“WAITING TO EXHALE”: THE LIVED EXPERIENCES OF WOMEN DIAGNOSED HIV- POSITIVE DURING PREGNANCY IN ESWATINI

by

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DECLARATION

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I declare that the above dissertation is my own work and that all the sources that I have used or quoted have been indicated and acknowledged using complete references.

I further declare that I submitted the dissertation to originality-checking software and that it falls within the accepted requirements for originality.

I further declare that I have not previously submitted this work, or part of it, for examination at Unisa for another qualification or at any other higher education institution.

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DEDICATION

I dedicate this thesis to:

- My father, Sizwe Magekeni Malambe, my superhero, not a day goes by that I do not think of you, how you would be so proud. Thank you for believing in me. Thank you for every sacrifice you made especially in my education, making my dream come true! I love you. This is for you!
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ABSTRACT

In Eswatini, pregnant women with the Human Immuno-deficiency Virus (HIV) continue to experience challenges to maintain an adequate quality of life. Although healthcare interventions are implemented at healthcare centres to reduce the risk of vertical transmission, understanding the unique challenges faced by women during their pregnancy can help enhance the efficacy of interventions targeted at improving the wellbeing of pregnant women with HIV. This study explored the lived experiences of pregnant women with HIV to understand the emotional and psychological response to their diagnosis. This study further extended to identifying the challenges and opportunities women face following their HIV diagnosis during their pregnancy. In this instance, a qualitative phenomenological study was conducted, comprising data collected from ten women diagnosed with HIV during pregnancy via semi-structured interviews. Data were analysed using thematic analysis and triangulation. Findings indicate that women experience an extensive array of emotions, ranging from fear, guilt, depression, shame, hopelessness, acceptance, and grief. The findings also indicate that stigma and social isolation associated with HIV diagnosis enable them to avoid disclosure of their diagnosis, which exacerbates social and emotional challenges, paving the way to anxiety and depression. Regardless, women continue to find resilience against their challenges by accepting their diagnosis, maintaining open communication, engaging in spiritual and religious practices, and pursuing knowledge regarding the management of their health concerns and preventing vertical transmission. These findings provide implications for healthcare providers and policymakers to implement interventions that incorporate counselling, mental health support, and educational resources to empower women to navigate the emotional, psychological, social, and economic challenges during their pregnancy and maintain positive life prospects.

***Keywords**: HIV, Pregnancy, Vertical Transmission, Experiences, Women, Eswatini.*

SICAPHUNO

Eswatini, bantfu labasikatsi labakhulelwe labaneLigciwane Lesandvulelangculazi (i-HIV) bayachubeka nekubukana nebumetima ekugcineni lizinga lelanele lemphilo. Nanobe kungenelela kwekunakekelwa kwetemphilo kwentiwa etikhungweni tetemphilo kute kwehliswe bungoti bekutseleleka lokucondzile, kuvisisa tinsayeya letehlukile bantfu labasikati lababukane nato ngesikhatsi bakhulelwe kungasita ekutfutfukiseni kusebenta kahle kwekungenelela lokuhloselwe kutfutfukisa inhlalakahle yebantfu labasikati labakhulelwe labane-HIV. Lolucwaningo lwahlola lokwenteka kubantfu labasikati labakhulelwe labane-HIV kute kuvisiswe kuphendvula kwabo ngekwemoya nangakwengcondvo ekucilongweni kwabo. Lucwaningo luchubekile lwafinyelela ekutfoleni tivimba nematfuba bantfu labasikati labahlangabetana nawo ngemuva kwekuhlolelelwa i-HIV ngesikhatsi bakhulelwe. Kwentiwe lucwaningo lwe-qualitative phenomenological, loluhlanganisa idatha legcogcwe ngetingcoco letingakahleleki ngalokuphelele letivela kubantfu labasikati labalishumi labatfolwe kwekutsi bane-HIV ngesikhatsi sekukhulelwa. Idatha yahlatiywa ngekusebentisa kuhlatiya kwe-thematic kanye ne-triangulation. Imiphumela ikhombisa kutsi bantfu labasikati babukana netinhlobonhlobo temiva, kusukela kwekusaba kuye ekutiveni banelicala, kucindzeteleka, emahloni, kuphelelwa litsemba kanye nelusizi lwekwamukelwa. Imiphumela iphindze ikhombise kutsi ngenca yekucwaswa nekuhlukaniswa emphakatsini lokuhambisana nekuhlolelwa i-HIV, bavamise kugwema kudzalula kucilongwa kwabo, lokwandzisa bumetima benhlalo nebengcondvo, lokuvula indlela yekukhatsateka nekudzangala. Nanobe kunjalo, bantfu labasikati bayachubeka nekucina ngalesikhatsi babhekene nalobumatima, bemukele kucilongwa kwabo, kugcina kukhulumisana lokukhululekile, kuhlanganyela emikhubeni yangekwemoya kanye nayetenkolo, nekuphishekela ngelwati loluphatselene nekuphatfwa kwemphilo yabo nekuvimbela kudluliselwa lokucondzile. Lemiphumela inemitselela kubanikati betinsita tetemphilo kanye nakubakhi betinchubomgomo mayelana nekusebentisa kungenelela kuhlanganisa kwelulekwa, kwesekelwa kwetemphilo yengcondvo, kanye nemitfombolusito yemfundvo kute kuhlonyiswe bantfu labasikati labatfolakala bane-HIV kute bancobe tihibe tangakwemoya, tengcondvo, tetenhlalo, netemnotfo lababukana nato ngesikhatsi bakhulelwe futsi bagcine ematsemba ekuphila lamahle.

Emagama lamcoka: *I-HIV (Sandvulelangculazi), Kukhulelwa, Kudluliselwa Lokucondzle, Lokuhlangenwe nako, Bantfu labasikati, Eswatini.*

KGUTSUFATSO

Eswatini bakatjhane ba nang le lokwanahloko ya Human Immuno-deficiency Virus (HIV) ba tswelapele ho ba le mathata a ho boloka boleng ba bophelo bo lekaneng. Le hoja ditshebedisano tsa tlhokomelo ya bophelo di kenngwa ditsing tsa tlhokomelo ya bophelo ho fokotsa kotsi ya ho fetisetsa tshwaetso ho ya hodimo, ho utlwisisa mathata a ikgethang ao basadi ba tobaneng le ona nakong ya bokgatjane ho ka thusa ho ntlafatsa katleho ya mehato e reretsweng ho ntlafatsa bophelo bo botle ba bakgatjane ba nang le HIV. Thuto e ile ya hlahloba diphihlelo tse phetsweng ke bakgatjhane ba nang le HIV ho utlwisisa karabelo ya bona ya maikutlo le kelello tlhahlobong ya bona. Thuto e ile ya tswela pele ho hlwaya ditshitiso le menyetla eo basadi ba kopanang le yona kamora tlhahlobo ya bona ya HIV nakong ya boimana ba bona. Ho ile ha etswa thuto ya boleng ba boiphihlelo ba batho ba ketso e itseng, e nang le dintlha tse bokelletsweng ka dipuisano tse hlophisitsweng ho tswa ho basadi ba leshome ba fumanweng ba e-na le kokwanahloko ya HIV nakong ya bokgatjhane. Dintlha di ile tsa hlahlobjwa ho sebediswa tlhahlobo ya sehlooho le ya kgutlotharo. Diphumano di bontsha hore basadi ba ba le maikutlo a mangata, ho tloha tshabong ho ya ho ho ikutlwa molato, kgatello ya maikutlo, dihlong, ho hloka tshepo le maswabi ho isa ho kamohelo.Diphumano di boetse di bontsha hore ka lebaka la sekgobo le ho itshehla thajana ho amanang le tlhahlobo ya kokwanahloko ya HIV, ba atisa ho qoba ho senola tlhahlobo ya bona, e leng ho mpefatsang mathata a setjhaba le a maikutlo, ho bula tsela ya ho tshwenyeha le kgatello ya maikutlo. Leha ho le jwalo, basadi ba tswela pele ho mamella ha ba tobane le mathata ana, ba amohela tlhahlobo ya bona, ho boloka puisano e bulehileng, ho kopanela mekgweng ya moya le ya bodumedi, le ho phehella tsebo e mabapi le tsamaiso ya bophelo bo botle ba bona le ho thibela tshwaetso ya ho fetela hodimo. Diphumano tsena di na le moelelo ho bafani ba tlhokomelo ya bophelo le baetsi ba melao mabapi le ho kenya tshebetsong mehato e kenyelletsang boeletsi, tshehetso ya bophelo bo botle ba kelello, le disebediswa tsa thuto ho matlafatsa basadi ba fumanweng ba e na le HIV ho hlola ditshitiso tsa maikutlo, tsa kelello, tsa setjhaba le tsa muruo tseo ba tobanang le tsona nakong ya bokgatjhane le ho boloka ditebello tse ntle tsa bophelo.

***Mareo a bohlokwa**: HIV, bokgatjhane, Phetiso e Emeng, Diphihlelo, Basadi, Swatsing.*

ABBREVIATIONS

AIDS	Acquired Immuno-deficiency Syndrome
AGYW	Adolescent Girls and Young Women
ANC	Antenatal Care
ART	Antiretroviral Therapy
HIV	Human Immuno-deficiency Virus
MTCT	Mother To Child Transmission
PLWHA	People Living With HIV/AIDS
PMTCT	Prevention of Mother To Child Transmission
UNAIDS	The Joint United Nations Programme on HIV/AIDS
WHO	World Health Organization

CHAPTER 1

INTRODUCTION AND BACKGROUND

1.1 INTRODUCTION

HIV/AIDS is a global pandemic affecting millions of people worldwide, with sub-Saharan Africa, having a massive two-thirds of the global HIV population (Graybill et al., 2020). Women are disproportionately affected by HIV/AIDS accounting for more than half of the adults living with HIV and face higher rates of infection, morbidity, and mortality than men (Sia et al., 2020). Women are also more vulnerable to HIV infection during pregnancy, as they may face increased exposure to the virus through sexual intercourse, blood transfusions, or vertical transmission from mother-to-child. It is estimated that 1.4 million pregnant women were HIV-positive in 2019, and 82% of them were in sub-Saharan Africa (World Health Organization, 2023a). Receiving an HIV diagnosis during pregnancy can have profound and lasting effects on the women psychologically and socially. Pregnant women diagnosed HIV-positive may experience a range of emotional, psychological, social, and economic challenges, such as fear, anxiety, depression, stigma, discrimination, violence, poverty, and lack of healthcare interventions (Andersson et al., 2020; Anderson et al., 2010). These challenges may affect their physical and mental health, their adherence to antiretroviral therapy (ART), their delivery and post-partum care, their breastfeeding and infant feeding practices, their sexual and reproductive health, their marital and family relationships, as well as the health and development of their children (Jones et al., 2020). Understanding the unique experiences and needs of women who are diagnosed HIV-positive during pregnancy is crucial for developing and implementing effective interventions that can enhance their quality of life and prevent mother-to-child transmission (MTCT) of HIV.

1.2 DEFINITION OF TERMS

- **Experiences**

Experience is something personally encountered, undergone, or lived through (Merriam-Webster Dictionary, n.d.). For this study experience refers to what women diagnosed HIV-positive during pregnancy live through.

- **Women**

According to Oxford Dictionary (n.d), women refers to adult female human beings. For the purpose of this study a woman is a female human being diagnosed HIV positive during pregnancy.

- **Diagnosis**

Diagnosis is the process of determining the nature of a disease or disorder and distinguishing it from other possible conditions (Rakel, 2023). For this study, diagnosis refers to HIV diagnosis given during pregnancy.

- **HIV/AIDS**

Human immuno-deficiency virus (HIV), according to WHO (2020), is an infection that attacks the body's immune system, that is, the white blood cells called CD4 cells and it destroys these CD4 cells, compromising one's immunity against opportunistic infections. AIDS on the other hand stands for Acquired Immune Deficiency Syndrome (Dorrington, Johnson, Bradshaw & Daniel, 2006).

, 2006) and refers to the time when the immune system has been compromised with opportunistic infections and malignancies manifesting (Van Dyk, 2008). For this study, the terms HIV and AIDS will not be used interchangeably as they are not the same thing.

- **HIV Positive**

Testing positive for Human Immuno-deficiency antibodies warrants an HIV-positive diagnosis (Dorrington et al., 2006). This study focuses on women who were diagnosed as HIV-positive during pregnancy.

- **Pregnancy**

Pregnancy is the process and series of changes that take place in a woman's organs and tissues as a result of a developing foetus. The entire process from fertilisation to birth takes an average of 266.270 days or nine months" (Huffman, 2021). For this study, pregnancy refers to a woman who is carrying a developing foetus and delivering a baby.

1.3 BACKGROUND

HIV is the human immuno-deficiency virus responsible for killing and destroying cells of the body's immune system (Saha & Bhattacharya, 2019). The final progression or stage of HIV infection is referred to as the Acquired Immuno-Deficiency Syndrome (AIDS). HIV spreads in multiple ways; via unprotected sex with a person who is infected, by sharing drug needles as well as through contact with the blood of an infected person. Women are said to be eight times more at risk compared to men (World Health

Organization, 2020). Women are also more prone to HIV infection during vaginal sex, unlike men because of their physiological makeup in terms of transmission, HIV infection from a man to his heterosexual partner is twofold higher compared to that of an HIV-infected woman to her heterosexual partner (World Health Organization, 2020). Women infected with HIV often develop medical and physiological complications, like recurrent vaginal yeast infections, severe pelvic inflammatory disease, and have a higher risk for cervical cancer (Stelzle et al., 2021). Women with HIV present with higher rates of non-AIDS comorbidities than men with HIV (Pond et al., 2021).

They experience different side effects from the HIV treatment, as well as the risk of infecting their baby while pregnant, during childbirth, and when breastfeeding (Kore, 2021). More so, young women aged between 15 and 24 are at a greater risk of HIV/AIDS, and new infections among them are as twice as high compared to men the same age (UNAIDS, 2020). Physical, biological, economic, and cultural factors conspire to simultaneously increase the incidence of infection and delay diagnosis in HIV-infected women (Becker et al., 2020). Hence, most women test for the first time for HIV during pregnancy when it is a mandatory part of ANC, and that is how most learn of their positive status.

Eswatini is a small, landlocked country situated in Southern Africa and has a population of about 1.1 million people (World Bank, 2023). Eswatini ranks the highest in the world when it comes to HIV prevalence, with an estimated 27.3% of adults aged 15-49 living with HIV in 2019 (Ministry of Health, 2019). The first case of HIV in Eswatini was recorded in 1986 (Ministry of Health, 2019). Swazi women are significantly affected by HIV with a prevalence of 32% while in men its 20.4% among people aged 14 to 49 (Ministry of Health, 2019). In 2020 Eswatini had about 200,000 people with HIV and 62% of those were women and girls (Minnery et al., 2020).

The HIV incidence was remarkably reduced from 3.1% in 2012 to 1.36% in 2019 after the implementation of the test and treat, test and start initiative (Ministry of Health, 2019). The Kingdom of Eswatini has come a long way in the fight against HIV and AIDS; however, it remains among the leading countries in the world concerning the new number of infections (Ministry of Health, 2019). The government of the Kingdom of Eswatini (2018) reported that 120,000 women and 90,000 men are living with HIV. This discrepancy is likely because women endure greater economic and educational barriers than men, also women with HIV are more prone to stigmatisation and discrimination.

In Eswatini, like many other African nations, women have historically faced unequal social, cultural, economic, legal, and political treatment because of their gender as well as patriarchal norms to subordinate them (Mavundla, Strode & Essack, 2022). Patriarchy is inscribed in Eswatini law, and it accords women with a minority legal status (Wals et al., 2020). Women remain more vulnerable to HIV transmission due to various social, economic, cultural, and political factors that place them in subordinate positions. Predominantly, their position as a marginalised group and underrepresented in society predisposes them to domestic violence, gender-based violence, polygamy, and poverty (Wals et al., 2020). Disempowered and financially dependent women are more vulnerable to HIV since they may be forced to stay in abusive relationships or participate in prostitution to survive. In all forms of Swazi marriage, women lack control over their sexual and reproductive health. For instance, Swazi women cannot access family planning without the husband's consent, and some must obtain consent to undergo HIV testing (Wals et al., 2020).

Eswatini also has a high burden of HIV among pregnant women, with about 41.1% of antenatal clinic attendees testing positive for HIV in 2019 (Ministry of Health, 2019, Mbatha & Dube, 2021). Over the years, the Eswatini Government has demonstrated a strong commitment to preventing the spread of HIV among its population (World Health Organization, 2020). The high prevalence of HIV among pregnant women in Eswatini has attracted the attention of the government both domestically and internationally. The NGOs have shown an interest in lowering the rate of transmission from mother-to-child (Etoori et al., 2018). According to Mamba and Hlongwane (2018), Eswatini has rapidly adopted the mother-to-child transmission (PMTCT) Option B+ intervention, which recommends that all HIV-positive, pregnant and nursing women begin a lifetime of antiretroviral medication regardless of their CD4+ status. Pregnant women are among the most vulnerable population groups where care and interventions are needed to ensure that mother-to-child transmission is prevented. For instance, globally, 99% of HIV-positive and pregnant women reside in 22 nations, and Eswatini is among these nations; as a result, the country has prioritised the elimination of mother-to-child HIV transmission (Etoori et al., 2018).

Standard care in Eswatini requires that pregnant women routinely have their blood samples collected during antenatal care visits to screen for STIs and HIV (Wals et al., 2020). Hence, most women learn of their HIV status during pregnancy, and HIV is known as the worst devastating infection in pregnancy, with medical and ethical dilemmas (Graybill et al., 2020). For instance, if the woman refuses treatment upon diagnosis or does not adhere well to treatment, the unborn child is at high risk of getting HIV. Also, pregnancy alone compromises one’s immunity, and with an HIV diagnosis, women become high-risk. It is known that pregnancy may cause many psychological, physiological, and socio-economical complexities for the mother, requiring adaptation and adjustment (Feyissa, Harris, Melka & Loxton, 2019).

1.4 STATEMENT OF THE PROBLEM

In Eswatini, pregnant women with the Human Immuno-deficiency Virus (HIV) continue to navigate challenges to maintain an adequate quality of life. Receiving an HIV diagnosis during pregnancy can have profound and lasting effects on the women psychologically and socially, such as fear, anxiety, depression, stigma, discrimination, violence, poverty, and lack of healthcare interventions (Andersson et al., 2020, Muthoni et al., 2020). These challenges and gaps call for more research and action to understand and address the experiences and needs of women diagnosed HIV-positive during pregnancy in Eswatini and to improve their health outcomes, their relationships, and their children.

Although healthcare interventions are implemented at healthcare centres to reduce the risk of vertical transmission, understanding the unique challenges faced by women during their pregnancy remains under-researched. The existing literature on the experiences of pregnant women diagnosed HIV-positive who receive PMTCT intervention is limited. Therefore, this study offers valuable insights into this particular population, expressed by women who received the HIV diagnosis during pregnancy. This study explored the lived experiences of women diagnosed with HIV during pregnancy to understand the emotional and psychological response to their diagnosis. This study further extended to identifying the challenges and opportunities women face following their HIV diagnosis during their pregnancy.

