide information can have a negative impact on women by raising fear and anxiety (Lerman et al., 2007).

### **5.5.3. Fear of losing the baby**

‘Fear of losing the baby’ was a theme that filtered through all interviews. This theme describes the degree of concern that was expressed by participants regarding the wellbeing of their babies. Participants addressed concerns regarding the survival of their pregnancies. Statements for this theme were categorised into ‘fear of losing the baby’ and ‘fear of the baby being harmed’. Most participants feared that something devastating could happen to their babies during childbirth (Dornelles et al., 2014). In many cases, the babies’ lives took precedence over that of participants:

*“Already you thinking about the child, is she still fine, you know, it was an emergency caesar, and they were saying, the child, so in my mind it was the child, I did not have time to concentrate on me mos.”* **Participant 4**

*“I thought I was going to lose him. The moment he was going to theatre, I was like wow, I’ve been there, I know how it feels. So, I thought that I was going to lose him because he was young and he had a small body. So yes, I thought I was going to lose him.”* **Participant 1**

*“You know they put the belt on, that you had to keep the baby monitoring, and sometimes that thing will beat so funny and I will scream, you know that there’s something wrong with my child, you know. I, I was terrified that the umbilical cord could get stuck around his neck... because I’ve been through so much.”* **Participant 5**

In addition to fearing for the baby's life, participants also feared that their babies may be harmed by the physical pain that was brought about by their pregnancy complications.

Some of these statements are below:

*"It's the pain that I had that made me scared. When you have pain, you worry about what is happening to the baby, are they being harmed in any way. Are they also in pain? So that made me scared."* **Participant 9**

*"I was frightened about the fact that I was pregnant, at the same time I'm having pain. What if that did something to the baby...so then that frightened me."* **Participant 2**

The fear of losing one's baby in women who experienced risky pregnancies is one of the most frequently reported fears. For example, in 2003, Berg and colleagues reported that women with high-risk pregnancies feared more for their baby's health when compared to women with low-risk pregnancies. Much later, Roomaney and colleagues' (2014) investigation came to similar conclusions. Their study revealed that participants who were diagnosed with HELLP syndrome (haemolysis, elevated liver enzymes and low platelet count) experienced intense fear of losing their babies. These findings have been recently corroborated by Isaacs and Andipatin (2020) who found that most fears that were experienced by women in their study were directed towards the potential harm or loss of their babies.

#### **5.5.4. Fear of losing one's own life**

'Fear of losing one's own life' was another sub-theme that emerged under the main theme of fear. This describes the degree of concern that participants experienced about the possibility of their own death due to pregnancy complications. Dying during a Caesarean Section was a common kind of fear that was related to the possibility of participants losing their own lives. This is expressed in the statements below:

*“I thought, I was going to die, I prayed a lot, I thought I was going to die, I don’t wanna lie, because to go to C-section.” Participant 1*

*“So I was scared that I’m pregnant and at the same time they will perform an operation, what if I die, yes I was scared and frightened.” Participant 2*

On the other hand, there were those participants who expressed different kinds of fears that related to losing their own lives. Below is the statement of one such participant:

*“I was scared I was going to die because they told me that I had a shortage of blood so after giving birth, they had to look for my blood type to give to me.” Participant 9*

As with the current study, fear dominates most studies that examined the emotional experiences of women diagnosed with a high-risk pregnancy (Cupido, 2017; Isaacs, 2018; Storeng et al., 2010; Laza Vásquez et al., 2012). Women with complicated pregnancies experience fear on a daily basis, from the prenatal period when they receive a diagnosis until the postpartum period (Dornelles et al., 2014). Authors have observed that the emotion of fear usually relates to having to deal with the uncertainty and unpredictability of women’s pregnancies, especially since the wellbeing of their babies is being threatened (Dornelles et al., 2014; Laza Vásquez et al., 2012).

#### **5.5.5. Anxiety**

Anxiety is another important theme that emerged in the data, as most participants in this study expressed a large degree of concern for the health and well-being of their babies. “Anxiety is something felt, an unpleasant affective state or condition. It’s a feeling of apprehensive expectation or dread” (Spielberger et al., 2013, p. 9). Participants in the current study described their pregnancies as highly stressful. In this study, anxiety was closely related

to the issue of not knowing what to expect. They described anxieties regarding anticipated events, such as attending antenatal care as is described below:

*“Whenever I had to go for my appointment I would be anxious, I would not sleep when I had to go for check-up the following day. So, it was difficult, it was not easy, it was just nerve-racking.”* **Participant 1**

High-risk pregnancy is often characterised by ever changing circumstances which for participants of the study were very unsettling, thus contributing to anxiety as described below:

*“The doctor said it was now time for a C-section. I think that just put me in a panic mode. I remember telling my husband that I’m so scared, I don’t know what to expect.”* **Participant 6**

The abovementioned statements demonstrate how being unsure of pregnancy outcomes caused great distress, which resulted in participants experiencing anxiety. In fact, anxiety has been commonly reported as a dominant emotion in studies that have closely examined experiences of women in high-risk samples (Roomaney et al., 2014; Isaacs, 2018; Laza Vásquez et al., 2012). Similar to fear, women usually experience anxiety the moment they are informed that their pregnancies are not normal and are labelled as high risk by medical experts (Kent et al., 2015; Laza Vásquez et al., 2012). A research study that examined medical records of women who had been diagnosed with high-risk pregnancies found anxiety to be the most prominent (77.2%) diagnosis (Medeiros et al., 2016). These findings echo the findings of this current study.

### 5.5.6. Hopelessness

Hopelessness in this study describes a situation whereby participants struggled to remain positive and maintain a sense of hope in the midst of challenges that were brought about by the diagnosis of a high-risk pregnancy. Participants describe feelings of being overwhelmed and being ready to give up on their pregnancies. Being unable to control circumstances contributed to the feelings of hopelessness, as illustrated below:

*“Yes, I was very hopeless as well... I thought maybe the baby is no longer there, the baby is no longer alive.”* **Participant 8**

*“I was ready, ready to give up.”* (With a sigh) **Participant 4**

Others felt that they could not live if they were to lose their babies, even alluding to ending their own lives:

*“It felt like my world was coming to an end, I felt like I would kill myself if anything were to happen to my child“* **Participant 5**

Findings in this study resonate with other studies that also explored the experiences of women who have been diagnosed with a high-risk pregnancy. In his research study, Berg (2003) previously observed that participants struggled to maintain a state of hope as there was a constant worry about their children’s health. These findings were later echoed by a South African study that observed that women with high-risk pregnancies often experienced hopelessness for extended periods (Kent et al., 2015). Likewise, Komorowska and Izdebski (2012) also reported that participants’ assessment of the threat to their children often increased feelings of hopelessness.

## 5.6. Main theme: Hospitalisation

All participants of the current study were hospitalised at some point during their pregnancies. In many cases, these admissions were sudden and unexpected. Hospitalisation was found to be quite stressful, requiring a great amount of social support for mothers (Kent et al., 2015). The ‘hospitalisation’ theme yielded five sub-themes which include sudden hospital admission, long waiting period for hospital admission, lack of compassion from medical staff and positive support from hospital staff.

### 5.6.1. Sudden hospital admission

The above-mentioned theme in this study denotes the unexpected way in which participants were admitted to hospital. This points to the unpredictable nature of a high-risk pregnancy, and the manner in which pregnancy has become institutionalised in order to control women's pregnancies. All of this can result in the neglect of the desires of women.

Most participants in the study reported that they were admitted during their routine antenatal care:

*“I woke up from my house, went to the hospital for a check-up (antenatal visit), and all of a sudden I’m being admitted.”* **Participant 8**

*“I think I was roughly just going for 6 months , and uhm, I went to work normal in the morning, and my left eye started tearing...and my friend said to me hey, your face is twisting and immediately my manager said to her, take her to the hospital.”* **Participant 5**

*“I think I was plus-minus 20 weeks, so I was told that my sugar levels were a little bit high, so it was a local clinic that I was attending, so I was told that I will be transferred to hospital, so I went with the ambulance to Mowbray hospital.”* **Participant 4**

These sudden hospital admissions as narrated by participants confirm the institutionalisation of pregnancy which resulted in the control of women's bodies and their pregnancies (Chadwick & Foster, 2013). When the severity of maternal complications increases, women are hospitalised for increased medical surveillance and intervention (Majella et al., 2019), and this was the case with participants in this study. These findings resonate with a study that was conducted by Smorti and colleagues (2021), whereby 43% of participants reported that admission to hospital was unexpected and shocking.

### **5.6.2. Prolonged waiting period for hospital admission**

The 'prolonged waiting period for hospital admission' describes the extensive waiting time that participants experienced before being admitted. It was often surprising for participants to have to wait for so long, especially since they had referral letters for admissions from previous healthcare facilities. Participants expressed themselves below:

*"I was there very early in the morning, about past seven and I was told that I will be admitted and I was kept there in the waiting room for like, for the whole day, I was only taken to the ward, around past seven in the evening."* **Participant 1**

*"I thought that everything would be sorted out for me because I had an appointment letter from where I was attending my antenatal. So I thought I would get there and be directed to my bed but then instead I had to go through that whole process of taking a folder and getting my high blood checked. So I got there 7 o'clock in the morning, so had to wait the whole day."* **Participant 7**

Prolonged waiting time has been identified as a major challenge in South African government healthcare facilities. The current study's findings resonate with a study that was conducted by Harris and colleagues (2011), who also found long waiting periods to be a major complaint for patients in public hospitals. Maphumulo and Bhengu (2019) attribute this

weakness to a number of factors, some of them being inadequate human resources and unequal distribution of resources among provinces and amongst private and public healthcare facilities.

### **5.6.3. Lack of compassion from medical staff**

This theme describes the disregard that some hospital staff had for participants of this study. These staff members displayed no empathy and acknowledgement for the difficult situations that participants found themselves in. Although being shouted at or scolded by healthcare providers is the most commonly reported form of hostility in studies (Chadwick, 2017), the current study brought other forms of maltreatment to light. For example, one participant was asked to clean up her own vomit in the midst of severe pain as recounted below:

*“I was vomiting mos, so that nurse said, and I remember it was a Coloured lady. So she told me to clean up my vomit, so I did that, I cleaned my vomit up and sorted everything out.”*

#### **Participant 8**

Some participants such as Participant 7 reported being shouted at or scolded by a healthcare provider:

*“I was in too much pain, there's that belt, I took that belt off. So now it (machine display) had a straight line. When they came in the morning, yoh, that cherry (nurse) was shouting, ‘You took this thing out a long time ago!’ she shouted and shouted.”* **Participant 7**

In other cases, participants felt they weren't cared for emotionally as expressed by this participant's statement below:

*“It’s about the wound. They just check up, checked my pulse, my blood pressure, check my wound and give me tablets, that’s all. Nobody is worried about you emotionally. Nobody’s asking about you emotionally, no there’s no such there.”* **Participant 1**

#### **5.6.4. Lack of support from medical staff**

In this study, lack of support is linked to lack of compassion but focuses more on providing physical support for participants who were admitted to hospitals, especially those who were struggling to do what they would normally be able to do for themselves. Due to lack of compassion from the hospital staff, participants in the current study did not receive any assistance whether it be in the form of making up their beds or being assisted with the care of their newborn babies after a Caesarean section.

*“I had to take care of the baby, I had to make up my bed. And I was like if I was at home, I would have someone to assist me with the baby. Even with healing, it was going to be easy.”*

**Participant 3**

*“Because the wound was still fresh, it was very painful. Nobody cared about you except for the doctors who came in and checked the wound and give you the tablets of course, but everything else, you are on your own.”* **Participant 8**

Lack of compassion and support in government hospitals is a long-standing challenge in South Africa, which is unfortunately not unique to this study. Hence, identifying mistreatment and disrespect of women during pregnancy and childbirth has been gaining attention (Chadwick, 2017; Curtin et al., 2019). Hospital staff members have consistently been reported as cold and hostile towards birthing mothers (Chadwick et al., 2014; Harries et al., 2014; Chadwick, 2017). For example, in a study conducted by Chadwick and colleagues (2014), participants reported shouting and lack of care from staff, lack of information about the labour and birth, neglect and abandonment. The identification of a high-risk pregnancy

already introduces additional stress and anxiety due to uncertainty in a pregnant woman (Jordan & Murphy, 2009). It therefore becomes imperative for those diagnosed with risky pregnancies to receive psychological support, sympathy and hope from clinicians (Janighorban et al., 2018), especially since an association between lack of support and PTSD has been long established (Brewin et al., 2000).

#### **5.6.5. Support from hospital staff: showing compassion**

Despite many participants experiencing indifference from clinicians, there were those who commented favourably and expressed appreciation toward healthcare providers. These participants acknowledged the emotional support provided by the medical staff.

For example, one participant painted a positive picture of the nursing staff that took care of her during her hospital stay. She described an environment where the door was always open for her to seek advice and to ask questions about her diagnosis whenever she felt anxious:

*“So, every time I had a problem I would connect with the nurses and was reassured.”*

#### **Participant 9**

Similarly, Participant 6 reported that the medical team was friendly and welcoming. She described her experience in the following abstract:

*“Everybody was nice, the doctors, the nurses. Everybody around me was nice”.* **Participant**

#### **6**

In addition to being friendly, Participant 4 reported that the hospital staff went as far as offering her a birthing partner as her husband was working in Limpopo during the time of the birth of her daughter:

*“I can say the staff was very very nice...I didn't have anyone, they offered someone during the process. The staff were very very supportive.”* **Participant 4**

These findings resonate with those of a study that was conducted by Behruzi and colleagues (2010) in Japanese public hospitals. Participants of the study reported that midwives challenged the traditional biomedical framework in providing comfort for birthing mothers. The same study found that one of the most essential features of hospitalisation was the provision of support by hospital staff, which was conveyed through behaviours such as listening, expression of care and concern, acknowledgement of feelings and reflective understanding. Recent research further suggests that for some high-risk samples, being hospitalised can be a protective factor when they have the necessary support from clinicians (Smorti et al., 2021).

## **5.7. Main theme: Coping mechanisms**

‘Coping mechanisms’ concerns itself with thoughts or actions engaged to manage stressful situations (Lou et al., 2016), such as spirituality (prayer, placing trust in God) and family support in the case of the current study. However, the aim of coping strategies is not necessarily to resolve or master a situation but it is rather an ongoing process of attempts to manage psychological stress that are context specific (Martins, 2018). The coping mechanisms theme produced three sub-themes which include prayer, placing trust in God and family support.

### **5.7.1. Prayer**

Prayer in this study is described as “an activity related to spirituality and religion” (Simão et al., 2016, p. 1). According to Esperandio and colleagues (2015), prayer is a tool that many people employ in difficult times, especially when facing illness. As participants struggled to make sense of, and more specifically to cope with complications of their

pregnancies, they turned to their spirituality for assistance and guidance, as exemplified below:

*“I prayed a lot. I’m a praying person. We are a praying family. I prayed a lot.”* **Participant 1**

*“I was scared, I was laying there, and I started praying and I just ask God, to just let everything just go smooth from here.”* **Participant 6**

*“...then I called my aunt from Transkei, and asked her to pray for me. And then she prayed for me and then we both hung up.”* **Participant 7**

Findings of the current study confirm previous discussions in literature whereby mothers utilised prayer as a coping mechanism when faced with difficult pregnancies (Esperandio et al., 2015; Bélanger-Lévesque et al., 2016; Hamilton & Lobel, 2008). Literature also reveals that more than anything else, prayer is being generally used to deal with personal, intense suffering, in other words, as a coping mechanism (Bélanger-Lévesque et al., 2016; Esperandio et al., 2015; Price et al., 2007). Simão and colleagues (2016) have even gone on to suggest a relationship between religious practices and improved physical and mental health outcomes.