1.5 THEORETICAL PERSPECTIVE

A feminist phenomenological approach is a way of doing philosophy that combines the insights and methods of feminism and phenomenology. Feminism is a movement and perspective that aims to challenge and transform the oppression and discrimination of women and other marginalised groups in society (Daly, 2019). Phenomenology is a branch of philosophy that studies the structures and meanings of human experience, especially as they are lived through the body and consciousness (Neubauer, Witkop & Varpio, 2019). The feminist phenomenological approach critiques the assumptions and biases of traditional phenomenology, which often ignores or misrepresents the experiences of women and other marginalised groups, and presents a universal and neutral account of human experience that is based on the male perspective (Daly, 2019). It uses phenomenological methods, such as description, reflection, and analysis, to explore and articulate the lived experiences of women and other marginalised groups and to reveal how they are shaped by social and historical factors, such as gender, race, class, sexuality, etc. (Cohen, Kassan, Wada & Suehn, 2022).

It challenges and transforms the dominant and oppressive structures and norms of society, such as patriarchy, sexism, racism, heteronormativity, etc., by exposing their effects on the experiences and identities of women and other marginalised groups. It also proposes alternative ways of thinking and acting that are more inclusive, diverse, and emancipatory (Butler, 2020). The feminist phenomenological approach explores topics such as the bodily experiences of women, like pregnancy, childbirth, menstruation, menopause, sexual violence, etc., and how they are influenced by cultural and medical discourses, practices, and expectations (Kosala, 2023). This approach is a valuable and innovative way of doing philosophy, as it combines the rigour and depth of phenomenology with the critical and transformative potential of feminism. It is a relevant and meaningful way of engaging with the world, as it aims to understand and improve the lives of women and other marginalised groups and to contribute to social justice and change (Daly, 2019).

The feminist phenomenological approach seeks to include women's experiences within the phenomenological investigation. Pregnancy and birth experiences are crucial in addressing the numerous ways in which masculine forms of embodiment are favoured in our ideas and actions (Shepherd & Marshall, 2019). According to Shabot (2021), phenomenology is feminist if it contains issues about gendered experiences and sexual differences within its area of study. The experiences of study participants must be regarded with attention, respect, and compassion. However, it should also be guarded with a critical eye; for instance, the disenfranchisement of pregnant women about mandated HIV testing if it is a helpful process for women, or if her right to voluntary testing is infringed? Feminist phenomenology employs a double booking, noting what participants say while simultaneously revealing what she does not or cannot say but which defines her discourse.

Phenomenology critiques the power structures present in academic disciplines and attempts to establish alternative methods of gathering data and communicating with study participants. Scientific knowledge creation and academic research techniques are questionable because they have been used to entrench the patriarchal status quo and as a weapon to exclude women from scientific ideas (Gilligan, 1982; Shabot, 2021)

Feminist research views itself as an instrument for women's empowerment, and its procedures and outcomes should directly improve the lives of study participants. Participants are treated with decency and respect and as experts in their own right. Feminist research seeks to build a unique voice for explaining and presenting their findings and it makes use of poetic approaches to depict the broad range of emotions that pervade their study settings (Simms & Stawarska, 2013). The hallmarks of feminist language practice in qualitative research include subtle, rich descriptions, enough leeway for the participants' voice, and awareness of the unspoken within what is stated (Simms & Stawarska, 2013). This study utilised a feminist phenomenological viewpoint and approaches to investigate the lived experiences of HIV-positive pregnant women to better understand and explain this phenomenon.

1.6 THE RESEARCH QUESTION

The main question guiding this study was:

What are the experiences of women diagnosed with HIV in Eswatini?

The sub questions of this study were:

- What are the emotional and psychological reactions and responses of women who are diagnosed with HIV during pregnancy in Eswatini?
- What are the social and economic challenges as well as opportunities encountered by women who are diagnosed with HIV during pregnancy in Eswatini?
- How does emotional, psychological, social, and economic challenges and opportunities that women who are diagnosed with HIV during pregnancy in Eswatini influence their physical and mental health?
- What are the best practices and strategies that can enhance the coping and wellbeing of women diagnosed with HIV during pregnancy in Eswatini?

1.7 RESEARCH AIM

This study aimed to provide a deeper and richer understanding of the lived experiences of women who are diagnosed with HIV during pregnancy in Eswatini.

The specific objectives of this study were:

- To explore and describe the emotional and psychological reactions and responses of women who are diagnosed with HIV during pregnancy in Eswatini.
- To explore and describe the social and economic challenges and opportunities that women who are diagnosed with HIV during pregnancy in Eswatini

encounter and experience.

- To examine how the emotional, psychological, social, and economic challenges and opportunities that women who are diagnosed with HIV during pregnancy in Eswatini influence their physical and mental health.
- To identify and recommend the best practices and strategies that can enhance the coping and wellbeing of women diagnosed with HIV during pregnancy in Eswatini.

1.8 DELIMITATIONS

The study only included women who were diagnosed with HIV during pregnancy in the Shiselweni region in Eswatini. It only recruited participants who were above age 19 due to ethical considerations and maturity to assert and express themselves freely.

1.9 SIGNIFICANCE OF THE STUDY

The study contributes to the existing literature and knowledge on the experiences and needs of women who are diagnosed with HIV during pregnancy, especially in the Eswatini context. It would also provide valuable insights and information for healthcare providers, policymakers, and other stakeholders who are involved in the design and delivery of HIV/AIDS and maternal and child health services and programmes. Furthermore, it would empower and support women who are diagnosed with HIV during pregnancy by giving them a voice and a platform to share their stories and perspectives.

1.10 STRUCTURE OF THE DISSERTATION

This dissertation is organised as follows: Chapter 2 provides a literature review that synthesises and evaluates the relevant sources that have been published on the topic of the experiences of women diagnosed with HIV during pregnancy. Chapter 3 describes the methodology that was used to conduct this study, including the research design, the data collection methods, the data analysis methods, and the ethical considerations. Chapter 4 presents the results of the data analysis and the themes that emerged from the interviews with the participants. Chapter 5 discusses the findings of the study and their implications, limitations, and contributions.

CHAPTER 2
LITERATURE REVIEW

2.1 INTRODUCTION

This chapter provides a review of the literature that is relevant to the topic of the experiences of women who are diagnosed with HIV during pregnancy in Eswatini. The literature review is divided into four main sections. The first section provides an overview of the epidemiology and the impact of HIV/AIDS in sub-Saharan Africa, with a focus on Eswatini. The second section discusses the challenges and opportunities that women who are diagnosed with HIV during pregnancy face in terms of their emotional, psychological, social, and economic wellbeing. The third section examines the effects of these challenges and opportunities on the health outcomes, the relationships, and the children of these women. The fourth section identifies the gaps and limitations in the existing literature and the research question and objectives of this study.

2.2 HIV PANDEMIC, WOMEN, AND ANTENATAL CARE

HIV/AIDS in sub-Saharan Africa and Eswatini is a global pandemic that has claimed millions of lives and caused immense human suffering and social and economic devastation. According to the Joint United Nations Programme on HIV/AIDS (UNAIDS), an estimated 38 million people were living with HIV in the world in 2019, of whom 25.7 million were in sub-Saharan Africa (UNAIDS, 2023). Sub-Saharan Africa is the most affected region in the world, accounting for 67% of the global HIV population and 70% of the global AIDS-related deaths in 2019 (Moyo et al., 2023). The HIV prevalence rate in people aged 15-49 in sub-Saharan Africa was 3.2% in 2022, compared to the global average of 0.7% in 2021 (World Bank, 2022; World Bank, 2021).

The HIV epidemic in sub-Saharan Africa is driven by multiple and interrelated factors, such as poverty, inequality, gender inequalities, cultural norms and values, stigma, discrimination, violence, mobility, and access to health care and education (Philip, King & Durham, 2023). Women are disproportionately affected by HIV/AIDS in sub-Saharan Africa, as they represent 59% of the adults living with HIV and face higher rates of infection, morbidity, and mortality than men (UNAIDS, 2023; Philip et al., 2023). Women are also more vulnerable to HIV infection during pregnancy, as they may face increased exposure to the virus through sexual intercourse, blood transfusions, or vertical transmission from mother-to-child (Muthoni et al., 2020). According to the WHO, an estimated 1.4 million pregnant women were living with HIV in 2019, and 82% of them were in sub-Saharan Africa (UNAIDS, 2023). Moreover, HIV-positive pregnant women have a higher risk of adverse pregnancy outcomes, such as miscarriage, stillbirth, preterm delivery, low birth weight, and congenital anomalies (Malaba et al., 2022).

They also have a higher risk of transmitting HIV to their infants during pregnancy, labour, delivery, or breastfeeding, unless they receive effective interventions to prevent MTCT of HIV (Graybill et al., 2020). It is estimated that 300,000 children were newly infected with HIV in 2020, and 89% of them were in sub-Saharan Africa (UNICEF, 2021). Without timely diagnosis and intervention, about half of the children who are born with HIV die before they turn two years old (Belachew, Tewabe, & Malede, 2020).

Eswatini is a small landlocked country in Southern Africa, with a population of about 1.1 million people (World Bank, 2023). Eswatini admittedly has the highest HIV prevalence rate in the world, with an estimated 32% of adults aged 18-49 living with HIV in 2022 (ICAP Global Health, 2022). Eswatini also has a high burden of HIV among pregnant women, with an estimated 41.1% of antenatal clinic attendees testing positive for HIV in 2019 (Dlamini, Ntuli & Madiba, 2021). The HIV epidemic in Eswatini is characterised by a generalised and mature pattern, with high and stable transmission rates across the population (Nkambule et al., 2021).

The main mode of HIV transmission in Eswatini is heterosexual intercourse, with multiple and concurrent sexual relations, low and inconsistent condom use, intergenerational sex, and transactional sex being the key drivers of the epidemic (Berner-Rodoreda et al., 2023). Other factors that contribute to the high HIV prevalence in Eswatini include poverty, gender inequality, cultural norms, stigma, discrimination, violence, low male circumcision, and limited access to health care and education (Golomski, 2023).

Eswatini has made significant progress in the response towards HIV/AIDS in the past decade, with the support of the government, and international partners. The country has adopted and implemented various policies and programmes to prevent, treat, and care for HIV/AIDS. Examples include the National Strategic Framework on HIV and AIDS 2018-2022, the National HIV Prevention Policy 2018, the National HIV Testing Services Policy and Guidelines 2016, the National ART Guidelines 2018, and the National PMTCT Guidelines 2018 (Minnery et al., 2020). Eswatini has also scaled up the provision and coverage of HIV testing, counselling, and treatment services, especially for pregnant women and children (ICAP Global Health, 2022). According to the World Health Organization, Eswatini had achieved the 95-95-95 targets for HIV testing, treatment, and viral suppression by 2019, becoming the first country in Africa to do so (World Health Organization, 2023b). The 95-95-95 targets simply mean that 95% of people living with HIV are aware of their status, 95% of those who are aware of their status are on treatment, and 95% of those on ART are undetectable and have a suppressed viral load (World Health Organization, 2023b). Eswatini has also reduced the MTCT rate from 4.1% in 2014 to 1.1% in 2019, reaching the elimination threshold of less than 5% (Nuwagaba-Biribonwoha et al., 2023). However, despite the remarkable achievements and efforts, Eswatini still faces many challenges and gaps in the response to HIV/AIDS, especially for HIV-positive pregnant women.

Many HIV-positive pregnant women still face barriers and challenges that limit their access to and uptake of HIV testing, counselling, and treatment services, such as stigma, discrimination, violence, poverty, lack of transport, long waiting times, stock-outs of drugs and supplies, and inadequate follow-up and retention (Becker et al., 2020). They also face difficulties and dilemmas in adhering to ART and PMTCT, such as side effects, drug resistance, disclosure, partner support, infant feeding, and family planning (Nkambule & Huang, 2023; Becker et al., 2020). The experience of a range of emotional, psychological, social, and economic challenges that affect their quality of life and wellbeing, such as fear, anxiety, depression, isolation, rejection, guilt, shame, and hopelessness is rife (Muthoni et al., 2020). These challenges and gaps call for more research and action to understand and address the experiences and needs of pregnant women who are HIV-positive in Eswatini and to improve their health outcomes, their relationships, and their children.

2.3 HIV MANAGEMENT IN PREGNANT WOMEN

Standard care in Eswatini requires that pregnant women routinely undergo screening for STIs and HIV (Wals et al., 2020). According to the World Health Organization (2016), HIV testing and counselling should be provided to all pregnant women as soon as possible during antenatal care (ANC) appointments, ideally during the very first visit. Whereas HIV testing is voluntary, it is mandatory in pregnant women (Olislagers et al., 2023). Testing pregnant women for HIV is an essential public health measure that can help prevent the transmission of the virus from a mother to her unborn child (Dlamini et al., 2021). Testing pregnant women has been the subject of a persistent and heated debate ever since HIV was first identified (Teasdale et al., 2020). It is essential to have a suppressed viral load throughout pregnancy and at the time of delivery to stop the transmission of HIV from mother to infant

(Penazzato et al., 2023).

It was reported by UNAIDS (2019) that in 2018, approximately 7,800 people in Eswatini became newly infected with HIV and of those newly infected individuals, 4,100 were women aged 15 and over, while the number of newly infected men was only 2,800. This indicates that women are more likely to acquire HIV than men, hence with HIV testing is an important component of antenatal care that aims to prevent the transmission of HIV from a mother to her child (Penazzato et al., 2023). Seemingly, this goal can be accomplished by testing pregnant women for HIV.

Vertical transmission of HIV from a mother to her infant is possible at any point during pregnancy, including during labour and delivery, as well as while breastfeeding (Ruff et al., 2023). If no preventative measures are taken, there is an approximate 15-45% chance of transmission (UNAIDS, 2021). This has led to the scaling up of the prevention of mother-to-child transmission (PMTCT), which serves as an essential entry point for the whole family to access HIV-related services (World Health Organization, 2023b).

In 2018, Eswatini saw the deadly effects of HIV in infants, and a national strategic plan was established to end AIDS and syphilis in children by eliminating the transmission of HIV and congenital syphilis between mother and child by the year 2023 (Eswatini Ministry of Health, 2018). This strategic plan also focused on the prevention of new infections among pregnant and lactating mothers, the prevention of unwanted pregnancies, and the promotion of diagnosis and effective management of HIV as well as syphilis in pregnant women and their male partners (Eswatini Ministry of Health, 2018). According to UNAIDS (2019), in 2018, less than 1,000 children between ages 0 and 14 were newly infected with HIV as compared to 1,300 in 2010; however, the number of pregnant women testing positive for HIV increased significantly from 64% in 2017 to 91% in 2018. In addition, the number of expectant women living with HIV on antiretroviral treatment (ART) was decreasing; it went down from 90% in 2016 to 79% in 2018, and this is detrimental not only to the unborn baby's development but the women's wellbeing too (UNAIDS, 2019).

The rate at which pregnant women attending ANC are testing positive for HIV in Eswatini is at a staggering 41.1%, while breastfeeding without supplementing during the first six months is at 32% among mothers living with HIV (Dlamini et al., 2021; Eccles, Du Toit & De Jongh, 2022). Exclusive breastfeeding is defined as feeding infants only breast milk without supplementation with liquids or solids (Dukuzumuremyi, Acheampong, Abesig & Luo, 2020). It is highly recommended that infants be exclusively breastfed for the first six months of life and breastfeeding is to be extended up until the second birthday or longer if possible (Perez-Escamilla, Buccini, Segura-Pérez & Piwoz, 2019). The rationale for advocating for breastfeeding is that it is said to be the most economical intervention for child survival as well as key in the prevention of about 13-15% of all child deaths in low-income countries (Ware et al., 2019). Mix feeding as opposed to exclusive breastfeeding in the first six months is risky as it is responsible for about 25-45% of mother-to-child transmission of HIV (Strehlau et al., 2019). The risk of MTCT in low-income countries like sub-Saharan Africa where breastfeeding is recommended among HIV-positive women varies from 25 to 40% (Dlamini et al., 2021). It is no wonder that a vast number of children infected with HIV acquired it from their HIV-positive mothers in utero while pregnant, at birth during delivery, or post-natal while breastfeeding (Eccles et al., 2022).

Interestingly, breastfeeding is hailed as one of the most effective child survival interventions, yet it is also one of the modes of HIV transmission to children, and this can be a dilemma for HIV-positive mothers (Reidy et al., 2019). This may explain why women living with HIV in high-income settings are recommended to avoid breastfeeding (Moseholm & Weis, 2020). The study conducted by Samburu et al., (2021) identified that exclusive breastfeeding reduces the risk of breast concerns regarding contraceptive effects and engorgement while providing mothers with feelings of satisfaction and a role in providing nourishment to the infant. Samburu et al. (2021) have further established that mothers also experience relief when infants are not diagnosed with HIV, but the intent for exclusive breastfeeding remains consistent irrespective of the risk of vertical transmission due to the lack of knowledge and counselling available for prenatal women with HIV.

2.4 THE PERSPECTIVES AND EXPERIENCES OF HIV-POSITIVE PREGNANT WOMEN

Women living with HIV exhibit reproductive desires that are similar to those of women who do not have the virus. According to Woldesenbet (2021), motherhood is commonly perceived as a positive experience, and the state of being pregnant is generally linked with a sense of regularity and a feeling of wholeness. The social and environmental context may be a crucial determinant of the pregnancy experiences and psychological wellbeing of women living with HIV (Dlamini et al., 2021). The study conducted by Carlsson-Lalloo, Mellgren, and Berg (2021) in Sweden highlights the importance of women living with HIV experiencing a sense of safety within themselves and in their interpersonal relationships. The qualitative research findings suggest that this aspect is critical for their overall wellbeing. This entails the existence of supportive relationships, such as those with healthcare providers who provide medical attention. How women who are afflicted with HIV communicate with their healthcare providers may have a notable impact on the quality of their pregnancy experience.

However, even with the increasing acceptance of pregnancy, the experience of motherhood for women living with HIV is associated with a distinct set of challenges during the prenatal period and post-partum phase (Graybill et al., 2020). Pregnant women who are living with HIV face unique challenges in addition to the typical adaptations that accompany motherhood, as they must learn to cope with additional sources of stress (Chilaka & Konje, 2021). The sources of stress that the mothers experience include their health, the ambiguity surrounding the infectious status of their new-borns, and the obligation to fulfil the specific needs of their infants, such as the dispensation of prophylactic medications (Schwartz et al., 2019). Furthermore, the state of being pregnant may exacerbate concerns regarding HIV disclosure, HIV-related stigma, and the possible adverse consequences of maternal HIV infection on offspring (Carlsson-Lalloo et al., 2021).