### **5.7.2. Placing trust in God**

Clements and Ermakova (2012) observed that individuals who believe that God is benevolent and powerful experience less stress when faced with adversity. Similarly, despite difficulties and challenges brought about by their high-risk pregnancies, participants in the current study described trusting in God as a fear alleviating factor. They reported that their faith in God was able to help them remain optimistic in times of difficulty during pregnancy complications. Therefore, participants turned their focus away from the negative statistics

given by clinicians about their pregnancies and focused their attention on their trust in God (Price, 2007), as described below:

*“On that day (delivery day), I had told myself that there is a God, and that all this will pass and that I will meet the baby. So those are the things that I was telling myself when I was there. So. I was telling myself that.”* **Participant 2**

*“Yes, I was hopeful that all will go well because I believed in God.”* **Participant 9**

*“I was having a deep conversation with God and telling him that today you gonna prove to me that there is a God.”* **Participant 5**

Findings of the current study have been reiterated in many studies. It has been observed that having trust in God helps to calm the fears of women with a high-risk pregnancy diagnosis. For example, participants in a study that was conducted by Bayrampour and colleagues (2012) reported that their trust in God helped them to not only stay calm but to also feel that they were not alone. Likewise, Laza Vásquez and colleagues (2012) observed that, independent of maternal religious orientation, mothers in their study found support in their faith in God to overcome adversity in their pregnancies. More recently, Mutmainnah and Afiyanti (2019) found that the women in their study’s strong beliefs in God’s power were a coping mechanism to overcome the anxiety and trauma of their pregnancies.

### **5.7.3. Family support**

Support has been found to improve wellbeing in pregnancy (Mirzakhani et al., 2020). In fact, Ford and Ayers (2011) found that a good social support system is a protective factor which can potentially reduce the severity of PTS symptoms and facilitate recovery in women diagnosed with high-risk pregnancies. All participants in the current study were fortunate to be in loving relationships and therefore received help in dealing with their challenging

experiences, particularly during the postpartum period. Sources of support included husbands and/or partners and immediate family members, such as mothers and sisters. Below are the expressions of some of the participants:

*“So my mother was helping me. When I was tired she took the baby off my chest, she will also put the baby on her chest so it was easy with my mom...She was helping me with everything, so that’s why when I was in hospital, I was thinking about my mother and thinking if I was at home. She was doing everything for me so yah. So she was helping me a lot.”* **Participant 1**

*“No, it (pregnancy complications) didn’t disturb me because I had the help of my sister, I was living with her. She would take the baby when I had to use the toilet, so I wasn’t that disturbed.”* **Participant 8**

*“My father was still alive, so my mother had to move from their bedroom, to sleep with me...so she can help me to look after the baby.”* **Participant 7**

These findings are in stark contrast with those of Mirzakhani and colleagues (2020) as well as those of Garfield and colleagues (2015) who concluded that women from low socioeconomic backgrounds experience their pregnancies in the absence of social support. However, our findings echo those of Oliveira and Mandú (2015) who found that participants in their study received various forms of help from family members. Further research goes on to suggest that receiving family support, especially after birth, is important for mothers in reducing the risk of adverse health outcomes, such as anxiety and depression (Biaggi et al., 2016). Therefore, having an understanding family that offers support for the needs of participants of this study was a great catalyst for coping with negative thoughts and feelings (Oliveira & Mandú, 2015).

## **5.8. Meaning-making / search for meaning**

In the current study, meaning-making refers to the manner in which participants processed and interpreted the experiences and challenges of their pregnancy complications. Participants made use of spirituality and religiosity, of which Fisher (2015) has observed that this method allows the individual to look beyond the difficult experience at hand, which primes them for a transcendent experience beyond themselves (Fisher, 2015). According to Morita (2009), the use of meaning-making interventions potentially alleviate worries and concerns for individuals. The meaning-making theme produced two sub-themes in the current study, which are: renewed relationship with God and gratitude.

### **5.8.1. Renewed relationship with God**

Despite all the worries and fears that surrounded participants of the current study, the birth of their babies brought them closer to God. Prinds (2014) observed that the experience of motherhood and spirituality mutually influence each other in the development of an identity as a mother. Participants reported having a renewed relationship with God. They experienced God as a source of love, strength and guidance (Martins & Gall, 2021).

For example, Participant 3 described how the survival of her risky pregnancy along with the decisions that she made along the way in order to protect her baby affirmed the existence of God and the major influence that he has in our lives. She described her feelings as follows:

*“It (the high-risk pregnancy experience) revealed to me that life is not only medical, you should always pray and go with your heart in what you believe. It actually made me to believe even more because I have now realised even more that our lives are from God.”*

#### **Participant 3**

Participant 5 articulated similar sentiments whereby she experienced a sense of renewal in her relationship with God, thus bringing about a shift in her worldview:

*“For me it actually brought my spiritual path more, it made me look at life differently, you know. I don’t take things for granted anymore. For me mostly, it was more spiritual, that’s how I took it.”* **Participant 5**

Again, Participant 4 also described how her pregnancy experience led her to a strengthened bond with God.

*“It brought me very very close to God. That was the time I became very close to God.”*

**Participant 4**

These findings resonate with other findings. For example, it has often been reported that pregnancy and motherhood trigger a renewed sense of spirituality which strengthens the relationship with God (Martins & Gall, 2021), and it is even more so for mothers who have undergone the trauma of a high-risk pregnancy (Mutmainnah & Afiyanti, 2019; Martins, 2018; Price et al., 2007).

Prinds (2014) noted that through motherhood, women's relationship with God strengthens and that they experience a greater sense of personal empowerment from participating in the creation of life. Moreover, placing faith in God not only helps women to cope with the demands of motherhood but it also aids them to maintain a positive attitude toward life. This is particularly important as existentialists view motherhood as a lifelong project which provides life-changing experiences for both parents and their children (To & Chan, 2013).

### 5.8.2. Gratitude

In this study, gratitude is defined as a positive emotion that occurs when participants recognise that the divine being or God has intentionally done something to their benefit (Cauble et al., 2023). Gratitude further implies a state of affirming goodness in one's life which is accompanied by a recognition that the source of this goodness lies at least partially outside the self (Ma et al., 2017). As such, participants of this study perceived their health and that of their babies as a gift from God which was unobligated (Cauble et al., 2023) as expressed in the following statements:

*“It was a miracle, and it’s still a miracle even today being able to hug her, I feel like I was very very blessed.”* **Participant 4**

For other participants gratitude was brought about by the overwhelming joy that they experienced:

*“Directly after giving birth...the emotions were just overwhelming when they put her on my chest and, I remember seeing her face for the first time, I think I was just overwhelmed and grateful that she was ok.”* **Participant 6**

*“When I think about all of that, I think God is great, He was there for me all the time until the end. So yah, I praise God, I praise God.”* **Participant 1**

These findings resonate with that of Bélanger-Lévesque and colleagues (2016) who reported that women in their study expressed gratitude when they overcame their high-risk pregnancy challenges. Similarly, Carvalheira and colleagues (2010) observed that participants of their study attributed overcoming their health problems to God's grace. Cregg and Cheavens (2020) have in their study further observed gratitude to improve wellbeing and reduce anxiety and depression.

## 5.9. PTSS/ PTSD Symptoms

Eight out of nine participants reported at least one PTSD symptom. Of those, three participants reported two symptoms, one participant reported three and four participants reported one symptom each. These symptoms fell into all three clusters of PTSD, which include: re-experiencing, avoidance and increased arousal. Avoidance and vigilance were the two dominant symptoms that were reported by participants.

### 5.9.1. Avoidance symptom: fear of having another baby

According to Ayers & Ford (2016), a traumatic birth can lead to severe fear of childbirth, also known as tokophobia. Seven out of the nine participants in this study displayed this fear. This fits the avoidance symptoms of PTSD as participants made it imperative to avoid a similar situation from occurring again (Ayers & Ford, 2016). Hence, the majority of participants concluded that childbirth is a risky process that should be avoided in order to prevent the possibility of experiencing the same risks again. Below are some of their statements:

*“I was so scared and it was a very traumatising experience for me...I never wanted to have another baby after that because really, I had a bad experience with my first baby.”*

#### **Participant 4**

*“...because I was told a baby that is premature is very sickly, so it was not easy. As a result, I don't want to ever, ever have a baby, I will never have a baby! I'm fine.”* **Participant 2**

*“All I know is that it's something that I would not do again...So, I will not have another baby.”* **Participant 7**

*“So, I told myself that I shouldn't take that risk of having another baby because of what happened, so I was scared of that.”* **Participant 9**

Findings of the current study are consistent with previous studies which have shown a strong relationship between the trauma experienced during pregnancy and childbirth and avoidance of future pregnancies (Scollato & Lampasona, 2013; Friedman et al., 2009; Hofberg & Ward, 2003). Although other factors may come into play as far as fear of having another baby is concerned, previous negative pregnancy and childbirth experiences are considered as the main cause of this kind of fear (Scollato & Lampasona, 2013; Ayers, 2016).

### **5.9.2. Increased arousal: being hypervigilant / overprotective**

Pregnancy complications have been observed to produce problematic mother-infant attachment styles (Nichols & Ayers, 2007; Todd, 2013). Most participants in the current study described increased arousal which is a type of hypervigilant behaviour consistent with an overprotective or anxious attachment style (Ayers & Ford, 2016; Beck, 2004; Nicholls & Ayers, 2007). They feared that their babies would not survive once born. In order to monitor their babies, participants performed frequent check-ups in order to detect if their babies were still breathing as described in the following statements:

*“It was very challenging for the first 6 months of the baby’s life because I was always on edge. I was always, you know, putting my finger by his nose to check if he’s breathing. It was so traumatising, for any small thing...I’m rushing to the doctor, you know.”* **Participant 5**

*“Coming so close to losing her, even though she was born healthy and everything. I think that fear always stays with you. I still have that separation anxiety. I don’t leave her. I won’t leave her if it’s not absolutely necessary. When she’s sleeping, I’m always checking if she’s breathing and stuff like that.”* **Participant 6**

One woman whose baby did not breathe immediately after birth described a situation whereby she couldn’t focus at work due to the constant worry that something dreadful might

happen to her baby. Moreover, her fears of losing her baby were holding her hostage as she found it difficult to leave her baby to use the toilet. She relayed her narrative below:

*“I was very protective, too much, like obsessive...Because I had to go back to work, I would call constantly. I was constantly thinking about this baby. I couldn’t go to the loo without thinking, is she ok? I had to be like her security. I had to constantly watch over her.”*

### **Participant 7**

Hypervigilant and overprotective behaviour was reported by all the participants who had high-risk infants who were nearly lost. These findings align with previous findings (Ayers & Ford, 2016; Beck, 2004) that estimated hyperarousal symptoms to be between 25-27% in their study. Ayers and colleagues (2009) had previously reported hyperarousal symptoms to be reported by 58% participants in their study.

### **5.10. Conclusion**

The current study, together with the abovementioned studies give a glimpse into some of the challenges that mothers who are diagnosed with high-risk pregnancies face. More specifically, these findings give insight into the never-ending challenges which continue through to motherhood for mothers diagnosed with high-risk pregnancy.

However, according to the existential theory, suffering is an essential and inescapable aspect of human existence and finding meaning in suffering is what makes pain more bearable and provides reasons for living (Wong, 2012).

## Chapter 6

### 6. Discussion

The current chapter presents a summary of findings as well as the strengths, limitations and recommendations for future research. The aim of the study was to explore the ways in which women (from resource-constrained communities) who experienced high-risk pregnancies made sense of their experiences and how those experiences have impacted their postpartum mental health. The study made use of an existential theoretical framework which is located within a qualitative exploratory inquiry (O'Brien et al., 2010).

While it is widely accepted that pregnancy is an unsettling time for most women, this study revealed that these emotions are amplified for those who have experienced pregnancy complications, and that a high-risk diagnosis directly harms women's experiences of pregnancy (Neiterman, 2012). Burdens brought about by a high-risk pregnancy increase the levels of stress and frustration, over and above the normal stressors of pregnancy (Cole-Lewis et al., 2014; McCoyd et al., 2020). However, women also expressed hope and gratitude, which suggests the complex mixture of emotions during a high-risk pregnancy. The challenges that are unique to women who are from resource-constrained environments was also brought to light by the study.

The study exposed that pregnant women are being labelled as 'high-risk' solely on statistical assessment to the exclusion of other factors, including psychological components such as life experience, coping strategies and the context in which the risk occurs (Rajbanshi et al., 2021). It emerged that health care professionals placed more emphasis on the chances of adverse outcomes of pregnancy including death. Hence, the perception of participants was that the risk status of their pregnancy was amplified (Lee et al., 2012). Consequently, the manner in which information about the risk was presented by clinicians elicited fear in

participants and subsequently took away the joy of pregnancy and replaced it with uncertainty, generating a host of negative emotions such as anxiety, loss of control, worry and hopelessness.

Nearly all participants described their overall pregnancy experiences using words that depict high levels of distress, with fear and anxiety emerging as dominating themes which were expressed quite frequently by all participants. These fears centred predominantly on worry for the health of the baby and that of self. Dying during a Caesarean Section or losing the baby as a result of pregnancy complications were two prominent fears reported in the current study. In most cases, the fear was so intense that it left participants in a state of hopelessness whereby they were ready to give up the possibility of being a mother.

In addition to fear, participants reported battling with an enormous amount of anxiety which was related to their poor pregnancy outcomes. According to Abrar and colleagues (2020), symptoms of anxiety are common among pregnant and postpartum women, and they are even more pronounced in women with high-risk pregnancies (Fairbrother et al., 2018).

Furthermore, living in resource-constrained areas subsequently increased participants' vulnerability to anxiety (van Heyningen et al., 2017). For example, van Heyningen and colleagues (2017) found that for every additional stressful event experienced by pregnant women in their study in the preceding six months, the risk for anxiety diagnosis increased by 1.3 times.

Existentialists, however, view anxiety as the most important feeling as they believe that it reveals that people are unique individuals (Ahmed, 2015). They believe that existential anxiety issues are dramatised within the context of a transformative life experience, where a definitive event forever changes one's social order, such as in the case of a high-risk pregnancy (Davidov & Russo-Netzer, 2022).

Findings further outlined varying perceptions and responses to the understandings of risk as well as the acceptance of surveillance that accompanied the risk label (Hammer & Burton-Jeangros, 2013). Biomedicine has enabled doctors to attain occupational prestige, higher economic statuses and cultural authority (Yao, 2019), of which this power in South Africa is further amplified by historical inequities within the various population groups due to the apartheid legacy (Chima, 2013).

Consequently, the autonomy of participants in the study whose powerlessness may have been even more pronounced due to their lower socioeconomic backgrounds (Marmot, 2004) was challenged. Autonomy may be defined as “women’s ability to make and execute independent decisions pertaining to personal matters of importance to their lives and their families” (Osamor & Grady, 2016, p. 192). Thus, when surveillance increased, participants felt forced to surrender their power and control of pregnancy-related decisions.

Another point to consider is that, the release of power could also be due to participants having a somewhat excessive degree of intrinsic trust that clinicians would never suggest anything that would not be beneficial to their pregnancies (Van der Zande, 2017).

However, not all participants in the study were fully ‘compliant’ with biomedical prescriptions. Some participants asserted themselves against clinicians and defied the biomedical way of viewing pregnancy and the associated risks. They were critical in their consideration of medical advice and relied more on their own assessments of knowledge than that of clinicians (Markens et al., 2010).