From 2013 to 2019, there was a collaboration between Medecins Sans Frontieres (MSF) and the Eswatini Ministry of Health to implement the Prevention of Mother-to-Child Transmission (PMTCT) Option B+ initiative. The 2020 research conducted by Medecins Sans Frontieres indicates that if left untreated, a significant proportion of children born to HIV-positive mothers, ranging from 25% to 40%, are at risk of contracting the virus (Medecins San Frontieres, 2020). In 2014, research conducted by USAID indicated that statistics provided by the Eswatini 2014 PMTCT showed an increment of 1% in the count of neonates and infants aged 6 to 8 weeks who were diagnosed with HIV (Mbatha & Dube, 2021). The significance of the report by the World Health Organization (WHO) in 2017 lies in the fact that it highlights the number of HIV-positive pregnant women who received antiretroviral therapy (ART) for the prevention of mother-to-child transmission (PTMCT). This includes the number of infants born to HIV-positive women who underwent virological testing within two months of birth, as well as the last mother-to-child transmission rate during the breastfeeding phase for those who received ART for PTMCT (Teasdale et al., 2020).

According to Mbatha and Dube (2021), the aforementioned development constitutes noteworthy progress in the pursuit of eradicating HIV from an entire cohort. According to UNAIDS (2021), by 2019, a cumulative number of 150,000 children who had been exposed to HIV but remained uninfected had benefited from the Prevention of Mother-to-Child Transmission (PMTCT) programme. Additionally, the programme had prevented 1800 new

HIV infections, while 10,433 pregnant women had received antiretroviral therapy (ARV) for PMTCT, achieving a coverage rate of over 95%.

Notwithstanding other public health concerns, HIV continues to be the most significant issue affecting the nation’s wellbeing. The effectiveness of the PMTCT Option B+ intervention is contingent upon the presence of functional public healthcare institutions, experienced community healthcare workers, and health education programmes. This is despite the limited knowledge available regarding the lives and experiences of HIV+ pregnant women (Dlamini et al., 2021). The objective of this research was to examine and elucidate the perspectives and encounters of expectant women who are HIV-positive concerning the Prevention of Mother-to-Child Transmission (PMTCT). The existing literature on the experiences of HIV-positive pregnant women who receive PMTCT intervention is limited. Therefore, this study offers valuable insights into this particular population. It is imperative to address the concerns expressed by HIV-positive pregnant women.

The outcomes of HIV-infected pregnant women in Africa are multifaceted and diverse, with a multitude of factors impacting their experiences. The prevalence of HIV in Africa poses a significant public health concern, particularly in sub-Saharan Africa, which is the region most severely impacted (Chipanta et al., 2022). As per the World Health Organization (WHO), a significant proportion of individuals diagnosed with HIV globally, amounting to approximately 82%, are located in sub-Saharan Africa (World Health Organization, 2023a). In the year 2020, the estimated number of individuals living with HIV in this region was 1.4 million (World Health Organization, 2023a). Expectant mothers are a population that is especially susceptible to contracting HIV and confront distinctive obstacles in the maintenance of their wellbeing and that of their babies (World Health Organization, 2021).

One of the primary obstacles encountered by expectant mothers with HIV in Africa pertains to the availability of healthcare services (Nkambule & Huang, 2023). Women residing in rural or underprivileged regions encounter restricted availability of healthcare amenities, thereby posing a challenge to their access to appropriate medical attention and support (Mavundla et al., 2022). According to research conducted by Khan et al. (2020), pregnant women residing in Eswatini rural regions were comparatively less likely to obtain antiretroviral therapy (ART) in contrast to their urban counterparts, despite the criticality of ART in averting mother-to-child transmission of HIV. Furthermore, the presence of stigmatisation and discrimination related to HIV can pose a challenge for expectant mothers seeking access to healthcare services, as they may harbour apprehensions about potential condemnation or maltreatment from healthcare practitioners (UN, 2019).

One of the challenges encountered by pregnant women who are HIV-positive in Africa is the potential for transmission of the virus from mother-to-child. In the absence of adequate medical intervention and attention, an estimated 30% of neonates delivered by HIV-positive mothers will contract the virus (Balis et al., 2022). Nonetheless, the implementation of antiretroviral therapy (ART) can significantly mitigate this hazard. According to a recent study carried out in Uganda, the utilisation of ART during pregnancy resulted in a significant reduction of 93% in the likelihood of mother-to-child transmission (USAID, 2021). Pregnant women diagnosed with HIV in Africa may encounter emotional and social obstacles in addition to the physical challenges that accompany the infection (Darteh, Abraham, Seidu, Chattu, & Yaya, 2021). The stigmatisation and discriminatory attitudes towards individuals living with HIV can result in their social isolation and exclusion, ultimately leading to adverse effects on their mental wellbeing (MacLean & Wetherall, 2021). Moreover, a considerable number of women encounter feelings of apprehension and distress concerning the wellbeing of their babies (Carlsson-Lalloo et al., 2021).

In Africa, notable advancement has been accomplished in terms of the prevention and management of HIV in recent times. WHO (2023b), advocates for the administration of antiretroviral ARTs to all pregnant women diagnosed with HIV as a preventive measure against mother-to-child transmission. Several African nations have made strides in enhancing the availability of ART to pregnant women. Notwithstanding, there remains a significant amount of work to be accomplished in guaranteeing that every pregnant woman living with HIV in Africa can obtain the requisite care and treatment, as per the World Health Organization (World Health Organization, 2022). Expectant mothers who are diagnosed with HIV in developing nations encounter distinct obstacles in comparison to their counterparts in developed nations (Belachew et al., 2020). The reduction of mother-to-child transmission of HIV has been the goal of the United Nations (2020) and World Health Organization (2019), which have emphasised the experiences of pregnant women living with HIV in developing nations. Access to ARTs poses a significant challenge for pregnant women with HIV in developing nations (Becker et al., 2020). Numerous developing nations face resource and infrastructure deficiencies that hinder their ability to offer ART to all expectant mothers who are HIV-positive (Kalungwe et al., 2022).

As per the United Nations report of 2020, it was found that in the year 2019, 82% of expectant mothers diagnosed with HIV in the sub-Saharan African region were administered

ART to avert the transmission of HIV from mother-to-child. This underscores the necessity for augmented resources and assistance to guarantee that every pregnant woman diagnosed with HIV can obtain ART. The issue of stigma and discrimination poses a considerable obstacle for expectant mothers living with HIV in developing nations (Arias-Colmenero et al., 2020). The apprehension of experiencing discrimination and social exclusion may dissuade certain pregnant women who are HIV-positive from pursuing testing and treatment (Arias-Colmenero et al., 2020). The prevalence of stigma and discrimination towards individuals who are living with HIV remains a substantial issue in numerous nations, particularly in developing countries (Abubakari et al., 2021). One of the challenges faced in certain developing countries pertains to insufficient awareness and knowledge regarding HIV among healthcare providers and pregnant women (Darteh et al., 2021). In numerous instances, women may lack knowledge of their HIV status until the onset of pregnancy, resulting in delayed ART initiation and heightened potential for vertical transmission (Teshale et al., 2022).

Furthermore, healthcare professionals in certain underdeveloped nations may possess inadequate training and insufficient resources to deliver suitable healthcare services to expectant mothers who are afflicted with HIV (Hlongwa, Mashamba-Thompson, Makhunga & Hlongwana, 2020). The United Nations and the World Health Organization have proposed a comprehensive strategy for the prevention and treatment of HIV among expectant mothers in developing nations in response to the obstacles posed by this issue (United Nations, 2020). The proposed measures entail augmenting the availability of antiretroviral therapy (ART) and furnishing assistance and guidance to tackle the issue of stigma and discrimination. This includes the enhancement of the consciousness and comprehension of HIV among expectant mothers and healthcare practitioners (Biomndo, Bergmann, Lahmann & Atwoli, 2021). In developing countries, the experiences of HIV-positive pregnant women underscore the necessity for sustained endeavours to enhance healthcare accessibility and diminish stigmatisation and prejudice.

2.5 HIV AND PSYCHOLOGICAL IMPACT ON PREGNANT WOMEN

Pregnant women who have been diagnosed with HIV encounter notable psychological obstacles, such as anxiety, fear, and depression. The diagnosis of HIV can elicit a distressing experience, particularly for pregnant women who are HIV- positive, who may harbour concerns regarding their health and that of their babies (Belachew et al., 2020, Finkelstein-Fox, Park & Kalichman, 2020). Moreover, the social disapproval and prejudice associated with HIV can adversely affect an individual's mental health (MacLean & Wetherall, 2021). Research has indicated that pregnant women who are diagnosed with HIV exhibit elevated levels of depression and anxiety in comparison to their HIV-negative counterparts (Abebe et al., 2022). Studies show that these levels of depression and anxiety increase as the pregnancy progresses (Psaros et al., 2020). The psychological ramifications of HIV infection during pregnancy may have an impact on the patient's adherence to ART and other facets of HIV management (Jones et al., 2020).

According to LeMasters et al. (2020), pregnant women who are HIV-positive and suffer from depression or anxiety may exhibit lower adherence to their treatment regimen, thereby elevating the risk of mother-to-child transmission of HIV. Studies show that group counselling sessions have a positive impact on the mental wellbeing of pregnant women with HIV and lead to a decrease in depression rates (Oshosen et al., 2021). The psychological welfare of expectant mothers who are HIV-positive is a crucial aspect to be taken into account in the provision of HIV care (Roberts et al., 2021). The provision of counselling and support services, coupled with interventions aimed at enhancing mental health, has the potential to enhance the outcomes of pregnant women living with HIV and their offspring (Osborn et al., 2022). Mental wellbeing is crucial for healthy gestation and fundamental for women's general wellbeing (Yousuf, Musa, Isa & Arifin, 2020). On the contrary, women living with HIV/AIDS endure stigmatisation and discrimination, which may cause emotional distress such as shame, isolation, self-hate, and guilt (MacLean, & Wetherall, 2021). "Stigma is a social process that marginalises and labels those who are different, and discrimination refers to the negative practices that stem from stigma" (Kim, Ahn, Hu & Peterson, 2023, p. 130). Stigma and discrimination can be real or perceived. Perceived stigma accounts for the shame associated with the illness, and actual stigma is a real experience of discrimination (Andersson et al., 2020). Even though stigma can be perceived, a majority of people living with HIV experience it (Roberts et al., 2021).

LeMasters et al. (2020) have inferred those pregnant women living with HIV endure psychological conditions like depression and suicidal ideations exacerbated by the stigma they experience. Also, it is stigmatised because it is associated with unacceptable behaviours such as homosexuality, promiscuity, and the use of intravenous drugs (World Health Organization, 2016). People who get infected with HIV are assumed to have engaged in these behaviours and are shunned and isolated. A lot of people living with HIV have not experienced stigma and discrimination first-hand but do not disclose it for fear of it, preventing them from receiving support and healthcare interventions (Psaros et al., 2020). Yet stigma remains a major problem, causing fear in the lives of people living with HIV. Stigma and discrimination prevent people living with HIV from getting the support they need causing psychological and physical distress (Moran et al., 2022).

It is important to bring to light the psycho-social implications of pregnancy in women diagnosed with HIV. One's psychological state and behaviour play a significant role in negotiating ill health; for instance, chronic distress, loneliness, depression, and social isolation impact the susceptibility or defence from certain diseases, suggesting their negative consequences on the mental and physical wellbeing of individuals (MacLean & Wetherall, 2021). It has been implied that pregnant women diagnosed with HIV tend to experience conflicted emotions in that they are living with an incurable disease, which is most likely to end in death, while they are carrying new life in them (Miller et al., 2021).

Chilaka and Konje (2021) indicate that pregnancy and positive serology are challenging emotional tasks because of these simultaneous feelings of life and death in the mind of the mother. Dadhwal et al., (2017) indicate that for the pregnant woman, recognising herself as infected by the virus implies the need to redefine the value of her own life and that of the foetus being generated, as well as the meanings of interpersonal relationships. Earnshaw et al. (2020) state that women suffer intense psychological impacts upon receiving an HIV diagnosis during pregnancy. Oshosen et al. (2021) determined that when the discovery of the pregnancy coincides with the diagnosis of the infection, the pregnancy becomes emotionally unstable. Financial instability remains a consequence of social constructions on contamination, marked by discrimination and stigmatisation (Toska, Laurenzi, Roberts, Cluver & Sherr, 2020). According to Woldesenbet et al. (2021), the intense fear that women experience is related to the disease's contagion and the life of the child.

Psychological disorders may be a common experience for people living with HIV. Adjustment disorders, sleep disturbances, anxiety, depression, sex difficulties, suicidal ideations, and appetite changes are common, especially after a diagnosis of HIV (Roberts et., 2022). Depressive disorders are said to be common among people living with HIV and are often unrecognised (Earnshaw et al., 2020; MacLean & Wetherall, 2021). Depression following an HIV diagnosis is common and a normal reaction; it may be short-term or long-term depending on intervention measures (Lofgren et al., 2020; MacLean & Wetherall, 2021). Depression impacts adherence to therapy and continuation with therapy, and this negatively affects the progression of the disease and mortality (AIDS Alliance, 2003; Kontomalonis, 2017). Several studies show increased rates of suicidal ideation, attempts, and contemplation among people living with HIV (Pelton et al., 2021). Depression, when not treated, may increase medical expenses, cause substance abuse and risky behaviour and poor adherence to treatment and quality of life (Valente, 2003; Angelino, 2002; Hodgson et al., 2014; Kontomanolis, Michalopoulos, Gkasdaris & Fasoulakis, 2017).

Anxiety is usually experienced upon receiving an HIV diagnosis (Yousuf et al., 2020). When negotiating HIV-related stressors, bouts of anxiety are considered to be normal (Garrido- Hernansaiz & Alonso- Tapia, 2020). However, if symptoms persist, treatment becomes necessary. Also, people living with HIV are said to experience grief over the loss of partners and family members as well as parts of themselves such as body image (Cavazos-Rehg et al., 2020).

2.6 HIV AND SOCIAL FACTORS

The transmission of HIV is significantly influenced by a variety of social variables. Several societal factors exacerbate the risk of HIV infection, mainly poverty, lack of education, gender inequality, and stigma (Ncitakalo, Mabaso, Joska & Simbayi, 2021). Notably, one of the most significant societal factors that play a role in the transmission of HIV is poverty. Living in poverty makes it more difficult to obtain healthcare, education, and fundamental resources such as clean water and cleanliness, which can raise the probability of contracting HIV (Obeagu, Alum & Obeagu, 2023). Due to the difficulty of their financial situation, poor individuals may also have a higher propensity to participate in high-risk behaviour such as transactional sex (Wal et al., 2021).

Inadequate education is another social element that contributes to an increased likelihood of contracting HIV (Worku, Tesema & Teshale, 2021). According to UNAIDS (2018), people who have lower levels of education may have limited information about the transmission of HIV and prevention strategies, which can lead to a higher risk of infection. It is also possible that they do not have the skills needed to negotiate safe sexual practices or obtain medical services. Inequality between males and females is another social element that is likely to contribute to the proliferation of HIV. Nearly 66% of all new HIV infections are found in women in sub-Saharan Africa, which demonstrates that women are disproportionately impacted by the virus (UNAIDS, 2021).

According to Obeagu et al. (2023), an individual’s susceptibility to HIV infection is determined by the degree to which they have complete control over the many aspects of their sexual lives. According to Abubakari et al. (2021), culture exerts an influence not only on aspects such as family relationships, social support, legal frameworks, and governmental structures but also psychological and biological aspects. HIV-positive women are frequently subjected to shame, humiliation, and discrimination from society, particularly regarding their ability to have children (Kontomanolis et al., 2017).

2.7 HIV AND CULTURAL FACTORS

Culture is one of the many factors that influence human behaviour; not only does it determine what kinds of behaviours are socially acceptable, but it also values systems, beliefs, and the practical information that people have (Amodu, Richter & Salami, 2020). According to UNAIDS (2005), the inability of women to take responsibility for their sexual lives, for instance in negotiating the timing of sex, conditions under which it happens as well as condom usage makes them prone to HIV infection. According to Ballard, Davis and Hoffner (2021), culture has an effect not only on the social embeddedness of individuals, such as their family relationships, social support, governmental structures, and legal systems but also on their psychological and biological states.

According to Abubakari et al. (2021), the stigma that surrounds HIV in many African communities can prevent women from accessing testing and treatment. On the other hand, Sullivan et al. (2020) note that societal taboos surrounding sex may discourage women from openly discussing sexual health. According to Karver et al. (2022), gender inequality in African societies can increase women's vulnerability to HIV infection. These researchers describe how societal norms and beliefs frequently place women in a subordinate position to males. Additionally, gender inequality in African societies can increase women's vulnerability to HIV infection. According to Mihretie et al. (2023), who highlights how women may engage in transactional sex to provide for themselves and their families, this can be exacerbated by economic dependency. These authors highlight how women may engage in transactional sex just to support themselves and their families.

2.8 SOCIAL SUPPORT

Research shows the significance of social support in improving positive coping (Kontomanolis et al., 2017). Women who lack social support or fear stigmatisation are likely to be in denial and not seek knowledge on prevention and treatment nor deal with risky behaviours (AIDS Alert, 2001; Kontomalonis, 2017). When women are in denial, they do not share their status with partners, friends, or family and place themselves and others at risk (Ataro, Mengesha, Abrham

& Digaffe, 2020). Social support is linked to emotional and mental wellness for people living with HIV and alleviates stress and depression (Kontomanolis et al., 2017). Keeping one's HIV status to oneself leads to a life without support but one is prone to isolation, depression, and loneliness (Mackworth-Young, Bond & Wringe, 2020). This means that women who keep their status from family and friends are more likely to succumb to emotional distress. Griswold and Pagano-Therrien, (2020) substantiate those emotional responses play a significant role in a patient's adherence to treatment, prioritisation of self-care and quality of life. For instance, more studies show how positive attitudes improve one's quality of life and how lack of support is linked to stress which has been shown to negatively impact one's immune system (Kontomanolis et al., 2017). This shows how social support buffers the effects of both psychological and physical distress and how it is key to optimising adherence to treatment and medical care (Kontomanolis et al., 2017). Furthermore, HIV-positive mothers who did not disclose their status to their families, in-laws, or partners were found to have challenges with exclusive breastfeeding in the first 6 months of life and were pressured to mix-feed (Griswold & Pagano-Therrien, 2020).

2.9 THE FEMINIST PHENOMENOLOGICAL PERSPECTIVE

In investigating the impact of HIV on women, it was imperative to have a theoretical framework that functions as a foundation and guide to examine how a positive HIV diagnosis in pregnancy may influence the wellbeing of women. For this study, the feminist phenomenological approach was used. The feminist phenomenological perspective emphasizes philosophical accounts of women's experiences and the world as perceived by women themselves (Butler, 2020). According to Loick (2020), disregarding women's accounts of their bodies has important implications for philosophical reflection since it leads to biased interpretations of women's conduct and sexual interactions. This restricts our knowledge of the extent and impact of social and cultural environments on individuals' subjective experiences, with the organisation of human experience.

Phenomenological feminism prioritises the impact of social and cultural environments on individuals' subjective experiences, with a particular focus on the experiences of women (Cohen et al., 2022). Taking a phenomenological feminist approach, it is imperative to prioritise the perspectives and voices of women who have been diagnosed with HIV during pregnancy to gain insight into the distinct obstacles they encounter. This perspective acknowledges that the encounters of these women are not ubiquitous and cannot be comprehensively comprehended solely through medical or scientific investigation. The approach underscores the importance of considering social and cultural factors, such as stigma and discrimination that influence individuals' experiences (Jolle, 2022). When viewed through a phenomenological feminist lens, the experiences of pregnant women with HIV are influenced by various intersecting systems of oppression, such as sexism, racism, and HIV-related stigma. The HIV-positive status of pregnant women may lead to discrimination and marginalisation, thereby compounding the difficulties associated with pregnancy and motherhood (Karver et al., 2022). Moreover, their experiences are further shaped by factors such as gender, ethnicity, socioeconomic status, and other societal affiliations.