Constructing pregnancy according to medically-established guidelines implies that it is experienced in the same way by all women (Neiterman, 2012). Existentialists believe that most of life’s important events consist of subjective rather than objective truths, which are products of the individual experience rather than consensus (Sandler, 2011). The view is that

some truths are much more individual and personal and need to be experienced first-hand before they can appear as truth (Sandler, 2011). We can therefore infer that the scientific way of viewing pregnancy is not a great paradigm for understanding pregnancy.

The study further affirmed that a high-risk pregnancy predominantly occurs in the context of sudden and unexpected hospitalisation. Although the hospital environment is portrayed as a safe place for birth, the study revealed that public hospitals can be hazardous and risky for pregnant women in South Africa. As such, “It's important to remember that exactly what is ‘offered’ may be linked to the social positioning of women.” (Lowe, 2016, p. 129). Hence, the study found that hospitalisation does not guarantee compassionate care for women from resource-constrained areas who are experiencing pregnancy complications. For these women, hospitalisation often leads to a loss of autonomy (Behruzi et al., 2014).

Once referred for a hospital admission, enduring a 12-hour waiting period before being directed to their wards was the first obstacle that was reported by participants in the current study. This is an ongoing challenge in South African public healthcare facilities which has also been raised in other studies (Young, 2016; Harris et al., 2011; Maphumulo & Bhengu, 2019), and is therefore not unique to the current study.

During hospitalisation, participants had to deal with hostile and cold healthcare professionals, and this was displayed in their lack of compassion and lack of physical assistance for the participants. Some of the narratives included being shouted at or scolded, not being assisted with the making up of beds after a Caesarean Section and being made to clean up one's own vomit in the midst of severe pain. Similar narratives have been captured by both international (Schroll et al., 2013; Sheppard, 2004) and South African studies (Chadwick et al., 2017; Tsawe & Susuma, 2014).

Sheppard and colleagues (2004) previously observed that women from poor backgrounds were more likely to experience hostility from healthcare providers in comparison to their affluent counterparts. Moreover, these findings were later corroborated by a South African study that discovered that most people who utilise the public healthcare system reported having some bad experiences (Jewkes & Penn-Kekana, 2015).

On the contrary, there were participants who painted a positive picture about the healthcare professionals in hospitals, reporting that they were warm and inviting. Behruzi and colleagues (2014) observed that women need and highly value the support and presence of healthcare professionals during the intrapartum period. In fact, Backes and colleagues (2006) contend that humanised care is something that can be achieved, as it is not a trick or a tool, but rather a feeling of closeness which manifests itself in their day-to-day activities in the workplace.

When what was meant to be a joyous experience turned out to be fearful and anxiety-provoking, participants in the study sought comfort and meaning for their suffering. They dealt with the traumatic experiences of a high-risk pregnancy by giving it meaning (Hall, 2010). Meaning-making usually involves spiritual methods whereby individuals may try to review their suffering as a growth opportunity or as God's purpose (Park, 2013). In this case, spirituality serves as a meaning system that informs how one views and interprets the world (Park, 2013). "Transcending" or "transcendence" are important terms in defining spirituality because spirituality meets the basic human need for self-transcendence (Wojtkowiak & Crowther, 2018). Wojtkowiak and Crowther (2018) describe transcendence as "the experience of losing or immersing oneself with an outside being".

Participants of the study reported utilising a spiritual connection in the form of prayer, whereby they asked God for protection. This act has also been reported in other studies. For

example, Esperandio and colleagues (2015) identified prayer to be a tool that many people employ in difficult times, especially when facing illness. Similarly, findings from this study indicate that participants took comfort from their faith and religion and used it as a way to keep calm when they sensed their life and that of their babies was in jeopardy.

Price and colleagues (2007) also observed that people make sense of their illnesses or threats to their health and well-being by using spiritual beliefs as a framework. It is also found that spiritual beliefs and practices influence health and recovery and often lead to better mental and physical well-being (Ahmadinezhad & Akbarzadeh, 2019). Participants reported that despite their fears and anxieties during pregnancy, they felt strong and hopeful as they knew that God would carry them through. In addition to good spiritual grounding, all participants had a solid social support structure in the form of their spouses and other family members.

More importantly, findings revealed that women with a high-risk pregnancy continue to experience challenges beyond pregnancy into motherhood. Therefore, the transitional process of mothers who were diagnosed with a high-risk pregnancy is not a typical one. Only one participant out of the nine did not describe any PTSD-related symptoms, while the remaining eight participants experienced at least one symptom. Participants mostly experienced avoidance and increased arousal cluster symptoms. Seven out of the nine participants displayed fear of having another baby, while all the participants who almost lost their babies exhibited behaviour that was consistent with hypervigilance and overprotectiveness. Consequently, most participants continued to experience motherhood in the context of fear and worry. Hence, the study has given insight into the uniqueness of a high-risk pregnancy which is not necessarily a happy event for mothers.

## **6.1. Strengths and limitations**

One of the main strengths of the study is its utilisation of a qualitative research design which allowed me to record rich and detailed experiences of mothers who were diagnosed with a high-risk pregnancy. Additionally, the study contributed to a body of knowledge on the understanding of the experiences of mothers from resource-constrained communities who were diagnosed with a high-risk pregnancy. Further to gathering information for research purposes, the interviews served as a therapeutic space for mothers, many of whom were sharing their experiences for the first time.

However, conducting interviews of such a sensitive nature over the telephone and virtually may be viewed as a limitation as factors such as reflexivity were difficult to ascertain during the data collection process because of the absence of body language. The flow of some of the interviews was interrupted by abrupt disconnections and interferences. This could have had an influence on the information that was shared. The study was limited to a small sample of women who reside in the Western Cape, in Cape Town's resource-constrained communities. Hence, this may mean that different findings could emerge in other cultural contexts. Therefore, despite producing such rich data, findings cannot be generalised to all women experiencing high-risk pregnancy as that is not the aim of a qualitative study.

## **6.2. Recommendations**

### **6.2.1. Recommendations for policy makers in South Africa**

- By now it may be clear that high-risk pregnancy causes great distress in mothers even after giving birth. This indicates that maternal mental health issues can begin during pregnancy and persist for longer than it is commonly realised. As a result, policy makers should focus their efforts on incorporating psychosocial support that is culturally sensitive to the needs of South African mothers.

- Government should implement strategies which include developing a legal and policy framework, capacity building and establishing funding for more research that focuses on women's mental health issues.
- The government has made great strides to increase the availability of healthcare services in the country, however, they need to take a closer look at the quality of care that is being provided to mothers.

### **6.2.2. Recommendations for mental health care professionals**

- The information collected can be used to inform change and improvement within health institutions to support women with a high-risk diagnosis. In view of these findings, it is suggested that health professionals, particularly midwives, play a more supportive role in the lives of women who have a high-risk pregnancy diagnosis.
- Given the fact that South Africa is a country that experiences a great amount of violence, efforts should be more focused on primary prevention such as screening women during pregnancy in order to identify vulnerability to PTSD (Ayers et al., 2016).
- Women should be in regular contact with healthcare services during pregnancy as midwives are in a key position to identify risk, educate and support women with their mental health.
- Support for mothers should not be terminated solely on the basis of physical health for both mother and baby.
- The use of spiritual support came out quite strongly in the current study. Therefore, health institutions need to consider developing spaces and freedom to allow mothers to practise their spiritual beliefs. More importantly, health professionals need to respect women's spiritual beliefs even when they are in conflict with their own practices.

### **6.2.3. Recommendations for future research**

- The study gave insight into the grossly neglected postnatal period, when mothers continue to struggle with the aftermath of a high-risk pregnancy. Based on the study's findings, it is imperative that mothers' mental health status is followed up on for at least a year after giving birth.
- In the future, wider research could be conducted to ascertain the depth of the challenge of post-traumatic stress symptoms following a high-risk pregnancy and also to assist in focusing intervention efforts to help mothers.
- Future research also needs to address the major gap in the literature on effective interventions in maternal mental health and well-being in pregnancy as this is the point of most intensive contact which provides considerable opportunity to improve maternal well-being.

### **6.3. Conclusion of the study**

This thesis explored ways in which women from resource-constrained environments who were diagnosed with high-risk pregnancy experienced and made meaning of their pregnancy. In addition, it also examined how those experiences impacted women's postpartum mental health. Due to COVID-19 restrictions at the time of the study, this was achieved by conducting semi-structured telephonic and virtual interviews. The experiences of women were explored and analysed through the lens of an existential theoretical framework. The study has given insight into the challenging nature of high-risk pregnancy which often leaves women feeling overwhelmed. Findings of the study concur with most literature in that high-risk pregnancy is a time of turmoil which changes the meaning of life for mothers. More importantly, this thesis has given women who were interviewed a voice by allowing them to relay their experiences.

## 7. References

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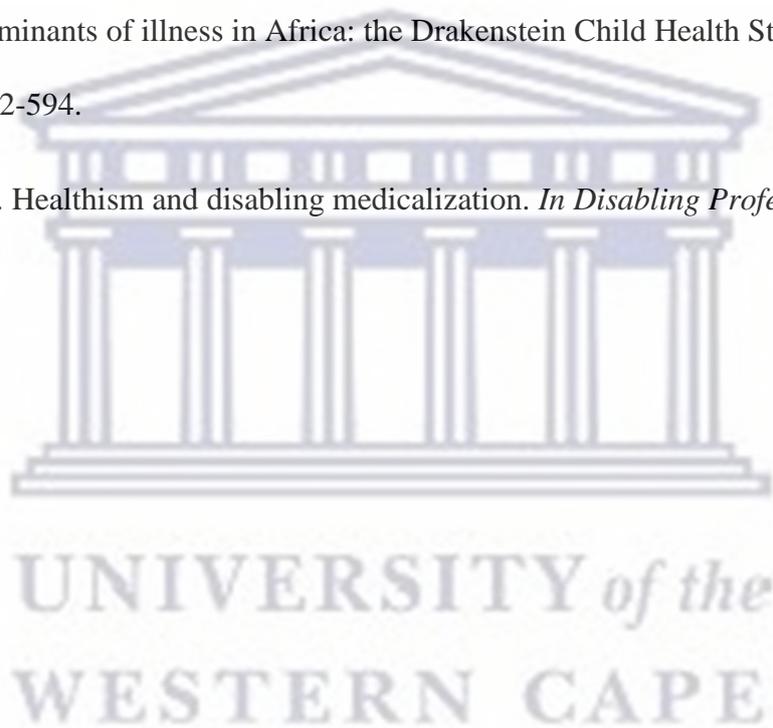
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## 8. Appendices

### Appendix A: English Interview Guide



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#### DEPARTMENT OF PSYCHOLOGY

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#### Section A: Participant Information

Age:

Marital Status:

What language do you regard as your mother tongue?

Place of Residence

Are you employed/unemployed?

How many live babies have you had?

How many miscarriages have you had?

When was your last high-risk pregnancy?

What were you diagnosed with?

What is the highest educational level you attained?

#### Section B: Interview Questions

I seek to uncover how women make sense of their distress and the meanings they have attached to it. This will be done through asking clarifying and probing questions such as;

1. Can you please tell me about your high-risk pregnancy?
2. Which feelings dominated your experience while going through the pregnancy?
3. How did you experience the birthing and birth of your baby?
4. Post birth: How would you describe your post-birth experience?
5. How do these experiences affect your daily functioning? Baby, family and social life
6. Do you have any intrusive thoughts or vivid dreams that relate to your pregnancy or the birthing experience?
7. Describe in your own words, how you made sense of this entire experience

## Appendix B: English Information Sheet



**UNIVERSITY of the  
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### INFORMATION SHEET

**Title of Research Project:** “Exploring the subjective meaning-making and perceptions of the impact of their high-risk pregnancies in a sample of women from resource constrained areas”

#### **What is this study about?**

This is a research project being conducted by Gugulethu Cebekhulu, a postgraduate student under the supervision of Professor Andipatin at the University of the Western Cape. We are inviting you to participate in this research project because your participation may provide us with a better understanding of how women who have experienced high risk pregnancy make sense of their experience.

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

You will be asked to participate in a recorded telephonic interview of approximately 40 – 60 minutes long and share your experiences of having being diagnosed with a high-risk pregnancy. The recording will ensure that I accurately capture everything that you have provided.

#### **Would my participation in this study be kept confidential?**

I will undertake to protect your identity and the nature of your contribution by not using your real name and by securing your information in my password locked computer. Apart from myself, only those that are involved in the research study will have access to information. To ensure your confidentiality, all data will be kept safe. All participants have the right to withdraw from the study at any time without any negative consequences.

#### **What are the risks of this research?**

There may be some risks from participating in this research study as speaking about one’s personal experiences may carry some amount of risks. I will nevertheless reduce such risks and act promptly to assist you if any discomfort or psychological harm is experienced during the process of your participation in this study. If, for any unknown reason, the study evokes any unprocessed emotional material, participants will be referred to the below FREE counselling services:

**South African Depression and Anxiety Group (SADAG):**

**Telephonic counselling contact: 080 056 7567, What's App: 076 882 2775**

**Lifeline Counselling Services (Cape Town):**

**Telephonic and face to face contact: 063 709 2620**

**What are the benefits of this research?**

A benefit of your participation includes creating awareness of the experiences of women with high risk pregnancy. I hope that the healthcare facilities and Department of Health might benefit from this study through their improved understanding and knowledge regarding the experiences of women who have been diagnosed with high risk pregnancy.

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

Your participation in this research is completely voluntary. You may choose not to take part. If you decide to participate in this research, you may stop participating at any time throughout the process. If you decide not to participate in this study or if you stop participating at any time, you will not be penalised.

**What if I have questions?**

This research project is conducted by Gugulethu Cebekhulu from the Department of Psychology at the University of the Western Cape. If you have any questions about the research study itself, please contact:

Masters Student: Gugulethu Cebekhulu

Department of Psychology

4047925@myuwc.ac.za

Supervisor: Professor Michelle Andipatin

Faculty of Community and Health Sciences

University of the Western Cape

mandipatin@uwc.ac.za

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:

MA HOD: Prof Anita Padmanabannuni

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University of the Western Cape

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Dean of the Faculty of Community and Health Sciences (CHS): Professor Anthea Rhoda

University of the Western Cape

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BMREC Office

021 959 4111

## Appendix C: English Consent Form



**UNIVERSITY of the  
WESTERN CAPE**

### DEPARTMENT OF PSYCHOLOGY

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-9592825, Fax: 27 21-9593515

### CONSENT FORM

Title of Research Project: **“Exploring the subjective meaning-making and impact on their high-risk pregnancy on a sample of mothers/women from resource constrained areas”**

The purpose of the study has been explained to me in a language that I understand. I freely and voluntarily agree to participate. I understand that I can withdraw from the study without giving a reason, and this will not affect me negatively in any way. I understand that my identity and all information stemming from my participation will be strictly confidential and will not be violated by the ethical code of this research. I hereby also give permission that the interview with me will be recorded for research purposes.

\_\_\_\_\_ I agree to be audio-recorded

\_\_\_\_\_ I do not agree to be recorded

Participant's name.....

Participant's signature.....

Date.....

## Appendix D: Isixhosa Interview guide



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#### **ICandelo A: linkcukacha zabathathi-nxaxheba**

Ubudala:

Ubume obuxela ukuba utshatile okanye awutshatanga:

ULwimi lweenkobe

Iindawo zokuhlala

Imeko yengqesho

Zingaphi iintsana ophilileyo osele unazo?

Zingaphi iizisu obunazo eziye zaphuma?

Kwakunini ukukhulelwa kwakho komngcipheko ophezulu?

Yintoni kwafunyaniswa ukuba unayo?