Additionally, power disparities and societal dynamics are significant contributors to the spread of HIV among women (Closson et al., 2022). The entrenched social norms and traditional perpetuate gender power imbalances influencing HIV transmission. Wamoyi et al., (2021) argue that men still enjoy greater power than women, which is perpetuated by societal institutions and gender-based practices. These norms also shape the extent and manner in which men engage in ANC (Muloongo, et al., 2019). Traditionally, men's roles in ANC have been limited to providing financial support and making decisions related to the pregnancy. They perceive ANC as a woman's domain (Muloongo, et al., 2019). Barriers to male involvement in ANC include work commitments, fear of HIV testing, and the belief that their presence may interfere with care (Muloongo, et al., 2019). Addressing these social norms and barriers through community education and policy changes is essential for enhancing male involvement in maternal and child health services, which can significantly benefit the well-being of mothers and children.

The phenomenological feminist perspective on the men's role in ANC highlights the need to understand and address the social and cultural constructs that limit male involvement while also recognizing the positive impact that supportive male participation can have on the health and well-being of mothers and children (Wamoyi et al., 2021).

From a feminist phenomenological perspective, the interactions among gender power dynamics, HIV, and pregnancy, particularly in the context of mother-to-child transmission (MTCT), are intricately linked to the lived experiences of women (Cohen et al., 2022). These experiences, shaped by societal structures and norms, influence women's ability to make autonomous decisions regarding their sexual and reproductive health (Karver et al., 2022). This methodology affirms the importance of considering how societal norms and expectations during pregnancy may limit women's access to HIV prevention and treatment services, thus impacting MTCT risks. Another key aspect of the feminist phenomenological perspective is the emphasis on women's agency and empowerment (Cohen et al., 2022). It would investigate how women can exert power and control over their health and well-being, despite the constraints imposed by gender power dynamics. This includes exploring strategies that women use to subvert these dynamics and protect themselves and their children from HIV.

A phenomenological feminist approach prioritizes the experiences and viewpoints of HIV-positive pregnant women, to comprehend their distinct needs and obstacles. This approach involves engaging in dialogue with expectant women who are HIV-positive to gain insights into their encounters. Additionally, it involves addressing the societal and cultural factors that foster stigmatisation and prejudice toward individuals living with HIV, as suggested by Butler (2020). Overall, a phenomenological feminist perspective concerning pregnant women diagnosed with HIV emphasizes the significance of the voices and experiences of these women. This approach aims to achieve a more comprehensive comprehension of their requirements and difficulties and to strive towards establishing more impartial and encouraging healthcare systems for pregnant women diagnosed with HIV. This methodology acknowledges the multifaceted aspect of HIV-associated stigma and prejudice, considering variables such as ethnicity, socioeconomic status, and gender expression that may intensify the encounters of women diagnosed HIV-positive during pregnancy.

By prioritizing the viewpoints of these women and acknowledging the existence of structural disparities, we can strive towards providing more empathetic and efficient healthcare services to all individuals impacted by HIV. This study purposed to provide a deeper and richer understanding of the lived experiences of these women and to identify the factors that influence their coping and wellbeing. This comprehensive approach helps illuminate the nuanced ways in which gender, power dynamics, HIV and pregnancy interact, revealing the broader impact of these factors on the health and wellness of women facing an HIV diagnosis during this critical period of their lives.

2.10 SUMMARY

This chapter reviewed literature that was relevant to the topic of the experiences of women who are diagnosed with HIV during pregnancy. HIV/AIDS presents several concerns and considerations to pregnant women, their partners, families, and healthcare workers during pregnancy. An overview of the epidemiology and the impact of HIV/AIDS in sub-Saharan Africa, with a focus on Eswatini, was discussed in detail. The literature shows that women who are diagnosed with HIV during pregnancy face various emotional, psychological, social, and economic challenges. This study has employed qualitative methods to provide a deeper and richer understanding of the lived experiences of these women and to identify and recommend best practices for better HIV care of pregnant women. The following chapter will focus on the research methodology.

CHAPTER 3
RESEARCH METHODOLOGY

3.1 INTRODUCTION

This chapter describes the research process in detail. The research methodology, design, and phenomenological perspective chosen for this study are presented in detail. The context of the study, the target population, the data collection methods, and the data analysis methods are also discussed. Lastly, the chapter concludes with the ethical considerations applied in the execution of this study and the measures taken to ensure the integrity of the research findings.

3.2 THE RESEARCH QUESTION

The main question guiding this study was:

What are the experiences of women diagnosed with HIV in Eswatini?

The sub questions of this study were:

- What are the emotional and psychological reactions and responses of women who are diagnosed with HIV during pregnancy in Eswatini?
- What are the social and economic challenges as well as opportunities encountered by women who are diagnosed with HIV during pregnancy in Eswatini?
- How does emotional, psychological, social, and economic challenges and opportunities that women who are diagnosed with HIV during pregnancy in Eswatini influence their physical and mental health?
- What are the best practices and strategies that can enhance the coping and wellbeing of women diagnosed with HIV during pregnancy in Eswatini?

Research Aim

This study aimed to provide a deeper and richer understanding of the lived experiences of women who are diagnosed with HIV during pregnancy in Eswatini. The specific objectives of this study were:

- To explore and describe the emotional and psychological reactions and responses of women who are diagnosed with HIV during pregnancy in Eswatini.

- To explore and describe the social and economic challenges and opportunities that women who are diagnosed with HIV during pregnancy in Eswatini encounter and experience.
- To examine how the emotional, psychological, social, and economic challenges and opportunities that women who are diagnosed with HIV during pregnancy in Eswatini influence their physical and mental health,
- To identify and recommend the best practices and strategies that can enhance the coping and wellbeing of women diagnosed with HIV during pregnancy in Eswatini.

3.3 RESEARCH METHODS

According to Gray (2021), qualitative research is typically employed when investigating phenomena that are unclear, or not well understood. This study used qualitative research to address the predetermined research objectives. This was because qualitative research gives a holistic perspective by describing a social phenomenon as it occurs naturally (Busetto, Wick & Gumbinger, 2020). Furthermore, the chapter presents narrative responses to interview questions allowing for multiple interpretations and analyses (Tavory, 2020). The core of qualitative research is investigating, describing and interpreting the social phenomena as experienced by participants (Adeoye-Olatunde & Olenik, 2021). This approach emphasizes expression and narration using words, hence the collection of data in the form of verbal accounts such as interviews or written reports (LaDonna, Artino & Balmer, 2021).

The data of this study was obtained through conducting interviews using semi-structured questions that enabled free expressions and gained rich descriptions of the lived experiences of the participants. The topic of pregnancy and HIV diagnosis demands a sensitive and empathic researcher, one who can focus while dwelling on the accounts given by the participants. I conducted the interviews, paying attention to establishing rapport and showing empathy. I made sure to set aside personal beliefs and assumptions to reduce the risk of personal bias allowing full exploration of the phenomenon as experienced by the research participants. I was mindful to pay attention to participants' narration while seeking clarification of what participants were describing without assuming meaning when describing a particular phenomenon. It is worth noting that there are many approaches within the realm of qualitative research (Adeoye-Olatunde & Olenik, 2021), nevertheless, the feminist phenomenological framework was the most befitting for this study due to its nature.

3.4 RESEARCH DESIGN

A research design refers to a plan determining the data collection and analysis processes of a study. Generally, a research design guides the researcher in participant selection and the research site in a way that enhances the answering of the research questions guiding the study (Paradis, O'Brien, Nimmon, Bandiera & Martimianakis, 2016). Sidharth (2023) suggests that a research design is often based on a research topic, research questions, research objectives, and the research methodology. Given that the research methodology chosen for this study was qualitative, a phenomenological research design was used. Phenomenology is a qualitative research design that focuses on commonalities and differences in individuals' lived experiences within a particular group with a set of characteristics (Tomaszewski, Zarestky & Gonzalez, 2020). Phenomenology seeks to explore and define the essence of phenomena by exploring how individuals experience them. This is done by exploring individuals' feelings, beliefs, and perceptions regarding their lived experiences (Patočka, 2019). A qualitative phenomenological approach enabled me to explore and articulate the lived experiences of pregnant women living with HIV and AIDS.

Furthermore, phenomenology defines and explores the essence of a phenomenon by embarking on a detailed exploration of the meanings that individuals have attached to it. This approach focuses on people's lived descriptions of their lived experiences and prioritises their conscious and unconscious understandings of these experiences (Kozyreva, 2018). Thus, the aim is to link the person with their lived experience by focusing on their memories, motivations, meanings, thoughts, and emotions, thereby understanding how people construct meanings and attach them to their realities (Rasid, 2021). A qualitative phenomenological research design was appropriate for this study because it enabled me to describe and interpret the lived experiences of the participants and to capture the essence and complexity of their phenomenon.

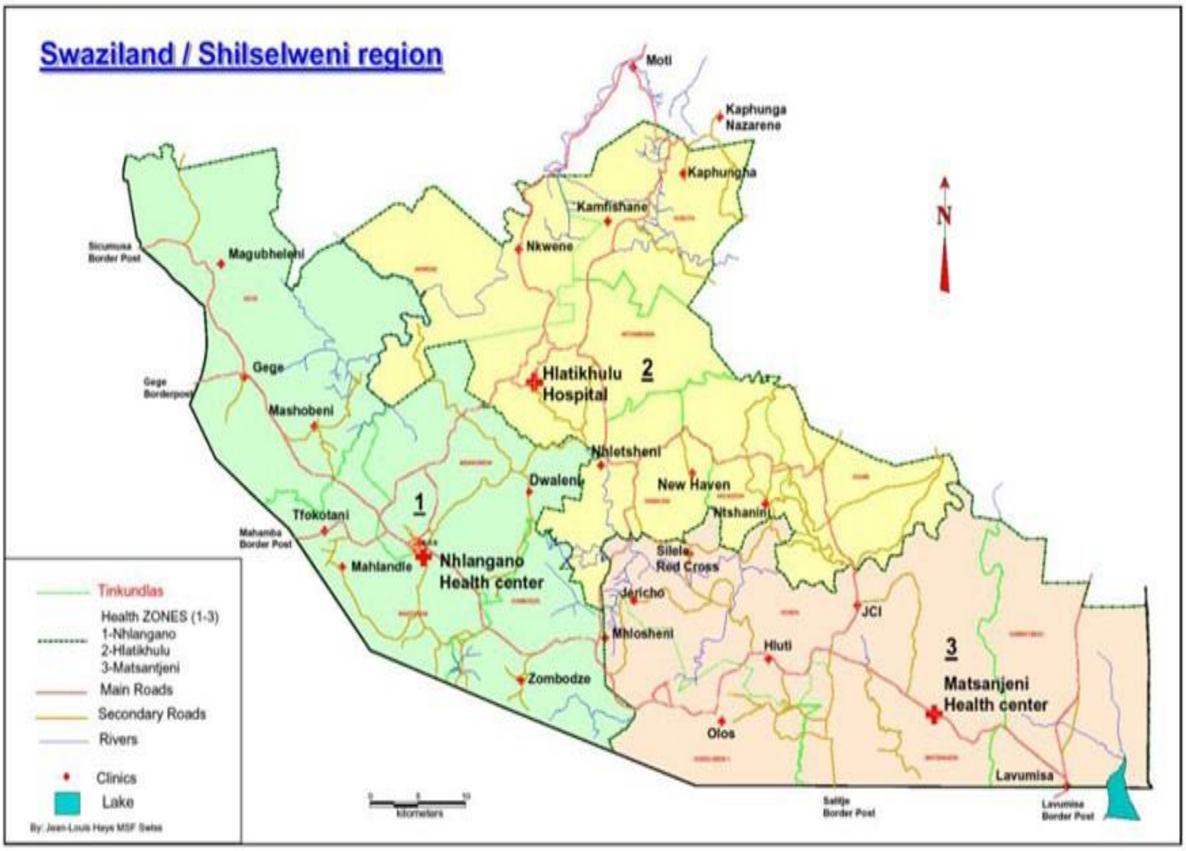
Phenomenological research has two primary approaches, descriptive and interpretive. Descriptive Phenomenology, founded by Edmund Husserl, aims to capture the essence of experiences as they are directly lived through a process called 'epoché,' where biases and preconceptions are set aside to view phenomena in their purest form (Thomas & Sohn, 2023). This approach focuses on participants' descriptions to uncover the universal nature of experiences without interpretation. In contrast, Interpretive Phenomenology, developed by

Martin Heidegger, goes beyond mere description to interpret the deeper meanings behind human experiences, acknowledging the influence of historical and cultural contexts (Emery & Anderman, 2020). In this study, Interpretative Phenomenology was employed to explore the experiences of women diagnosed with HIV during pregnancy, particularly examining the emotional, psychological, social, and economic challenges they face in Eswatini and the impact on their health outcomes, relationships, and children. Additionally, feminist phenomenology was integrated to highlight the gendered nature of these experiences, encouraging a critical examination of gender inequalities and their roots in socioeconomic and political contexts (Simms & Stawarska, 2013; Weiss, 2021).

3.5 RESEARCH SETTING

This study was conducted in the primary health care facilities in the Nhlangano Zone found in the Shiselweni region of Eswatini. Shiselweni is one of the regions in Swaziland seriously affected by the pandemic, causing several losses of lives. It is situated in the south of the country, covering an area of 3,786.71 km² and a population of 204,111, and is divided into 14 Tinkhundla (Shiselweni Region, 2017). Its administrative centre is Nhlangano and borders Lubombo in the northeast and Manzini Region in the northwest (Shiselweni Region, 2017). According to Walker et al. (2020), Shiselweni is one of the regions critically affected by HIV/AIDS in the Kingdom of Eswatini, with a prevalence rate of 25.9%. The health care facilities in the Shiselweni region offer women and children ANC and HTC services, hence befitting a location for this study. This study sought to explore in-depth, the experiences of women diagnosed HIV-positive during pregnancy. The Shiselweni region consists of three zones, namely Matsanjeni, Hlathikhulu, and Nhlangano. There are about nine primary clinics in the Nhlangano Zone, namely Magubheleni, Gege, Mahlandle, Tfokotani, SOS, Zombodze, Mkhitsini, FTM, and Dwaleni. HIV testing and counselling, as well as treatment, takes place in all these clinics.

Figure 3: Clinics in the Shiselweni region/Eswatini



Source: Turashvili et al., 2014

3.6 TARGET POPULATION AND SAMPLE

Population refers to a defined set of elements that the researcher utilised to accomplish their practical project. The entities in question could potentially be either inanimate objects or individuals. This action was being implemented to ensure equitable outcomes in the final analysis. Stratton (2022) defines population as the group or collection of individuals that a researcher aims to generalise about. Stratton (2022) further asserts that a research population refers to the complete collection of cases from which a sample is selected.

The study's population consisted of women who were aged 19 and 35 years. The study employed a qualitative approach using a phenomenological design, utilising interviews as the primary data collection tool. The participants were selected from the nine primary clinics located in the Nhlangano zone of the Shiselweni region in Eswatini. These clinics were specifically designated for women to undergo HIV testing and receive monthly treatment.

3.6.1 Sampling Criteria

The sampling strategy of this study was purposive sampling, which is a type of non-probability sampling involving the selection of participants based on specific criteria and characteristics that were significant to the research questions and objectives. Purposive sampling enriched the study as it allowed me to identify and select information rich sources who were able to explain the issues under investigation (Aspers and Corte, 2019). The sampling criteria for this study were:

- The participants had to be women who were diagnosed with HIV during pregnancy in Eswatini.
- The participants were aged between 19 and 35 years.
- The participants had to have participated in the PMTCT programme in Eswatini.
- It had to be women who could express themselves well in their preferred language.

The sample size for this study was ten participants, which was considered adequate for a qualitative study with a phenomenological research design. The sample size was determined by the principle of data saturation, which meant that the data collection and analysis continued until no new or relevant information was obtained from the participants. I analysed the data collected from the participants in a continuous manner and starting from the eighth up to the tenth interview. No new information emerged from the interviews and I stopped data collection.

The participants for this study were recruited through collaboration and assistance by the healthcare workers at the antenatal clinics and the community health centres in Eswatini. I obtained permission and the consent of the regional health office to access and contact the potential participants who met the sampling criteria. I also explained the purpose and the procedures of the study to the potential participants and invited them to participate. I informed the potential participants about the voluntary and confidential nature of the study and the potential benefits and risks of participating in the study. Informed written consent from the participants who agreed to participate in the study was obtained.

3.6.2 Characteristics of Sample Group

The study’s participants were from four of the nine clinics, specifically Magubheleni (1), Gege (5), Mahlandle (3), and Dwaleni. (1). Out of the total of 15 participants, only 10 individuals attended the scheduled interviews. Upon provision of study details and satisfactory resolution of participant inquiries, those who remained interested in participating were presented with a consent form. Following this, interviews were arranged and executed using a voice recording device with prior permission given. The study participants used isiSwati, which was their native tongue and the language in which they felt most at ease, as their primary language of communication.

3.7 DATA COLLECTION

The data collection instrument for this study was an interview guide which is Appendix C of this dissertation. The interview guide is a list of open-ended questions and prompts that are designed to elicit the experiences and perspectives of the participants on the research topic. The interview guide was based on the research questions, objectives of the study, and literature review. The interview guide was also flexible and adaptable to allow me to investigate the emerging themes and issues during the interviews. The interviews were carried out in the clinics in a private room used for counselling. I ensured that the interviews were conducted in a private and quiet setting to ensure confidentiality and the comfort of the participants.

I engaged in building rapport and trust with the participants before and during the interviews to encourage them to share their experiences and feelings openly and honestly. I adhered to the interview guide to guide the conversation and to ask the questions and prompts that were relevant to the research topic. I also used probing and follow-up questions to elicit more details and clarifications from the participants. The interviews were recorded with the permission of the participants using a digital voice recorder, and I also took notes during the interviews to capture the key points and the non-verbal cues of the participants. The interviews lasted for about ±30 minutes each.

Before the interview, the interviewees' consent was attained. Additionally, all pertinent information was conveyed to the interviewees in a comprehensible language. (Please refer to Appendix B). The interview was carried out in siSwati and then transcribed and translated into English. Semi-structured questions facilitated the discovery of novel dimensions of the issue at hand through a thorough examination of the participants' accounts. The interviews were scheduled to take place at the nine primary clinics located in the Nhlangano Zone, situated in the Shiselweni Region of Eswatini. These are primary healthcare facilities where HIV testing and counselling services were provided, as well as where individuals living with HIV received their antiretroviral therapy (ART). The implementation of an interview schedule facilitated the direction of the interviews. Pseudonyms were assigned to every participant to guarantee the confidentiality of participants. Adeoye-Olatunde and Olenik (2021), assert that semi-structured interviews are a useful method of obtaining a comprehensive understanding of a participant's beliefs, perceptions, or interpretations of a specific topic.