#### **ICandelo B:**

Ndifuna ukutyhila ukuba abafazi bayayenza njani ingcinezelo yabo kunye neentsingiselo abanamathele kuzo. Oku kuyakwenziwa ngokubuzo imibuzo ecacisayo kunye nephononongayo efana;

1. Ungandixelela ngokukhulelwa kwakho okusemngciphekweni omkhulu?
2. Zeziphi iimvakalelo ezilawula amava akho ngelixa ukhulelwe?
3. Ukhe wakuva njani ukuzalwa nokuzalwa komntwana wakho?
4. Emva kokuzalwa: Ungawachaza njani amava akho emva kokubeleka?
5. La mava ayichaphazela njani imisebenzi yakho yemihla ngemihla? Usana, usapho kunye nobomi bentlalo
6. Ngaba unayo nayiphi na ingcinga engathandekiyo okanye amaphupha acacileyo anxulumene nokukhulelwa kwakho okanye amava okuzala?
7. Chaza ngawakho amazwi, uyive njani yonke lento ibisiyenzeka ngexesha ukhulelwe?

## Appendix E: Isixhosa Information sheet



UNIVERSITY of the  
WESTERN CAPE

### DEPARTMENT OF PSYCHOLOGY

Private Bag X 17, Bellville 7535, South Africa

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### Uxwebhu lolwazi

#### Isihloko seProjekthi yoPhando:

Le yiprojekthi yophando eqhutywa nguGugulethu Cebekhulu, umfundi onesidanga sokuqala phantsi kolawulo uProfesa Andipatin kwiYunivesithi (yaseNtshona Koloni) University of Western Cape. Siyakumema ukuba uthathe inxaxheba kule projekthi yophando kuba ukuthatha kwakho inxaxheba kungasinika ukuqonda okungcono malunga nendlela abasetyhini abaye bafumana umngcipheko omkhulu wokukhulelwa benza ingqiqo yamava abo.

#### Yintoni endiza kucelwa ukuba ndiyenze ukuba ndiyavuma ukuthatha inxaxheba?

Uya kucelwa ukuba uthathe inxaxheba kudliwanondlebe olubhaliweyo malunga nemizuzu engama-40 ukuya kuma-60 kwaye wabelane ngamava akho okuchongwa ukuba ube nokukhulelwa obunnengozi. Ukurekhodwa kuya kuqinisekisa ukuba ndiyifaka ngokuchanekileyo yonke into oyibonisileyo.

#### Ingaba ukuthatha inxaxheba kwam kolu phando kungagcinwa kuyimfihlo?

Ndiza kuzimisela ukukhusela isazisi sakho kunye nohlobo lwegalelo lakho ngokungasebenzisi igama lakho lokwenyani nangokugcina ulwazi lwakho kwikhompyuter yam etshixiwe. Ngaphandle kwam, kuphela abo babandakanyekayo kuphando lophando abanokufikelela kulwazi. Ukuqinisekisa ukuba yimfihlo kwakho, yonke idatha iya kugcinwa ikhuselekile. Bonke abathathi-nxaxheba bayakhuthazwa ukuba bagcine imfihlo. Unelungelo lokurhoxa kuphando nangaliphi na ixesha ngaphandle kweziphumo ezibi.

#### Ngowuphi umngcipheko kolu phando?

Kunokubakho umngcipheko ekuthatheni inxaxheba kolu phando njengoko ukuthetha ngamava akho buqu kunokuthatha umngcipheko othile. Kodwa ke ndiza kuyinciphisa loo mingcipheko ndize ndikhawuleze ndisebenze ukuze ndikuncede xa kukho ukungahambi kakuhle okanye ukwenzakala ngokwasengqondweni ngexesha lokuthatha kwakho inxaxheba kolu phando. Ukuba, nangaliphi na isizathu esingaziwayo, uphononongo luveza naziphi na izinto ezingasetyenziswanga zovakalelo, abathathi-nxaxheba baya kuthunyelwa kwezi nkonzo zilandelayo zokufumana iingcebiso SIMAHLA:

#### South African Depression and Anxiety Group (SADAG)

Unxibelelwano ngomnxeba nokucebisa ngomnxeba:

**080 056 7567, uWhats app: 076 882 2775**

**Lifeline Counselling Services (Cape Town): 063 709 2620**

### **Zithini izibonelelo zolu phando?**

Uncedo lokuthatha kwakho inxaxheba lubandakanya ukudala ulwazi ngamava abasetyhini abakumngcipheko ophezulu wokukhulelwa. Ndiyathemba ukuba amaziko okhathalelo lwempilo kunye neSebe lezeMpilo banokuzuza kolu phando ngokuqonda kwabo okuphuculweyo kunye nolwazi malunga namava abasetyhini abafunyaniswe benomngcipheko omkhulu wokukhulelwa.

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

Ukuthatha kwakho inxaxheba kolu phando ngokuzithandela. Unokukhetha ukungathathi nxaxheba. Ukuba uthatha isigqibo sokuthatha inxaxheba kolu phando, unokuyeka ukuthatha inxaxheba nangaliphi na ixesha kuyo yonke le nkqubo. Ukuba uthatha isigqibo sokungathathi nxaxheba kolu phando okanye uyeke ukuthatha inxaxheba nangaliphi na ixesha, awuyi kohlwaywa.

### **Ndingathini ukuba ndinemibuzo?**

Le projekthi yophando yenziwa nguGugulethu Cebekhulu ovela kwiSebe lezeNzululwazi kwiYunivesithi yaseNtshona Koloni. Ukuba unemibuzo malunga nophando ngokwalo, nceda unxibelelane:

#### **Umfundi weMasters: Gugulethu Cebekhulu**

ISebe lezeengqondo

University of the Western Cape

4047925@myuwc.ac.za

#### **Umphathi: UProfesa Michelle Andipatin**

I-Faculty yoLuntu kunye neNzululwazi yezeMpilo

University of the Western Cape

mandipatin@uwc.ac.za

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

UMququzeleli weNkqubo ye-Psychology: Prof Anita Padmanabannuni

Department of Psychology

University of the Western Cape

apadmana@uwc.ac.za

#### **I-Dean yeFakhalthi yoLuntu kunye neNzululwazi yezeMpilo: uProfesa Anthea Rhoda**

Dean of the Faculty of Community and Health Sciences of the University of the Western Cape

[chs-deansoffice@uwc.ac.za](mailto:chs-deansoffice@uwc.ac.za)

#### **BMREC Office**

021 959 4111

## Appendix F: IsiXhosa Consent form



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WESTERN CAPE**

### **DEPARTMENT OF PSYCHOLOGY**

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### **IFOMU YEMVUME**

Isihloko se Projekthi “Ukuphonononga intsingiselo yentsingiselo kunye nefuthe lokukhulelwa kwabo kusemngciphekweni kwisampulu yoomama / abafazi abasuka kwiindawo ezixineneyo kwizibonelelo”

Injongo yesifundo ndiyichazelwe ngolwimi endiliqondayo. Ndivuma ngokukhululekileyo nangokuzithandela ukuthatha inxaxheba. Ndiyaqonda ukuba ndingarhoxa kuphononongo ndingakhange ndibeke sizathu, kwaye oku akuyi kundichaphazela kakubi nangayiphi na indlela. Ndiyaqonda ukuba isazisi sam kunye nalo lonke ulwazi oluvela ekuthatheni inxaxheba kuya kuba ngokungqongqo ziyimfihlo kwaye azizophulwa yimigaqo yokuziphatha yolu phando. Ndinika imvume yokuba udliwanondlebe nam luya kurekhodwa ngeenjongo zophando.

\_\_\_\_\_ Ndiyavuma ukurekhodwa

\_\_\_\_\_ Andivumelani nokurekhodwa

Igama lomthathi-nxaxheba .....

Utyikityo lwabathathi-nxaxheba .....

Umhla .....