3.7.1 Researcher reflexivity

According to Janis (2022), reflexivity is a continuous process in which researchers reflect on their own preconceived values and those of their participants. This particularly considers how the participants' perceptions of the researcher may influence the data collected. Nicholls (2017) emphasize the necessity for researchers to reflect on their actions, feelings, and conflicts experienced during research to ensure the credibility of the study.

Being from Eswatini, a country with one of the highest HIV prevalence rates globally, I developed a keen academic interest in HIV, pregnancy, and women's health. This interest is coupled with a motivation to contribute new knowledge to these fields and a curiosity about the psychosocial, physical, and medical aspects of women's health. Also, this study serves as a platform to further my education and professional development while exploring the intersection of pregnancy and HIV diagnosis.

Baldwin et al. (2022) note that personal beliefs, values, and emotions can introduce bias, affecting how data is collected, analysed, and interpreted. To counteract this, I maintained a journal to reflect on my influence over the research process, helping to mitigate bias and maintain some level of objectivity. This practice of reflexivity was crucial for approaching the research without a preconceived attachment to any specific theory or outcome, fostering a non-judgmental and open-minded exploration of the data.

Positionality was crucial in establishing trust and rapport with participants, disclosure that I am a psychologist in training might have influenced participants’ expectations and openness in sharing their life stories. I also arranged for psychological support for participants needing intervention, offering referrals to a regional psychologist.

Epoche which refers to the suspension of judgements about the natural world to focus on the structure of experience while bracketing is the process of setting aside preconceptions and biases to engage with the phenomena as they present themselves, as described by Thomas and Sohn (2023), helped me to suspend judgments and set aside biases, focusing solely on the phenomena of experiences. This rigorous approach ensured that the study captured the essence of the participants' experiences, free from external preconceptions.

3.8 DATA ANALYSIS

The data analysis method of this study was thematic analysis and triangulation. Thematic analysis is a method of identifying, organising, and interpreting the patterns and themes that emerge from the qualitative data (Clarke and Braun, 2017). Thematic analysis was suitable for this study because it allowed me to capture and describe the complexity and diversity of the experiences and meanings of the participants and to answer the research questions and objectives (Nowell et al., 2017; Castleberry and Nolen, 2018). Thematic analysis entailed going through a data set to identify, report and analyse the repeated patterns. I followed the six steps in thematic analysis as proposed by Braun and Clarke (2017) that include familiarising with the data, generating initial codes, searching for themes, reviewing themes, defining themes, and producing the report for coherent meanings and findings from the data in line with the research objectives.

Verbatim data comprising audio recordings of the interviews were transcribed by the researcher, and the transcripts were checked and edited as transcripts for accuracy and completeness. I assigned pseudonyms to the participants, and the documents to protect their identities and confidentiality. The transcripts were translated from the local language, siSwati, to English while ensuring accuracy and clarity in data. I read the transcripts in order to familiarise with the data and to identify the initial codes as proposed by Braun and Clarke (2017). Afterwards, codes and categories were used to identify and develop the themes and subthemes from the data. I used both latent and manifest themes to capture and describe the patterns and the meanings of the data. Latent themes were based on the underlying and implicit aspects of the data, whereas manifest themes were based on the surface and explicit aspects of the data. I used both deductive and inductive coding to generate the codes and the categories from the data. Deductive coding was based on the predefined codes and categories that were derived from the research questions, objectives and the literature review. Inductive coding was based on the emergent codes and categories that were derived from the data, whereas descriptive coding was based on the factual and observable aspects of data. Interpretive coding was based on the inferential and subjective aspects of the data.

The same transcripts were imported to the qualitative data analysis software NVivo (by independent analyst expert in the use of the software), which was used to manage, organise, and code the data. The data analysis followed four main stages which are identifying the text extracts in relation to the laid out research objectives, coding the identified text extracts, grouping the themes into categories that highlight the trends emerging from the results and consolidating the development of a grouping model for the emerging themes (Kadio et al 2024). Memos and annotations were used to record the reflections and the insights that emerged during the coding process. I also used thematic network analysis to visualise and illustrate the relationships and connections among the themes and the subthemes using diagrams and maps.

Triangulation is a technique of using multiple sources and methods of data collection and analysis to enhance the validity and reliability of the findings (Santos et al., 2020). Applying triangulation in research significantly enhances the depth and credibility of the study (Lemon & Hayes, 2020). Triangulation primarily aims to enhance the validity and credibility of research findings by providing multiple perspectives on the same phenomenon (Lemon & Hayes, 2020). It can be specifically applied to data analysis through the following:

- Methodological Triangulation: Different analytical methods or techniques can be used to analyze the same set of data (Moser & Korstjens, 2023). This study used different analytical techniques namely thematic analysis and Nvivo software. The findings from both techniques were compared and contrasted, identifying themes that were consistent across both techniques. There were no discrepancies in themes that were noted. Lemon & Hayes (2020), insists that the goal of triangulation is not necessarily to arrive at the same conclusion through different methods or techniques, but to add breadth, depth, and rigor to the research design.
- Investigator Triangulation: Multiple researchers can analyze the same data independently to compare and contrast their findings, which can help to identify biases and validate the results (Bans-Akutey & Tiimub, 2021). I did thematic analysis while Nvivo was done by an independent analyst.
- Theory Triangulation: Researchers can use different theoretical frameworks to interpret the same data, which can provide a more comprehensive understanding of the research question (Bans-Akutey & Tiimub, 2021).This study used descriptive phenomenology and feminist phenomenology to answer the research question.
- Data Triangulation: Although this typically involves the collection of data from different sources, it can also refer to the use of existing data collected at different times, from different places, or involving different people to analyze a research question (Bans-Akutey & Tiimub, 2021).This study used existing data from different times, places and people to analyze the research question. Data source triangulation involved comparing and contrasting the findings from different sources, such as the participants and the documents.

Lemon & Hayes (2020) attests that using triangulation solely during the analysis phase can still significantly strengthen the research by ensuring that the findings are robust, consistent, and well-substantiated. Triangulation was appropriate for this study because it enabled cross-checking and corroboration of the findings from different techniques thus reducing biases and errors that could have arisen from using a single technique.

3.8.1 Establishing Trustworthiness

Qualitative research is distinct in terms of how data are gathered. Its data, which are often storied and narrated, are process-based. It is particularly close to how humans perceive and feel about their reality. However, the extent to which the stories or narrations are presented must be trusted. The concept of trustworthiness pertains to the extent to which research findings are supported by the data obtained from study participants, exhibit methodological rigour, and are underpinned by a robust argument derived from the results (Kumar, 2018). It is also imperative that the presented stories are indeed true (Stahl & King, 2020). Different measures enhance trustworthiness in the analysis of findings from qualitative research. These measures are credibility, dependability, transferability, and confirmability.

(i) Credibility

Credibility refers to the extent to which the research findings are reflective of the phenomenon being studied (Brown, 2020; Moser & Korstjens, 2023). Thus, the findings should be reflective of the research aims and research questions developed to guide the study. There are several ways of ensuring the credibility of the findings, and these measures include triangulation, peer debriefing, audit trails, thick descriptions, and researcher reflexivity. In the current study, triangulation, audit trail, epoche and reflexivity were used to ensure the credibility of the findings.

The positionality stance I considered when engaging with the research participants was of one coming from outside the sphere of the research participants seeking to understand the lived experiences of pregnant mothers who are HIV positive. As such, I allowed for a non-judgmental conversation in which the participants freely expressed their feelings and thoughts while I actively listened in an unbiased manner. I also probed into the participant's responses to avoid assuming meaning in the participant's responses. During the data collection exercise, I captured the participant's perceptions and experiences within the context of their localities.

- ***Triangulation***

Triangulation is a process wherein different sources, such as individual interviews, data sources, theories, observations, etcetera, are used to gain further information about the findings of the study. As a technique, it allows for the cross-checking of information to ascertain that there is consistency in the primary findings. Triangulation is about the use of numerous sources of data, including settings, places, or persons (Moser & Korstjens, 2023; Lemon & Hayes, 2020; Stahl & King, 2020). Hence, different sources of data, which consisted of primarily women who negotiated pregnancy and HIV diagnosis were reviewed. The use of different sources of data provided two strengths for this study. First, it provided different and similar insights into the experiences of women diagnosed HIV-positive during pregnancy. Secondly, through analysing multiple data on women living with HIV, I minimised the potential for being biased towards the findings obtained from Swazi women diagnosed HIV-positive during pregnancy. The use of data triangulation strengthened the credibility of the primary findings for the current study, and it provided further insights into the phenomenon under study.

- ***Audit Trail***

Audit trails involve thick descriptions that the researcher provides regarding how data were collected, how decisions were made throughout the research process, and why they were made (Lemon & Hayes, 2020). In line with the use of the audit trail, I maintained a research journal from the initial stages of the research proposal developed for the current study until the data collection and analysis processes were concluded. In doing so, I was able to follow the trail of the research process, thus verifying and confirming that the research findings were in line with the research aim, research questions, and the collected data. In this study, I opted for a qualitative phenomenological research design to explore the experiences of pregnant women who are HIV positive. A proposal was approved by the Unisa ethics committee before the commencement of the data collection exercise. Standardised interview guides were also used to collect to collect data from the pregnant women in a manner that can be replicated in the future by other researcher.

(i) Dependability

This refers to the extent to which the research process would enable consistency across time, researchers, contexts, and analyses if the study were to be repeated by other researchers (Moser & Korstjens, 2023). Although qualitative studies are not intended for generalisation, the idea of dependability ensures that the study is repeatable. The technique used to ensure the dependability of a study includes audit trails (Moser & Korstjens, 2023), a technique that is also linked to credibility, as described above. The study's dependability was also enhanced through the addition of detailed descriptions of the research design and its implementation, the methodological decisions, and the data gathering, and analysis processes followed in the appropriate sections and chapters of the study. The detailed descriptions of the research processes were added to ensure that should any researcher seeking to repeat the study components, would have sufficient information.

(ii) Confirmability

Confirmability refers to the extent to which the research findings and the research processes are not influenced by the researcher's preconceptions, ideas, feelings, and beliefs, and as much as possible, the findings should represent the voices of the research participants (Muzari, Shava & Shonhiwa, 2022; Moser & Korstjens, 2023). In addition to the data analysis triangulation mentioned above, I maintained a reflexive stance throughout the research process. This study enabled me to acknowledge the strengths and weaknesses of the research, including areas of growth that had become evident throughout the research process.

(iii) Transferability

Transferability refers to the extent to which a study's findings and conclusions can be applied in future research conducted in a different context and involving a different sample. In qualitative research, transferability allows future researchers, who may believe that their study is similar to the current one, to compare and relate their findings with the current study's findings with as much sufficient context as possible to do so (Stahl & King, 2020). As such, a measure that was taken to ensure transferability in the current study was to provide thick, contextualised descriptions of the research process, the experience of both the researcher and participants, and the context of the interview process. This was done to provide contextualised meanings about the research findings. The study contributes to the existing literature and knowledge on the experiences and needs of women who are diagnosed with HIV during pregnancy, especially in the Eswatini context. It would also provide valuable insights and information for healthcare providers, policymakers, and other stakeholders who are involved in the design and delivery of HIV/AIDS and maternal and child health services and programmes.

3.9 ETHICAL CONSIDERATIONS

According to Bless, Higson-Smith and Kagee (2006), social scientists are highly concerned about research ethics due to numerous instances of infringement upon individuals' rights in the guise of social research. To uphold the ethical standards of the study and mitigate potential harm to participants, the research process incorporated several key ethical considerations, including obtaining informed consent, maintaining confidentiality, and exercising prudent management of information.

The significance of the participants' rights in any research endeavour cannot be overstated. The study placed significant importance on the physical and emotional wellbeing of the participants, as well as the protection of their privacy. All study participants had to receive a debriefing session to ensure that the genuine purposes of the research were effectively communicated (Snyder, 2019). The researcher must acknowledge and differentiate the latter, particularly when handling delicate subjects like investigating the encounters of pregnancy and HIV diagnosis. The subsequent segment provided a comprehensive account of the ethical concerns that were duly deliberated on, and I had to demonstrate familiarity with ethical principles, as they were a necessary component for the completion of the master's degree. I conducted a comprehensive examination of the ethical regulations and principles of UNISA.

The ethical considerations of this study were based on the principles of respect, beneficence, and justice. The ethical considerations were as follows:

I obtained ethical approval from the relevant institutional review boards and the research committees before conducting the study. I also obtained permission and the consent of the Regional Health Officer and the relevant authorities to access and contact the potential participants and the documents for the study.

I informed the participants about the purpose and the procedures of the study and invited them to participate in the study. I also informed the participants about the voluntary and confidential nature of the study and the potential benefits and risks of participating in the study. I then obtained written informed consent from the participants who agreed to participate in the study. I also allowed the participants to ask questions and to withdraw from the study at any time without any consequences.

I protected the confidentiality and anonymity of the participants and the documents by using pseudonyms, codes, and encryption to identify and store the data. I also ensured that the data were only accessed and used by myself and the supervisor for the study. I also deleted and destroyed the data after the completion of the study as per the ethical guidelines.

I respected the dignity, rights, and interests of the participants and the documents by treating them with courtesy, honesty, and sensitivity. I also acknowledged and addressed the power dynamics and the cultural differences that may have existed between myself, the participants, and the documents. I avoided any harm or discomfort to the participants and the documents by minimising the potential risks and maximising the potential benefits of the study. The participants were provided with documents with the necessary support and assistance during and after the study, such as counselling, referral, feedback, and dissemination.

3.9.1 Research Ethics: The Feminist Ethic of Care

The Feminist Ethic of Care is an ungendered framework designed to enhance moral decision-making. In research, the framework can be used to guide individuals on how to apply values and standards that are in line with feminist thought (Teke Lloyd, 2018). At the core of its existence, the feminist ethic of care seeks to promote care for people engaged in human relationships. Within each relationship, it is seen as morally acceptable that empathy, sensitivity, mutual respect, collaboration, and justice are continuously promoted.

Given that this study was framed by the feminist theory, it was necessary to use this framework to engage in ethical practices throughout the research process. Although there are various feminist schools of thought, there are central values and standards that guide the researcher to engage with each participant throughout the research process. The morally good values and standards included sensitivity, mutual respect, empathy, and nurturance, subject-centredness, and justice (Johnson & Parry, 2022; Ramdas, 2016).

Green (2012) alludes that sensitivity in research is an ethical practice evident in different ways in the research process. It involves how access to each participant was gained, how the participants were informed of the study, and how their consent was gained (Borgerson, 2007, O'Riordan et al., 2023). For example, as means of gaining access to each participant, I ensured the use of the assistance of a gatekeeper who was well-informed about the study. I also ensured that each gatekeeper was sufficiently informed about the nature of the study and its purpose as a means of minimising chances that participants initially agreed to participate when they were not well-informed about the study. Furthermore, I showed sensitivity through how participants' consent was obtained, specifically by explaining the nature of the study and that their participation in it would be in a language understandable to them. I also assured the participants they had the right to ask questions that sought clarification on hazy issues. So, sensitivity was evidenced by the extent to which participants' informed consent was sought and emphasised in the study.

Empathy was maintained as an ethical standard underpinning the study. Throughout the interview processes, the researcher and the participants were mutually respectful and understanding of the diverse lived experiences that existed (Van Dijk, 2019). This empathy that was reciprocated between myself and the research participants allowed for the building of a higher level of rapport and mutual respect. I also maintained empathy and mutual respect by respecting and being sensitive to the participants' knowledge and being continuously curious about their lived experiences (Ross & Parks, 2018) and this furthered the participants' level of participation in the research process, as there were often genuine interests in each other's experiences.

Subject-centred participation involved ensuring that throughout the research, the researcher managed power imbalances with the research participants (Johnson, 2022). In this instance, I put the experiences of the research participants at the centre of the inquiry. This was done by often minimising control of the interview process, as well as minimising the imposition of own meanings on the participants. As guided by the Feminist Ethics of Care, I perceived the participants as the knowers of their reality and promote their participation to collaboratively experience the building of knowledge with each one of the research participants.

3.9.2 Institutional Permission and Ethical Clearance

The Eswatini Health and Human Research Review Board granted permission to conduct interviews with key informants (please refer to Appendix A). The research protocol was presented to the Eswatini Health and Human Research Review Board, and it was approved. The Shiselweni regional health management granted permission for this study to be carried out in the clinics in the region (please refer to Appendix E). The research proposal and interview schedules underwent rigorous scrutiny by the UNISA ethics committee, resulting in the granting of ethical clearance in December 2022. (Please refer to Appendix D).

3.9.3 Informed Consent

Blanche, Blanche, Durrheim and Painter (2006) define the notion of informed consent as the obligation of a researcher to supply prospective participants with full and clear-cut details about the study, its methodologies, potential risks and advantages, as well as the guarantee of voluntary participation and the liberty to decline or withdraw from the study without any adverse consequences. Typically, the process of obtaining informed consent involves the solicitation of participant signatures on a document that attests to their comprehension of the research and willingness to participate. The attainment of informed consent is accomplished through the provision of a comprehensive explanation of the research, an unrestricted opportunity for participants to discontinue their involvement without any negative repercussions, and complete disclosure of any potential hazards associated with the study (please refer to Appendix B).

Upon receiving information about the study's objectives, participants were required to consent to partake in the study and furnished with written consent. As per the ethical regulations of the University of South Africa, it was imperative to obtain written consent from prospective research participants before their inclusion in any study. The participants were informed about the steps taken to ensure their confidentiality, potential risks or discomforts, benefits to both themselves and the clinic, the supervisor's identity, and the availability of a summary of the findings. The participants were informed that they retained the right to discontinue their involvement in the research at any point during the course of the study. If patients elected to depart from the clinic, no punitive measures or service restrictions would be imposed upon them.

3.9.4 Confidentiality

According to Gray (2021), confidentiality is typically not a significant limitation in research. Hence, it is plausible to entirely exclude the names of the participants or assign numerical identifiers to the participants instead of utilising their names. In the interest of advancing scientific knowledge, numerous individuals were willing to disclose highly sensitive information, provided that their identities remain undisclosed and anonymous to others (Bless et al., 2006). It was necessary to highlight to the participants that their privacy was being upheld. The principle of confidentiality entails that only the researcher is granted access to individual data and the identities of the participants, while the participants are informed beforehand about who will be authorised to access the data (Gupta & Gupta, 2022). The information obtained was restricted to myself and the supervisor and was treated as confidential.

3.9.5 Management of Information

The information collected from the participants was kept safe and only shared with the research supervisor at the Department of Psychology at UNISA. The scientific community could also see it, but it came as the final report, as research is meaningless if it is not shared amongst the scientific community. This research adhered to the standards in ethical considerations, namely, informed consent, anonymity, confidentiality, and management of information with the research participants before the interviews were conducted.

Regarding the management of the information provided by participants anonymously and confidentially, I adhered to recommendations by Holloway and Wheeler (1995) by ensuring that:

a. all-important materials including tapes, notes and transcripts were securely stored at all times.
b. Anonymity was achieved by not writing participants' names on the tapes, notes, and transcripts.
c. By allocating pseudonyms the identities of participants were preserved.
d. By destroying and erasing audio recordings and transcripts after completion of the research.