## Appendix G: Afrikaans Interview guide



**UNIVERSITY of the  
WESTERN CAPE**

### **DEPARTMENT OF PSYCHOLOGY**

Private Bag X 17, Bellville 7535, South Africa

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#### **Afdeling A: Deelnemersinligting**

Ouderdom:

Huwelikstatus:

Watter taal beskou u as u moedertaal?

Woonplek:

Werk u of is u werkloos?

Hoeveel lewende babas het u al gehad?

Hoeveel miskrame het u gehad?

Wanneer was u laaste hoërisiko-swangerskap?

Waarmee is jy gediagnoseer?

Wat is die hoogste opvoedkundige vlak wat u bereik het?

#### **Afdeling B: Onderhoudsvrae**

**Ek wil ontbloot hoe vroue hul nood en die betekenis wat hulle daaraan heg, verstaan. Dit sal gedoen word deur verhelderende en ondersoekende vrae te stel soos;**

1. Kan u my vertel van u hoërisiko-swangerskap?
2. Watter gevoelens het hierdie ervaring oorheers terwyl u deur die swangerskap gegaan het?
3. \Hoe het u die geboorte en geboorte van u baba ervaar?
4. Na geboorte: Hoe sou u u ervaring na geboorte beskryf?
5. Hoe beïnvloed hierdie ervarings u daaglikse funksionering? Baba-, gesins- en sosiale lewe
6. Het u indringende gedagtes of helder drome wat verband hou met u swangerskap of geboorte-ervaring?

Beskryf in u eie woorde hoe u sin gemaak het van hierdie hele ervaring

## Appendix H: Afrikaans Information sheet



UNIVERSITY of the  
WESTERN CAPE

### DEPARTMENT OF PSYCHOLOGY

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#### INLIGTINGSBLAD

**Titel van navorsingsprojek:** “Verkenning van die subjektiewe betekenisgewing en persepsies van die impak van hul hoërisiko-swangerskappe in 'n steekproef van vroue uit hulpbronbeperkte gebiede”

#### **Waaroor gaan hierdie studie?**

Dit is 'n navorsingsprojek wat uitgevoer word deur Gugulethu Cebekhulu, 'n nagraadse student onder toesig van professor Andipatin by die Universiteit van Wes-Kaapland. Ons nooi u uit om aan hierdie navorsingsprojek deel te neem, omdat u deelname vir ons 'n beter begrip kan gee van hoe vroue wat swangerskap met 'n hoë risiko ervaar, sin maak uit hul ervaring.

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

U sal gevra word om deel te neem aan 'n opgeneemde telefoniese onderhoud van ongeveer 40 – 60-minute en u ervarings van u diagnose met 'n hoërisiko-swangerskap te vertel.

#### **Sou my deelname aan hierdie studie vertroulik gehou word?**

Ek sal onderneem om u identiteit en die aard van u bydrae te beskerm deur u regte naam nie te gebruik nie en deur u inligting op my rekenaar met 'n wagwoord te beveilig. Afgesien van myself, het slegs diegene wat by die navorsingstudie betrokke is, toegang tot inligting. Om u vertroulikheid te verseker, sal alle data veilig bewaar word. Alle deelnemers het die reg om te enige tyd uit die studie te onttrek sonder enige negatiewe gevolge.

#### **Wat is die risiko's van hierdie navorsing?**

Daar mag 'n paar risiko's in verbond met deelname aan hierdie navorsingstudie, aangesien gesprek van 'n persoon se persoonlike ervarings 'n mate van risiko's kan inhou. Ek sal nietemin sulke risiko's verminder en dadelik optree om u te help as enige ongemak of sielkundige skade ervaar word tydens u deelname aan hierdie studie. As die studie vir enige onbekende rede onverwerkte emosionele material oproep sal deelnemers verwys word na die onderstaande GRATIS beradingsdienste:

#### **Suid-Afrikaanse Depressie- en Angsgroep (SADAG):**

**Telefoniese beradingskontak: 080 056 7567, WhatsApp: 076 882 2775**

#### **Lifeline Counselling Services (Kaapstad):**

**Telefonies en aangesig tot aangesig kontak: 063 709 2620**

### **Wat is die voordele van hierdie navorsing?**

'N Voordeel van u deelname sluit in die bewusmaking van die ervarings van vroue met hoërisiko-swangerskap. Ek hoop dat die gesondheidsorgfasiliteite en die Departement van Gesondheid voordeel sal vind by hierdie studie deur hul beter begrip en kennis aangaande die ervarings van vroue wat gediagnoseer is met hoërisiko-swangerskap.

### **Moet ek aan hierdie navorsing deelneem en mag ek enige tyd ophou deelneem?**

U deelname aan hierdie navorsing is heeltemal vrywillig. U kan kies om nie deel te neem nie. As u besluit om aan hierdie navorsing deel te neem, kan u enige tyd ophou deelneem. As u besluit om nie aan hierdie studie deel te neem nie, of as u op enige tydstip ophou deelneem, sal u nie geenaliseer word nie.

### **Wat as ek vrae het?**

Hierdie navorsingsprojek word uitgevoer deur Gugulethu Cebekhulu van die Departement Sielkunde aan die Universiteit van Wes-Kaapland. As u vrae het oor die navorsing, kontak asseblief:

#### **Meestersstudent: Gugulethu Cebekhulu**

Department of Psychology

University of the Western Cape

4047925@myuwc.ac.za

#### **Studieleier: Professor Michelle Andipatin**

Fakulteit Gemeenskaps- en Gesondheidswetenskappe

University of the Western Cape

mandipatin@uwc.ac.za

As u enige vrae het rakende hierdie studie en u regte as navorsingsdeelnemer, of as u enige probleme wat u met die studie ervaar het, wil kontak, kontak:

#### **Hoof van die departement: Prof Anita Padmanabannuni**

Department of Psychology

University of the Western Cape

apadmana@uwc.ac.za

#### **Dekaan van die Fakulteit Gemeenskaps- en Gesondheidswetenskappe: Anthea Rhoda**

Dean of the Faculty of Community and Health Sciences

University of the Western Cape

[chs-deansoffice@uwc.ac.za](mailto:chs-deansoffice@uwc.ac.za)

#### **BMREC Office**

021 959 4111

## Appendix I: Afrikaans Consent form



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WESTERN CAPE**

### **DEPARTMENT OF PSYCHOLOGY**

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### **TOESTEMMINGS VORM**

**Titel van navorsingsprojek:** “Verkenning van die subjektiewe betekenisgewing en persepsies van die impak van hul hoërisiko-swangerskappe in 'n steekproef van vroue uit hulpbronbeperkte gebiede”

Die doel van die studie is aan my verduidelik in 'n taal wat ek verstaan. Ek stem vryelik en vrywillig in om deel te neem. Ek verstaan dat ek my aan die studie kan onttrek sonder om 'n rede daarvoor te gee, en dit sal my nie negatief beïnvloed nie. Ek verstaan dat my identiteit en alle inligting wat voortspruit uit my deelname streng vertroulik sal wees en nie deur die etiese kode van hierdie navorsing geskend sal word nie. Hiermee gee ek ook toestemming dat die onderhoud met my opgeneem sal word vir navorsingsdoeleindes.

\_\_\_\_\_ Ek stem in om opgeneem te word

\_\_\_\_\_ Ek stem nie in om opgeneem te word nie

Deelnemer se naam .....

Deelnemer se handtekening.....

Datum.....



UNIVERSITY of the  
WESTERN CAPE



17 August 2021

Ms G Cebekhulu  
Psychology  
Faculty of Community and Health Sciences

Ethics Reference Number: BM21/5/16

**Project Title:** Exploring the subjective meaning making and perceptions of the impact of high-risk pregnancies in a sample of women from resource constrained areas.

**Approval Period:** 16 August 2021 – 16 August 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.

Any 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.**

*Permission to conduct the study must be submitted to BMREC for record-keeping.*

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

NHREC Registration Number: BMREC-130416-050

Director: Research Development  
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FROM HOPE TO ACTION THROUGH KNOWLEDGE.