3.10 SUMMARY

This chapter discussed the study's methodological framework. The objective of Chapter 3 was to discuss the study's research paradigm, research methodology, and research design. The chapter also addressed the measures of the trustworthiness of qualitative research. It also discussed the precautions implemented throughout the research to safeguard the participants from any potential harm. The chapter contextualised the study's methodological framework to ensure that the research process was carried out effectively and scientifically.

CHAPTER 4

REPORT ON FINDINGS, DATA ANALYSIS AND INTERPRETATION OF RESULTS

4.1 INTRODUCTION

This chapter presents the results of the data analysis and the themes that emerged from the interviews with the participants. The chapter is divided into four main sections. The first section provides a profile of the participants. The second section describes the emotional and psychological challenges and opportunities that the participants faced after being diagnosed with HIV during pregnancy. The third section describes the social and economic challenges and opportunities that the participants encountered and experienced after being diagnosed with HIV during pregnancy. The fourth section describes the effects of these challenges and opportunities on the health outcomes, the relationships, and the children of the participants.

4.2 BIOGRAPHICAL DATA

Gray (2021) asserts that biographical information can be utilised to construct a more comprehensive profile of the individuals participating in the research and to gain deeper insights into how their distinct circumstances and life events may have influenced their cognitive, affective, and behavioural patterns. The table below presents the biographical data of the participants.

Table 4. 1: Profile of Participants

Participants	Pseudonym	Age	Marital status	No. of children	Education level	Occupation	Awareness of HIV status before pregnancy
1	Siphelele*	32	Widowed	4	Form 5	Factory worker	No
2	Takhile*	28	Single	3	Grade 7	Unemployed	No
3	Sindiswa*	28	Single	5	Form 2	Unemployed	No
4	Tandzile*	25	Single	2	Grade 4	Unemployed	No
5	Nomusa*	22	Single	2	Form 3	Factory worker	No
6	Sito*	24	Married	2	Grade 7	Unemployed	No
7	Nontobeko*	33	Single	3	Form 4	Housekeeping	No
8	Nongcebo*	21	Single	1	Form 5	Unemployed	No

9	Tanele*	30	Married	4	Form 2	Unemployed	No
10	Tsandzi*	25	Single	4	Form 5	Unemployed	No

Not their real names*

The participants of this study were ten women who were diagnosed with HIV during pregnancy in Eswatini. The participants were aged between 19 and 35 years. The participants had different marital statuses, such as single, married, cohabiting, and widowed, with a mean age of 26.4 years. They had different levels of education, ranging from primary school to high school. The identified participants had different occupations, such as unemployed or employed and had different numbers of children, ranging from one to five. They had all been diagnosed HIV-positive during ANC visits. The participants had different levels of adherence to ART and PMTCT with different infant feeding practices, such as exclusive breastfeeding or formula feeding. All had different HIV statuses of their children, ranging from negative to positive.

The interviews were conducted face to face with participants in a private room at the clinic using semi structured questions.

4.3 FINDINGS AND DISCUSSION OF RESULTS

This section presents the themes that emerged during the data analysis process. There is also a review and discussion of how the findings relate to the reviewed literature and the theoretical frameworks underpinning the current study in each theme and subtheme.

Table 4.2: Summary of Themes and Sub Themes derived from the study

Theme	Sub- Theme
Emotional and psychological challenges and opportunities	• Compulsory HIV testing • Shock of an unexpected HIV positive diagnosis • Apprehension overload and preoccupation with baby • Worst moment of my HIV journey
Social and economic challenges and opportunities	• Growing a thick skin

	Something about the healthcare workers The medication became my friend The breastfeeding dilemma
Emotional, psychological, social and economic challenges and opportunities	Lack of disclosure, social support and stigma Normalisation and Acceptance Open communication with partner and family Faith and pursuit of knowledge

4.3.1 EMOTIONAL AND PSYCHOLOGICAL CHALLENGES AND OPPORTUNITIES

The first theme that emerged from the data analysis was the emotional and psychological challenges and opportunities that the participants faced after being diagnosed with HIV during pregnancy. The participants reported various emotions and feelings that they experienced after receiving their HIV test results, such as shock, disbelief, denial, anger, sadness, fear, anxiety, depression, guilt, shame, hopelessness, acceptance, and relief. The participants also stated various factors that influenced their emotional and psychological reactions and responses, for instance, their knowledge of HIV, assumptions of their HIV status, their experiences with HIV, their coping and resilience skills as well as their sources and levels of support. The participants further revealed various effects of their emotional and psychological challenges and opportunities, such as their physical and mental health which was negatively impacted as they experienced accumulative distress; their adherence to ART and PMTCT. As much as it was fear-driven the outcome was positive, their delivery and post-natal experience was anxiety evoking, their infant feeding options, their reproductive health, their relationships as well as their children's health and development. The subthemes that were identified under this theme were:

Theme 1: Compulsory HIV testing is a good move
Theme 2: The shock of an unexpected HIV-positive diagnosis
Theme 3: Apprehension overload and preoccupation with the baby

Theme 4: The worst moment of my HIV journey

This study used an interview guide that was based on the research questions, objectives of the study, and literature review. It consisted of semi structured questions, the question was: What does it mean to be pregnant and HIV-positive?

4.3.2 Theme 1: Compulsory HIV testing is a good move

This theme unpacks participants' experience with mandatory as opposed to voluntary HIV testing. They all mentioned that the reason they consulted at the clinic was not to test for HIV but to seek antenatal care services and were told to access services, they had to test for HIV first. This is what participants had to say regarding compulsory testing and the verbatim responses are typed in *Italics* below:

> *Making HIV testing in pregnancy compulsory is a good move. If it were according to me, I wouldn't want us as women to view it as an obligation but a blessing. This is because you find that under normal circumstances going for HIV testing is hard, it is not something that you can just do unless you are compelled by a situation. So being pregnant is another opportunity to know your HIV status. You find other people have never tested at all so pregnancy affords them that opportunity and you get to know your status, and you get to get care for both you and the baby* (Siphelele).

> *Nowadays, when you are pregnant you have to protect the unborn child so that the child cannot later blame you for being infected this way being made to test when pregnant helps* (Takhile).

> *The reason they are following you up with the tests is that they want you to deliver a healthy baby who'll have a bright future, basically, they are helping the baby and so you should do everything they say you must do so that you can protect the baby* (Sindisiswa).

> *When you are pregnant I don't think that is a problem because you must get tested for the baby whom you are going to bring on earth…actually at that point, the most important thing is the baby and to avoid the baby being a problem to yourself in future you must get tested and you must not think only for yourself but also think about the baby you would be bringing on earth* (Nomusa).

> *What I know is that a child belongs to the government, and they are concerned about the baby. Also when you are not pregnant and you do not want to get tested they don't force you but once you are pregnant then HIV testing is compulsory because of the baby if you don't want to get tested then you are the one who is infringing the right of the baby.* (Tsandzi).

> *I regretted why I tested in the first place. However, there was no way I would have avoided it anyway because they said it was compulsory for all pregnant women to be screened for HIV* (Siphelele).

Discussion

It appeared that with pregnancy, the power and right to choose if and when to be tested for HIV is lost. In Eswatini, HIV testing is voluntary for all except for pregnant women. It was evident that had it not been for the pregnancy, most participants would not have tested for HIV. However, almost all participants experienced compulsory testing in a positive light as it offered them the opportunity to protect their unborn baby and better care for themselves. Literature shows that this issue of mandatory testing in pregnancy is complex and controversial, involving ethical, social, and political dimensions (Razzaq, Raynes- Greenow & Alam, 2021). According to the feminist phenomenological perspective, the lived experiences of women are important sources of knowledge and critique and should be respected and valued in the decision-making process (Cohen et al., 2022). The women in this study perceived mandatory HIV testing as a way of protecting and promoting their health and wellbeing as well as that of their baby, as it enabled early diagnosis and treatment of HIV infection. The treatment reduces the risk of mother-to-child transmission and improves the quality of life for the mother and baby. The controversy around mandatory HIV testing of pregnant women from a feminist phenomenological perspective is that it can be seen as a violation of human rights and the autonomy of women as it imposes a coercive and paternalistic intervention on the women for the sake of the foetus (Hlongwa et al., 2020).

4.3.3 Theme 2: The shock of an unexpected HIV-positive diagnosis

This theme discusses participants' reactions upon receiving an HIV diagnosis. The reactions most participants reported were regret, shock, fear, tension, denial, depression, and uncertainty. Joseph & Bhatt (2013.p.30) alluded that "receiving an HIV diagnosis is the beginning of a long road of challenging life events and unique personal changes which can overwhelm even the most psychologically adjusted person." The following are the participants' reactions:

> *It pained me a lot because I had confidently taken the test knowing that I was negative because when I got my first child I had tested, and it was negative…. immediately I regretted why I tested in the first place. However, there was no way I would have avoided it anyway because they said all pregnant women needed to be screened for HIV* (Siphelele).

> *The shock and fear were too much such that even when I had given birth and every time my baby was due for testing, I would not be the one to take him to the clinic, I would ask my mother every time. Until the nurse noticed and she called me and sat me down. She assured me that the fact that I was able to protect my baby while I was pregnant, and he was safe during delivery and I did not put him at risk by not breastfeeding him, there was no need to fear, I needed to believe that the baby was negative and not at risk anymore, but it took me a long time because I recall that the very first time I took him for testing, he was 2 years. All the while he was brought by my mother. It was only after the talk with the nurse that I was confident enough to bring him myself for testing. Again, they assured me that the baby was fine. However, it was an extremely difficult time* (Takhile).

> *I was very shocked, and I don't want to lie, I was very sad such that I even thought of ending it all and then again I thought I was pregnant so I thought about my baby* (Tandzile).

> *the shock wasn't that much because I felt like let me just accept my situation to live, it never bothered me, like it never affected me in any way, I wouldn't lie…what affected me was when I was already taking the treatment that I would feel some hotness and the difficulty in swallowing them, that is how they affected me otherwise everything was fine* (Participant 5).

> *with the pregnancy result, it didn't bother me that much compared to the HIV results which was difficult for me, it was very difficult, I even thought of killing myself I lost weight and*

> *I also lost appetite…I was stressed. I was thinking that I am pregnant at the same time I am HIV-positive* (Nomusa).

> *I cried a lot I could not believe my status; I had to check and recheck it was so hard to believe that my life will be based on medication* (Nontobeko).

> *I was so depressed by the diagnosis it was hard to accept the situation, I was really afraid I was afraid at first that I might die, maybe I might infect the baby and the baby might die…you see all those things I was thinking about? (Tanele).*

> *I became shattered by the situation and I was so worried if my baby would be healthy and make it. I was told that I was positive and this was painful for me I asked about the baby, and they said they can only be able to test the baby once I have delivered.* (Tsandzi).

Discussion

The participants' reactions were congruent with what other researchers found. Previous research identifies the following emotional reactions upon receiving an HIV diagnosis: shock, worry, disbelief, denial, sadness, guilt, and bereavement (Minaar & Bodkin, 2009; Sanders, 2008). It seems these are common reactions regardless of gender or pregnancy. As seen in the above excerpts. The majority of participants reported experiencing shock, suicidal ideation, fear, and worry over the baby was the only exception. Other stressors that were found to be associated with receiving an HIV diagnosis were uncertainties about living with the disease, anxiety over future health, concerns about health and dying, and changing interpersonal relations and finances (Holt et al., 2005). This may explain why some participants thought of killing themselves upon receiving the diagnosis. The participant's experiences showed the emotional distress caused by an HIV diagnosis and the impact it had on their mental health. Kapetanovic et al. (2014) found that these feelings of shock, worry, sadness, and depression could have a significant impact on the health of the mother as well as the health of the baby during pregnancy. Mavhu et al. (2020) confirm that there is an emotional weight that comes with knowing one's HIV status, and the above extracts are evidence.

4.3.4 Theme 3: Apprehension and preoccupation with the baby

Receiving an HIV diagnosis is often a life-changing and traumatic event (Finkelstein-Fox et al., 2020; Anderson et al., 2010). Participants confirmed this as follows:

> *It was the hardest time of my life this pregnancy because of the fear of infecting my child, delivery as well was a stressful moment as I was overcome with what if my baby gets*

> *infected. I breathed again when my baby was tested negative at birth and there and there, I decided I will not breastfeed lest I infect my baby* (Siphelele).
>
> *It affected me a lot because before I knew about it, I would find myself a human being amongst human beings (ngingumuntfu ebantfwini) and I would not distance myself from the people and I felt they loved me but then after I got to know my status I felt like maybe if I didn't join my friends then it wouldn't be like this…yes…* (Sito).
>
> *I already knew about HIV that it is not the end of the world but then I was so worried about the pregnancy as to what will happen to my baby* (Nongcebo).
>
> *My main worry was my baby if he'll be able to survive HIV and how we are going to cope with it if he gets infected, so I didn't know whether the baby will be born with deformities because of the virus because they say with the other STI's it happens, so that's what I was afraid of* (Tsandzi).

Discussion

As seen in the participant's reflection, an HIV diagnosis becomes more complex when it is preceded by pregnancy. Participants not only worry about themselves but their unborn baby as well. After doing all they could to protect their baby, that is optimum adherence to ART, which significantly eliminates the risk of infection, the anxiety of infecting their babies lingers on. Studies confirm that the levels of depression and anxiety increase as the pregnancy progresses (Kapetanovic, 2014). Ion, Greene, Mellor, Kwaramba, Smith & Barry (2016) allude that motherhood is commonly perceived as a positive experience, and the state of being pregnant is generally linked to a sense of regularity and a feeling of wholeness.

However, from the above extracts, it is evident that an HIV diagnosis makes pregnancy and motherhood a time of distress, worry, and uncertainty. Knettel, Cichowitz, Ngocho, Knippler, Chumba, Mmbaga, and Watt (2019) confirm that pregnant women who have HIV frequently experience great fear and anxiety connected to their health as well as the health of their unborn child. This is in line with what other researchers found, as a considerable number of women living with HIV encounter feelings of apprehension and distress concerning the wellbeing of their babies (Carlsson-Lalloo et al., 2021). Zhang et al. (2018) state that persons who have been diagnosed with HIV experience severe stress and anxiety, which could have a detrimental influence on their psychological wellbeing as well as their treatment adherence. Pregnancy on its own can be quite a challenge and adjustment. It seems preoccupation with their babies’ wellness acted as a buffer for the participants.

The maternal instinct as a way of coping is seen as participants shifted all focus from self and focused on protecting their unborn babies at all costs. The notion of having a baby during pregnancy became a positive coping or a distraction from the impact of the diagnosis. The following were their statements:

> *Putting the child first helped me to deal with the shock and forget everything else. I had been taught about the dangers I would pose to the baby if I do not take care of myself and how it could affect the baby* (Siphelele).

> *I was shocked at first and then I asked the Counsellor if I am positive, how about my baby she said to me that is why I have to start taking the treatment very early so that the virus cannot be passed on to the baby* (Takhile).

> *Anyway, when I got the diagnosis, all that mattered to me was my baby* (Tandzile).
>
> *And I told them that they should give me the treatment so that I can protect my baby so that when I deliver the baby, I’ll find that he is in a good condition and also to avoid being sick and end up also having a sick baby* (Sindiswa).

Discussion

Kapetanovic (2014) confirms that pregnant women diagnosed with HIV exhibit elevated levels of depression and anxiety compared to their non-HIV-positive counterparts. As much as the majority of the participants reported experiencing shock, fear, pain, suicidal ideations, and worry, preoccupation with the baby became a coping mechanism. They shifted all focus and energy from themselves to the unborn baby. The maternal instinct to nurture and protect took over as a coping measure and a defence mechanism to numb and avoid their pain and distress. Caregiving is a role that women excel in, sometimes to the detriment of their wellbeing. In prioritising their unborn baby by adhering well to treatment, they enhanced their wellbeing-being. The HIV diagnosis brought distress in that they experienced perpetual apprehension throughout pregnancy and post-partum about their baby’s health. The women in this study were able to combat depression by focusing on protecting their unborn babies, thus adhering well to their treatment. All ten of them gave birth to HIV-free babies, with only one who converted later due to mixed feeding (encouraged by the family who did not know her status as a result of fear of disclosure).

Also, under normal circumstances, when diagnosed with HIV, one is allowed to take all the time they need to process the news, and upon acceptance of the new reality, then one can start treatment, but it appears for the women in this study upon receiving HIV diagnosis they opted for immediate ART initiation for the sake of the baby. The medical benefits of rapid initiation of antiretroviral therapy among pregnant women are viral suppression and boosting of the immune system, meaning optimum health for mother and baby (Ford et al., 2018, AIDS Community Research Initiative America, 2018).

However, from a psychological perspective, being diagnosed with HIV is a significant and challenging experience due to persistent HIV-related stigma, preoccupation about the health effects of HIV, and anxieties of living with a chronic medical condition. For this reason, intensive emotional preparedness is critical before ART initiation to avoid poor adherence, stopping ART after initiation and mental health issues (Wells et al., 2023). Furthermore, studies show that people newly diagnosed HIV-positive often experience the diagnosis as a traumatic loss (Wells et al., 2023, Brion, Menke & Kimball, 2013). Zeligman and Wood (2017), allude that grief associated with HIV diagnosis also counts as bereavement. Negotiating both HIV and pregnancy can be a complex phenomenon for women; hence, this study employed the feminist phenomenology approach, which focused on women’s experiences as told by them, like pregnancy, motherhood, and dealing with chronic conditions. It challenges the undermining and minimisation of women's experiences and advocates for women’s voices to be heard, thus shedding light, raising awareness, and bringing insight into women's issues. Expectant mothers are a population that is especially susceptible to contracting HIV and confront distinctive obstacles in the maintenance of their wellbeing and that of their babies (World Health Organization, 2021).

4.3.5 Theme 4: The worst moment of my HIV journey

The post-delivery phase is deemed the most vulnerable time in the continuity of care for women living with HIV globally, with data demonstrating a decline in adherence to treatment and retention in care (Momplaisir et al., 2018). This is what the women in this study reported about challenges in their post-partum journey:

> *Nothing in all my life prepared me for what I experienced when I had my baby. It was the worst moment of my life. I hated myself for what I had done to my baby. Thinking about it still brings me to tears. I resented those HIV testing sessions for my baby, they were a nightmare! Watching my baby go through that affected me. I would cry while holding him and crying hysterically. I tested once for HIV and it was a prick on my finger and that was it but for my baby one they struggle to get the vein, secondly it’s a lot of blood they draw*

for the test and thirdly the test is not once off but continuous. Did I mention the wait for the results? It's like you stop breathing until you get the results. Your life stands still, even eating becomes a problem (Siphelele).

My greatest challenge was taking my baby for the routine HIV testing. The only time I can say I regretted being HIV-positive, to date I still hear my baby crying in my head, watching helplessly while his tiny body is being poked with that needle. All my fault, what did my baby do to deserve this cruelty (Tandzile).

The joy when your baby is done with routine testing for HIV is priceless but the journey to get there is a nightmare. I decided there and there that no more babies. I just can't! I will not bring a baby to suffer such pain, why? That would be so selfish of me. My baby is innocent why does he have to suffer for my sins? The pain of watching my baby being poked over and over still haunts me. I understand it had to be done for his welfare, but it messed me up, I beat myself for bringing all this to my baby. Another nightmare is waiting for the results. It is the longest wait ever! Your world comes to a standstill. Yes, you give him the meds accordingly and you take yours well, but the fear is something else. You only get to breathe once you get the results and then the next time the process starts all over again. It is crazy! Ngiyabonga mine! No more babies I am done! (Nontobeko).

Even though I did not breastfeed my baby because I did not want to risk infecting him, he still had to undergo routine HIV testing because he was put on nevirapine for 6 months and that was the real test for me personally. The very first time I understood what it meant to be HIV-positive was when I brought my baby for testing. It is unfair! Unfair in that the innocent baby is the one who suffers more, the endless pokings even if it's for a while but what a traumatic way to start life! What a welcome. What is even worse is that the baby has these routine tests as well as the regular vaccination. This is way too much for the baby. The baby is the one who suffer more. To witness your baby going through that and unable to help them is death itself. I wished I could take his place but unfortunately, I couldn't. It had to be done, he had to go through that. The guilt and self-blame is a topic for another day (Tanele).

Forget the side effects, forget the fatigue of taking pills every single day at the same time, forget the fear of infecting your baby. Let me tell you the worst moment of my HIV journey to date, every time bloods had to be taken from my baby I died, I completely shut off, mind

> *you I had to hold my tiny baby while being poked everywhere looking for a vein and this nightmare is monthly. Every time we due for hospital visit, I wish the earth would open and swallow us. After that nightmare follows the wait for the results and that is another struggle even though you know you are doing everything you are told to do at the clinic, giving my baby her meds accordingly yet the fear strikes you like a thief* (Nongcebo).

> *Yes, it is for my baby's good to ensure that he is well and if not, necessary precautions are taken but ya it is not for the faint-hearted. When I saw the lady with the injection and the tube, I wondered hhayibo what is going on. I was expecting a prick on the finger, little did I know, it's on the vein and it's a lot of blood. Ye make (a vernacular expression referring to calling one's mother when in trouble)! I almost fainted. That I will never forget and that I never want to go through ever again. It's unfair, it's selfish, the baby is innocent, why go through this? I am the one who deserves it, not my baby. I say no!* (Tsandzi).

Discussion

The reflections above, as expressed by the women in this study, show the multifaceted effects of HIV in pregnant women. Knowing there was something they could do during pregnancy to prevent mother-to-child transmission alleviated distress; however, it seems they were unprepared for any anxieties and distress associated with infant HIV testing. Carlsson-Lalloo et al., (2021) assert that pregnant women living with HIV face unique challenges in addition to the typical adaptations that accompany motherhood. They must learn to cope with additional sources of stress about their health, the ambiguity surrounding the infectious status of their new-borns, and the obligation to fulfil the specific needs of their infants, such as the dispensation of prophylactic medications. The women reported feeling the major impact of an HIV diagnosis during the testing of their babies.

For the women, this was the worst moment in their HIV journey, and as a result, some vowed not to have any more children. This correlates with what Nardell et al. (2023) found that the emotional stress that people living with HIV endure is more detrimental than the virus itself. The women struggled with guilt, distress, and blame, seeing their babies in discomfort. Nevertheless, they continued adhering well to their treatment and antiretroviral prophylaxis for their babies. Participants endured significant distress due to procedural continuous infant HIV testing. Also worth noting is that the women were without support from their partners or family during this trying process. As much as they understood the importance of testing their babies, they were not exempted from experiencing the distress that comes with the procedure.

4.4 SOCIAL AND ECONOMIC CHALLENGES AND OPPORTUNITIES

The findings revealed that the women in this study faced numerous social and economic challenges after being diagnosed with HIV during pregnancy, namely, stigma, discrimination, rejection, poverty, unemployment, lack of resources and lack of services. They also reported attaining opportunities for growth through support, acceptance and information from family, partners, and healthcare workers. The findings further revealed that the participants' social and economic challenges and opportunities were influenced by several factors, such as their gender, age, education, occupation, and income. The subthemes that were identified under this theme were:

Theme 1: Growing a thick skin
Theme 2: Something about the healthcare workers Theme 3: The medication became my best friend Theme 4: The breastfeeding dilemma

4.4.1 Theme 1: Growing a thick skin

According to Mathule and Matule (2020), an HIV-positive person's fear of disclosure might prevent them from getting treatment. The experiences of the participants showed the significance of support and disclosure in coping with issues associated with an HIV diagnosis while pregnant. Below are the participant’s statements:

> *My mother’s support was beneficial; it calmed my nerves. I had a great fear of losing my baby that he would die. My mother helped me overcome this fear she was competent in childcare and very supportive. She was the first person that I disclosed my status to when I got back from the clinic. Even when I disclosed to her she was warm and accepting. She assured me that life goes on as long we are there for each other. Her support helped me in my journey, even though it was not easy at all but to know that someone was sharing the burden with me, and I was not alone, helped a lot* (Siphelele).

> *I even told my children that I am now living under this condition, and they even remind me to take my treatment when it is time for my treatment* (Takhile).

> *I informed my mother that I was pregnant and secondly that I will now start taking the treatment and she said that is not a problem and then I came back here (clinic) and met (counsellor) and at that time I had already counselled myself because I have an aunt who started taking the treatment and I never saw her having any headaches or falling sick thereafter and then I told her later that there was something like this happening in my life and she said do not worry as you can see that I am also fine so I came and told the*

counsellor that I was now fine and she can give me the booklet and the treatment (Sindiswa).

I told my mother and sisters because it is very important to have someone at home who you are going to tell and also because you are going to be away and yet your baby has to take the medication of which they are the ones who are going to give it to the baby hence they should know what medicine the baby is taking and the purpose of that medication (Tandzile).

He would ask me if I was taking my treatment…yah…it was that…because there was nothing that was a challenge for me that would have made me to ask for assistance or guidance, everything was just fine for me…. I was doing everything they had said I should do (Nomusa).

It was difficult as I wondered how I am going to put it at home, it actually took several days before I talked about it. It took me some time until I was able to then tell one of my sisters who was then able to introduce it to the family who then counselled me that life is like that, it was then that I was able to accept (Sito).

It never made me sad but then instead I only thought what will my partner say (Nomusa).

As for me, I chose not to disclose my status at home. I am not yet ready to disclose to them because before you disclose you have to look at their personalities but then the only person, I disclosed to is the father of the baby who was very supportive, and I encouraged him to go and get tested and he tested positive and then we supported each other (Nongcebo).

I was afraid that maybe at my baby daddy's home, they were going to say I came with the virus and things like that, so I was afraid, really afraid. what helped me was to sit down with him and I told him that I have discovered that I have this thing and if you cannot accept me the way I am there's nothing I can do, and he also went there and got tested and then he gave me some courage to take my treatment without hiding because I was hiding when taking them because I was afraid. I knew that my husband would never cook pap so I would hide the treatment in the mealie-meal (laughter), he was 100% sure that I was not on the treatment because he had never seen them yet when the alarm rings, I would leave him in the sitting room and go to the kitchen where we keep the mealie-meal and take my treatment (Tanele).

I couldn't tell them at home about the challenge I have come across and I am only able to talk to the father of the baby and that helped me as well, like when I would vomit after taking the pill, he would tell me to wait for 30 minutes and retake the pill (Tsandzi).

Discussion

The above excerpts show that some participants overcame their fear, disclosed their HIV status, and were accepted and supported. Some disclosed to family members, while others preferred their partners. The importance of receiving support, be it from family members or partners, is witnessed as family members give support in the form of encouragement and reassurance. According to Ayieko et al. (2021), having support from one's family may be an extremely helpful factor in assisting individuals in coping with the emotional and psychological issues that are associated with receiving an HIV diagnosis. Madiba (2019) attests that coming out about one's HIV status and receiving support from family members can enhance one's mental health, social functioning, and adherence to antiretroviral medication (ART).

4.4.2 Theme 2: Something about the healthcare workers

One of the primary obstacles encountered by expectant women who are HIV-positive in Africa pertains to the availability of healthcare services (World Health Organization, 2021). The women in this study had this to say about their experience with healthcare workers and the services offered:

Yes, the woman is HIV-positive, but the focus should be now on protecting the baby from being infected (Siphelele).

It was the way they were talking to me at the clinic and then I listened to all the instructions they gave me (Sindiswa).

The nurses I got were able to counsel me and the person I was staying with was also able to counsel me (Tandzile).

They (health care workers) encouraged me through telling me what type of food I need to eat, which has to be a balanced diet and they also encouraged me to make sure I take my treatment as prescribed (Tsandzi).

At the clinic, they supported me and encouraged me to disclose to him, but I was afraid

(Nontobeko).

They were willing to answer and willing to help and I cannot lie about that (Nongcebo).

for me as much as I was afraid, they counselled me and then I felt at home and they took good care of me and then again I was pregnant and again they told me that my baby would not get infected if I take my treatment as prescribed (Tanele).

Discussion

Carlsson-Lalloo et al., (2021) found that the existence of supportive relationships, such as those with healthcare providers who provide medical attention and how women who are diagnosed with HIV communicate with their healthcare providers may have a notable impact on the quality of their pregnancy experience. All the participants in this study reported having positive experiences with healthcare workers, and they had great rapport which meant anytime they needed help or had questions, they did not hesitate to reach out to them. The healthcare workers that participants referred to were nurses and counsellors who did HIV testing and counselling. Also, they mentioned making use of the materials and resources found at the clinic. This shows that the services and resources were effective and beneficial. They had access to treatment and adherence counselling. The presence of stigmatisation and discrimination related to HIV may pose a challenge for expectant mothers seeking access to healthcare services, as they may harbour apprehension about potential condemnation or maltreatment from healthcare practitioners (UN, 2019). None of the participants mentioned experiencing any stigma or discrimination by healthcare workers. This may explain the positive outcomes of their good adherence to treatment and coping with both HIV and pregnancy. A research study carried out in Uganda revealed that group counselling sessions had a positive impact on the mental wellbeing of pregnant women with HIV, leading to a decrease in depression rates (Rotheram-Borus et al., 2011). This study showed the benefit of support from the nurses and lay counsellors in giving education and encouragement and supporting women in negotiating HIV and pregnancy.

WHO (2021) found that women residing in rural or underprivileged regions encounter restricted availability of healthcare amenities, thereby posing a challenge to their access to appropriate medical attention and support. In this study, all the participants were from rural areas in the Shiselweni region, and they reported having access to much-needed healthcare services.

4.4.3 Theme 3: The medication became my best friend

This theme focuses on the participant’s experiences regarding ART (Anti-Retroviral Therapy). According to WHO (2013), HIV-positive pregnant and nursing women are recommended to start ART regardless of CD4 cell count. This is what participants had to say about ART:

> *I was relieved that there was medication to suppress the virus and the medication became my best friend. Anything else did not matter* (Sindiswa).

> *I started the treatment there’s nothing negative to report like a headache or anything like that, I am just fine* (Takhile).

> *You can take the treatment without any problems, yes there are side effects when you have just started the treatment even though with me nothing happened, I didn’t experience any side effects* (Tanele).

> *I just took the treatment there and then. I didn’t have any issues* (Sito).

> *It was hard and difficult to believe that he could escape getting the virus during pregnancy and birth. I would say that the anxiety was a result of not being taught well about the HIV treatment, because I was taking them well, every day but I did not know what they were doing unlike today they speak of viral load, being undetectable etc. It means I could protect my baby from the virus because I started ART at 4 months* (Siphelele).

Discussion

The above excerpts indicate that the overall experience with ART during pregnancy was predominantly positive despite initial concerns. The participants exhibited a high level of acceptance towards the treatment despite the inherent difficulties associated with pregnancy symptoms. Additionally, they expressed appreciation for the availability of ART in the country at no cost. According to (WHO, 2022), there remains a significant amount of work to be accomplished in guaranteeing that every pregnant woman living with HIV in Africa can obtain the requisite care and treatment. None of the participants had challenges accessing antiretroviral therapy, and it was easily available. This is evident in that all participants reported being on treatment even though some admitted to poor adherence due to lack of disclosure.

The study by Medecins San Frontieres (2020), indicates that if HIV is left untreated, a significant proportion of children born to HIV-positive mothers, ranging from 25% to 40%, are at risk of contracting the virus. The participants expressed profound relief and satisfaction regarding the effectiveness of antiretroviral therapy (ART) in preventing the transmission of HIV to their infants. This observation is consistent with wider public health research. For instance, a recent study conducted in Uganda revealed a significant 93% decrease in rates of transmission from mother-to-child among individuals who received antiretroviral therapy (ART) during pregnancy (USAID, 2021). Furthermore, the research emphasises the participants' achievement in effectively protecting their infants, as indicated by the absence of HIV in all the new-born's test results. This underscores the significant contribution of antiretroviral therapy (ART) in reducing the likelihood of HIV transmission during pregnancy.

4.4.4 Theme 4: The breastfeeding dilemma

According to USAID (2021), one of the challenges encountered by expecting women who are HIV-positive in Africa is the potential for transmission of the virus from mother-to-child, and with the absence of adequate medical intervention and attention, an estimated 30% of neonates delivered by HIV-positive mothers will contract the virus. However, the implementation of antiretroviral therapy (ART) can significantly mitigate this hazard. Breastfeeding is considered one of the most beneficial and effective child survival interventions, yet it is also one of the modes of HIV transmission to children (UNAIDS/WHO, 2006). This theme highlights women's experiences with breastfeeding.

The following are statements of participants:

> *I followed the instructions they had given me that I should exclusively breastfeed and not mix-feed and I did that and also with the meds I followed the instructions and then when the baby was tested, he was negative* (Takhile).

> *when breastfeeding the baby isn't going to get infected when you take the treatment as prescribed because when your viral load is suppressed then it is almost impossible to infect the baby because it is important to check your viral load every 3 months when you are pregnant or breastfeeding so that you can always know where you stand in terms of your viral load"* (Sindiswa).

> *It was after the 18-month test that I could breathe again, otherwise, I had been worried when I was breastfeeding in terms of how things are going with my baby, he tested negative and then I stopped breastfeeding* (Sindiswa).

> *I was breastfeeding the baby the normal way because when you are taking your treatment in time or the way it was prescribed to you then it is not easy for the virus to pass onto the baby* (Sito).

Discussion

In the above excerpts participants acknowledged the significance of adhering to ART in the suppression of viral load and the mitigation of mother-to-child transmission during lactation. The extracts show that the challenges pregnant women diagnosed HIV-positive face transcend beyond post-partum. One would assume that relief comes with a baby testing HIV negative at birth, that is, during initial testing at 6 weeks, but it is evident that anxiety lingers through breastfeeding; hence, some opted not to breastfeed at all while others had to stop breastfeeding when the fear of infecting their babies intensified. Even though the participants were well adherent to treatment, with an undetectable viral load, meaning the risk of transmission was eliminated, they were still not at ease while breastfeeding. The anxiety every time their babies are due for testing seems to be another distress, not to mention the guilt every time their babies are subjected to the testing process. This is contrary to Shongwe's (2015) findings that HIV-positive mothers experience a tremendous sense of mental relief when the baby's 6-week DNA-PCR test comes back negative. Primarily, the choice to abstain from breastfeeding among some participants emanated from the deep-seated apprehension regarding the potential transmission of HIV to their offspring, a way to combat psychological distress. This apprehension and dilemma about breastfeeding was justifiable because those studies show that the risk of MTCT in low-income countries like sub-Saharan Africa where breastfeeding is recommended among HIV-positive women is between 25 and 40% (Dlamini et al., 2021). Also, many children infected with HIV acquire it from their HIV-positive mothers during pregnancy, delivery, or breastfeeding (Eccles et al., 2022). The feminist phenomenological perspective stresses the significance of comprehending the context within which these women arrive at their choices.

The participant below made a conscious decision to abstain from breastfeeding due to fear of transmitting HIV to her offspring; luckily, she had the means to afford formula. *Siphelele* indicated the following:

> *I was taught that the baby could be infected during pregnancy, delivery and when breastfeeding. And there was no way my baby could skip any of those stages. I thought to myself that since I was pregnant, and I was going to deliver my baby and I was intending on breastfeeding him then the chances of infecting him were very high. So, I decided to take the medication since I was taught that it would help protect my baby from being infected with the virus. In the end, I decided not to breastfeed. I looked at the different ways I could infect him and thought to myself if he escaped getting the virus during pregnancy and delivery and there was no way to avoid those stages, then I would avoid the breastfeeding one. I was lucky that I could avoid it because I was working, and I could afford to buy formula. Also, the fact that I had only 3 months of maternity leave, if I were to breastfeed what would I do then, when I had to go back to work, formula was the best option. So, I decided not to breastfeed at all but exclusively use formula. To me it was like breastfeeding would be giving him the HIV* (Siphelele).

Discussion

Exclusive breastfeeding during the first six months of life was at 32% among HIV-positive women in Eswatini (Shongwe, 2015; MOH, 2008). This correlates with the findings of this study whereby participants associate breastfeeding with HIV infection and an anxiety-provoking experience and avoid it. Most indicated that if they had the means, they would have opted not to breastfeed at all. The World Health Organization and United Nations Children's Fund strongly advocate for exclusive breastfeeding for the first six months of life of every infant, with breastfeeding extended till the second birthday or more (UNAIDS/WHO, 2006). This recommendation is for both women living with HIV and those without. Mixed feeding in the first six months is said to increase the risk of transmission. About 25%-45% of mother-to-child transmission of HIV was found to have occurred through breast milk during mixed feeding (Horvath et al., 2009, Taha, 2011). As seen in this study, some participants did not adhere to the recommendation of exclusive breastfeeding, which is critical in the prevention of HIV transmission.

> *I don't want to lie because I breastfed the baby for about 1-2 months and then I gave him bottled milk because I was too afraid that I might infect him and then with this one who is below 2 years old I decided not to breastfeed at all* (Tanele).

> *I had that challenge again of apprehension when I was breastfeeding to the extent that the baby daddy said I should stop because I am saying I am afraid. So I stopped breastfeeding and gave the baby bottled milk* (Tsandzi).

> *They had said I should exclusively breastfeed the baby for 6 months and then when I felt that the baby was too much for me at 5 months I then spoke to the Nurse, she said I shouldn't deviate from what they told me, none the less I continued to make thin porridge for the baby and I don't want to lie to you, that is something I did because I felt the baby was sucking me too much* (Nomusa).

> *I would prefer that when you know that you are HIV-positive it is best that you do not breastfeed at all because you are going to make mistakes along the way. I blame myself to date for not doing that, I do, because even when he was tested at 6 months where they found that he's negative, if I knew I would have weaned at that point but then I didn't* (Tandzile).

Discussion

Shongwe (2015) found that HIV-positive mothers who were exclusively breastfeeding associated breastfeeding with relief from breast problems like engorgement, contraceptive effect, feelings of satisfaction, and calming effect on the baby. This is contrary to most participants' experiences regarding breastfeeding in this study as they associated it with perpetual fear, something to avoid, a challenge, and risk to their babies. It seems participants equated no breastfeeding to no stress.

4.5 EMOTIONAL, PSYCHOLOGICAL, SOCIAL, AND ECONOMIC CHALLENGES AND OPPORTUNITIES

Pregnant women with HIV face significant challenges regarding the disclosure of their diagnosis due to the fear of social exclusion and societal norms, which inhibit their emotional, psychological, and social wellbeing. Stigma and discrimination against HIV are rooted in social dynamics, which inhibits women from sharing their health concerns, whereas the gendered nature of responsibility inhibits their intention to disclose their diagnosis. However, women continue to cope by incorporating strategies based on acceptance and social support to navigate the challenges associated with experiencing HIV during pregnancy. Hence, the following themes have emerged from the analysis:

Theme 1: Lack of disclosure, social support, and stigma
Theme 2: Normalization and acceptance
Theme 3: Open communication with partner and family
Theme 4: Familial and community support

4.5.1 Theme 1: Lack of disclosure, social support and stigma

The extract below shows the implications of the lack of disclosure and support:

> *When I was eating the baby would cry for my food and then my grandmother would say I should give him the food and I did that and at that point, he was 5 months old because when he was 6 months old, he got tested and was clean and then when he was 9 months, they found that he was positive. I blame myself every day and wished I had told my grandmother the truth, but I was very scared, and I am still scared* (Tandzile).

Discussion

The above participant had not disclosed her status due to fear, so when she was compelled to mix-feed the baby, something she was advised against at the clinic. She gave in, putting the baby at risk, which resulted in her baby converting and contracting HIV, and this led to chronic guilt for her. This shows the importance of disclosure and its effect not only on support but adherence as well. Griswold and Pagano-Therrien (2020) concur that HIV-positive mothers who withhold disclosure of their status to their families, in-laws, or partners have challenges with exclusive breastfeeding in the first 6 months of life and are pressured to mix-feed.

> *When I discovered about my status my boyfriend ran away and did not accept that we are HIV-positive, and I felt so lonely* (Sindiswa).

> *Lack of support from my partner who disappeared upon disclosure made me feel unimportant it was very bad to feel discriminated by the person I loved* (Tandzile).

Discussion

Lack of support from significant others can follow disclosure of one's HIV status, as seen with Sindiswa and Tandzile’s experience. This lack of support may lead to feelings of isolation and inadequacy in the individual who has been diagnosed with HIV, affecting their mental health. Another participant indicated fear of being blamed for bringing HIV into the family as a barrier to disclosure. There seems to be a misconception among couples that the first to test and learn of their HIV diagnosis are the ones responsible for HIV infection should the other partner test positive as well. This does not take into consideration that often when it comes to help-seeking behaviour, men are more likely than women not to seek help from health professionals (Galdas, Cheater & Marshall, 2005; Sagar-Ouriaghli et al., 2019).

Also, men are known to be reluctant when it comes to HIV testing and are never subjected to compulsory testing, unlike pregnant women (Hlongwa et al., 2020). Hence, women are most likely to be the first to know their HIV status and endure being blamed and labelled upon disclosure. On the one hand this results in some women not disclosing and suffering in silence. On the other hand, it is observed that men tend to display a significant aversion towards utilising health services, such as undergoing HIV testing. This behaviour can be attributed, at least in part, to the prevailing societal norms surrounding masculinity, which discourage men from engaging in health-seeking activities (Siu, Seeley, & Wight, 2014). The gendered dynamic becomes more intricate within the realm of prenatal care, as pregnant individuals commonly undergo HIV screening as a customary element of antenatal care protocols (Centres for Disease Control and Prevention, 2020). The feminist phenomenological perspective argues that mandatory HIV testing exposes women to potential harm and risks such as violence, abuse, and abandonment by their partner (Kuchukhidze et al., 2023). Also, it can reinforce the stereotypes and prejudices that blame and stigmatise women for being responsible for the HIV epidemic and ignore the structural and systematic factors that perpetuate the vulnerability of women (Kalichman et al., 2020).

> *I was afraid that maybe at my baby daddy's home, they were going to say I came with the virus and things like that, so I was afraid, really afraid* (Tanele).

> *Men usually say that they are not responsible for the HIV infection of their partners, and yet when you know as a woman that you haven't had any other sexual partner except your man, you must then accept even though they are very insulting…even the mother-in-law will say that you are the one who wants to kill their children but then when you know the truth* (Sito).

Discussion

Sito’s experience highlights the difficulty of grappling with partners who are unwilling to acknowledge their responsibility in the transmission of HIV, exacerbating the marginalisation of women who are already burdened with the emotional weight of a diagnosis of HIV. The feminist phenomenological methodology emphasises the need to comprehend and address the distinct encounters and obstacles that are faced by women who are living with HIV in the context of prejudice and marginalisation. This is done by placing emphasis on the necessity of understanding and confronting these specific encounters and obstacles.

The stigmatisation and discriminatory attitudes towards individuals living with HIV can result in their social isolation and exclusion, ultimately leading to adverse effects on their mental wellbeing (MacLean & Wetherall, 2021). Stigma and discrimination can be actual or perceived; the participant above assumed she would not be accepted; hence, she withheld disclosure and faced the negative consequence of her child contracting HIV. Sometimes, stigma and discrimination are learned. Participants reported that the way their family members responded when others disclosed their status made them vow never to disclose to them.

As seen with the participant below, who also did not adhere well to treatment because she had not disclosed:

> *I would take the treatment and at times I wouldn’t, because I hadn’t told my partner… as time went on, he fell ill, and I advised him to go to the hospital and get tested and so we are now both on the treatment and we now put our bottles together and we take our treatment* (Nontobeko).

Discussion

The apprehension of experiencing discrimination and social exclusion may dissuade some pregnant women who are HIV-positive from disclosing their status and getting the support they need. This was evident as some participants could not disclose their status because of fear of stigma and discrimination, and this, in turn, affected their adherence to treatment and care for babies, resulting in unfavourable outcomes. However, the majority of the participants, with time, were able to disclose their issues to family members and get the support needed not just for themselves but with their children as well. The issue of stigma and discrimination has been found to pose a considerable obstacle for expectant mothers living with HIV in developing nations (WHO, 2016; Wei, 2016).

4.5.2 Theme 2: Normalization and acceptance

The experiences of the participants provide insight into a variety of strategies that they utilised to address stigma and discrimination associated with HIV during pregnancy. These strategies are normalization, acceptance, open communication, social support, information searching, and faith. Participants indicated that acceptance and normalization of having HIV help to reduce stigma, as seen in the following excerpt.

> *When you are pregnant and yet you have the virus, there isn't much of a difference to someone who doesn't have the virus except that in your case you have to follow what is being said at the clinic, there's no difference really because you breastfeed your baby like other women out there and also the baby will not get infected if you are taking your treatment and checking your viral load now and then (Sindiswa).*

> *I was nervous but then again, I felt everything would be fine simply because I was looking at the high number of people who are on the treatment and I felt let me continue as everything will be fine* (Nontobeko).

Discussion

Sindiswa and *Nontobeko* highlighted the importance of accepting and normalising the experience of living with HIV even during pregnancy, suggesting that there was no significant difference between someone who was pregnant and HIV-positive and someone who was not, as long as the individual was adhering to medical advice and took the necessary precautions. This viewpoint is consistent with Earnshaw and Chaudoir (2009), who contend that normalization and acceptance of the illness are necessary for eliminating the stigma associated with HIV.

4.5.3 Theme 3: Open communication with partners and family

The participants also expressed that open communication with their close family members and partners helped them cope with the situation, as it let them express their thoughts and open up about their status. The excerpts below show this:

> *What helped me was to sit down with my partner and I told him that I have discovered that I have this thing and if you cannot accept me the way I am there's nothing I can do and he also went there and got tested and then he gave me some courage to take my treatment*

> *without hiding because I was hiding when taking them because I was afraid…another thing that I did, I knew that my husband would never cook pap so I would hide the treatment in the mealie-meal (laughter), he was 100% sure that I was not on the treatment because he had never seen them yet when the alarm rings I would leave him in the sitting room and go to the kitchen where we keep the mealie-meal and take my treatment* (Tanele).

> *I did not worry much about people, talking about everything to my partner opened a room for acceptance, compassion, and self-confidence* (Sito).

Sito and *Tanele* highlighted the importance of honest and open communication with partners and family members, which may promote an environment of acceptance, compassion, and self-confidence. They also underlined the importance of maintaining healthy relationships. Smith, Rossetto and Peterson (2008) demonstrate that open communication and disclosure may result in greater social support and improved mental health outcomes for people living with HIV.

4.5.4 Theme 4: Faith and pursuit of knowledge

The need for social support was recognised as a significant factor throughout the research. *Tandzile* and *Nomusa* emphasised the role of family and community support in helping them cope with the challenges of living with HIV. This is consistent with other studies that show social support is essential for enhancing the psychological wellbeing and consistent quality of life of people living with HIV (Rueda et al., 2016).

> *My family supported me we had discussions as to how to be more positive, and I prayed a lot (Tandzile).*

> *My mother organised the ladies from church who are a support group in telling me that life will be normal after all (Nomusa).*

Discussion

Participants said that their faith and spirituality provided them with a source of strength while negotiating HIV and stigma during pregnancy. The importance of faith and spirituality in navigating HIV-related issues is shown in *Tandzile's* remark on the role of prayer as their coping strategy. Maragh-Bass, Sloan, Alghanim, and Knowlton (2021), discovered that spirituality and religious coping have a good influence on the mental health and wellbeing of people living with HIV.

Some participants sought knowledge within their sphere of influence to gain insight, empower themselves, and combat distress. Participant 8's technique of seeking information on living with HIV throughout pregnancy was a great example of the importance of being informed and educated about the illness. According to Kalichman and Grebler (2010), providing individuals who are affected with access to factual information may help minimise the stigma associated with HIV and promote self-efficacy as well as coping abilities.

> *Through reading the leaflets we get at the clinics of which I would read them a lot and I don't want to lie about that because I wanted to know what was happening to my baby and what is happening to me…I would read a lot…and so seeing that the chances of having an HIV-negative baby were high, it then made me feel that my baby could be protected, like at 6 months I realised that the ball was in my court and so for me to have an HIV-negative baby is through treatment taking (Nongcebo).*

The experiences of the participants and the strategies they used to combat prejudice and stigma connected to HIV during pregnancy demonstrate the importance of acceptance, normalization, open communication, social support, gaining knowledge, and spirituality.

4.6 EXECUTIVE SUMMARY OF THE FINDINGS

This chapter synthesized the experiences of women diagnosed with HIV during pregnancy, addressing the emotional, psychological, social, and economic challenges and opportunities they face. The analysis reveals a spectrum of emotional responses, from shock and fear to acceptance and relief, shaped by factors such as participants' understanding of HIV and the support they receive. Social and economic difficulties are marked by stigma and discrimination, compounded by resource constraints. Conversely, support from families, partners, and healthcare providers presents significant growth opportunities.

Key themes identified include the impact of mandatory HIV testing, the initial shock of testing positive, preoccupation with mother-to-child transmission, the emotional strain of routine infant HIV testing, and breastfeeding challenges. These themes highlight the complex realities of the participants' experiences. Adaptive strategies like normalization, acceptance, open communication, and active support-seeking are crucial in helping participants manage the implications of an HIV diagnosis during pregnancy.

From a feminist phenomenological perspective, the study underscores the necessity for supportive interventions tailored to the intricate needs of these women. It calls for healthcare policies and practices that are informed by the lived experiences and voices of women diagnosed with HIV during pregnancy, ensuring that interventions are empathetic and comprehensive. From the findings it is evident that the medical care received by the participants was efficient in that availability and access was not a challenge. However the psycho-socioeconomic component can be prioritized. Safe spaces where the women can be helped to unpack their fears, struggles and stresses and be empowered with healthy coping strategies. This can prevent and alleviate development of disorders and also enable early identification and intervention of psychological conditions. Support groups for these women can also include economic empowerment programs to enable them to gain their independence and autonomy in decision making and having means to take care of themselves without relying on anyone which eliminates the risk of abuse. Interventions that will not only focus of ART and adherence but giving on-going psychological support and care to assess risk, anxiety, depression, stress, abuse etc. and intervene accordingly. Capacitate women to deal with stigma and discrimination. Psychological screenings to be carried out with every ANC appointment. Psycho-education on mental health conditions and management. Involving partners in ANC can increase support and facilitate disclosure. Economic empowerment for the women can give them autonomy in decision making for instance with regards to breastfeeding. Emotional preparedness and awareness needed before routine infant testing. The subsequent chapter will present conclusions derived from these discussions, outline the study's limitations, and suggest directions for future research.

CHAPTER 5

RECOMMENDATIONS AND CONCLUSIONS

5.1 INTRODUCTION

This chapter summarises the findings of the study and states their implications, limitations, contributions and recommendations. The chapter is divided into four main sections. The first section discusses the findings of the study, the research question and objectives and the literature review. The second section discusses the implications of the findings for the health care providers, policymakers, and other stakeholders who are involved in the design and delivery of HIV/AIDS and maternal and child health services and programmes. The third section discusses the limitations of the study and the challenges and difficulties that were encountered during the study. I conclude by offering the fourth section which discusses the contributions of the study and the originality, significance, relevance of the findings and recommendations.

Numerous pieces of evidence show that receiving an HIV diagnosis can be the beginning of life challenges and extraordinary personal adjustments, which can be psychologically overwhelming (Roberts et al., 2021). This study sought to explore and describe the lived experiences of women diagnosed HIV-positive during pregnancy. The main research question that guided this study was: what are the experiences of women diagnosed with HIV in Eswatini?

The sub questions of this study were:

- What are the emotional and psychological reactions and responses of women who are diagnosed with HIV during pregnancy in Eswatini?
- What are the social and economic challenges as well as opportunities encountered by women who are diagnosed with HIV during pregnancy in Eswatini?
- How does emotional, psychological, social, and economic challenges and opportunities that women who are diagnosed with HIV during pregnancy in Eswatini influence their physical and mental health?
- What are the best practices and strategies that can enhance the coping and wellbeing of women diagnosed with HIV during pregnancy in Eswatini?

This study aimed to provide a deeper and richer understanding of the lived experiences of women who are diagnosed with HIV during pregnancy in Eswatini.

The specific objectives of this study were:

- To explore and describe the emotional and psychological reactions and responses of women who are diagnosed with HIV during pregnancy in Eswatini.
- To explore and describe the social and economic challenges and opportunities that women who are diagnosed with HIV during pregnancy in Eswatini encounter and experience.
- To examine how the emotional, psychological, social, and economic challenges and opportunities that women who are diagnosed with HIV during pregnancy in Eswatini influence their physical and mental health,
- To identify and recommend the best practices and strategies that can enhance the coping and wellbeing of women diagnosed with HIV during pregnancy in Eswatini.

The study used a qualitative approach, with a phenomenological design. The study employed face to face, semi structured interviews with 10 women who were diagnosed with HIV during pregnancy in the Shiselweni region of Eswatini to gain deeper insights into their experiences.

5.2 SUMMARY OF THE KEY FINDINGS

The findings of the study are based on the data analysis of the interviews with the participants and the documents that were related to the research topic. The findings show the different emotional, psychological, social, and economic challenges and opportunities that the participants faced after being diagnosed with HIV during pregnancy in Eswatini. They further show how these challenges and opportunities affected their health outcomes, their relationships, and their children. The findings are discussed in the research question, objectives and literature review.

5.2.1 Emotional and Psychosocial Challenges and Opportunities

The first objective of the study was to explore and describe the emotional and psychological reactions and responses of women who are diagnosed with HIV during pregnancy in Eswatini. The findings revealed that the participants experienced various emotions and feelings after receiving their HIV test results, such as shock, disbelief, denial, anger, sadness, fear, anxiety, depression, guilt, shame, hopelessness, acceptance and relief. The findings also revealed that the participants' emotional and psychological reactions and responses were influenced by various factors, such as their knowledge and awareness of HIV, their expectations and assumptions of their HIV status, their previous and current experiences with HIV, their coping and resilience skills, and their sources and levels of support. The study revealed that women diagnosed HIV-positive during pregnancy experience the same grief reactions and responses upon diagnosis as the general population except for anxiety that accumulates as the pregnancy progresses and lingers through the infant testing routine.

The findings also revealed that the participants' emotional and psychological challenges had various effects and outcomes on their physical and mental wellness. Adherence to ART and PMTCT, delivery and post-natal care, breastfeeding and infant feeding options, reproductive health, their relationships, and their children's health and development were also revealed. The findings of the study are consistent with the literature review, which indicated that pregnant women who are diagnosed with HIV experience a range of emotional and psychological challenges such as fear, anxiety, depression, stigma, discrimination, violence, poverty, and lack of access to health care and support services (Osborn et al., 2022; Kuchukhidze et al., 2023; Yousuf et al., 2020). The literature review also indicated that these challenges affect their physical and mental wellbeing, their adherence to ART and PMTCT, their delivery and post-partum experience and their children's health and development (Kapetanovic et al., 2014 & Mavhu et al., 2020).

The findings of the study are also consistent with the feminist phenomenological theoretical framework which was used as a lens to guide the research. The findings of the study showed that the participants experienced stress after being diagnosed with HIV during pregnancy and that they used various coping strategies, such as spirituality, acceptance, and social support, to deal with their stress and adjust to their situation. The findings also provided some new insights and perspectives that are not well documented or explored in the existing literature. For example, the findings of the study showed that the participants experienced significant emotional and psychological reactions during infant HIV testing and that they were unprepared for the experience. Forewarned is forearmed. This lack of awareness and preparation caused significant distress and drastic decision-making regarding their reproductive health. Their responses, such as shock and disbelief, anger and sadness, fear and anxiety, guilt and shame that they moved back and forth among these stages and phases bear testimony.

5.2.2 Social and Economic Challenges and Opportunities

The second objective of the study was to explore and describe the social and economic challenges and opportunities that women who are diagnosed with HIV during pregnancy in Eswatini encounter and experience. The findings revealed that the participants faced various social and economic challenges after being diagnosed with HIV during pregnancy, such as stigma, discrimination, rejection, poverty, unemployment, and lack of resources like baby feed options. The opportunities they had were finding support, acceptance and information. The findings also revealed that the participants' social and economic challenges and opportunities were influenced by factors, such as their gender, education, occupation, income, location, family and community.

It was revealed that the social and economic challenges had effects on their physical and mental wellbeing, their infant feeding options, their relationships and their children's health and development. The findings of the study are consistent with the literature review, which indicated that pregnant women who are diagnosed with HIV encounter and experience various social and economic challenges such as stigma, discrimination, violence, isolation, rejection, poverty, unemployment, lack of transport, lack of education, lack of information, lack of resources, lack of services, as well as opportunities such as support, acceptance, empowerment, solidarity, advocacy, awareness, income, employment, transport, education, information, resources, and services (Yousuf et al., 2020; Mackworth-Young et al., 2020; Psaros et al., 2020).

The literature review also indicated that these challenges and opportunities affect their physical and mental health, their adherence to ART and PMTCT, their breastfeeding and infant feeding practices, their sexual and reproductive health, their marital and family relationships, and their children's health and development (Osborn et al., 2022; Biomndo et al., 2021). The findings of the study are also consistent with the theoretical framework of the study, which was the feminist phenomenological model. This model proposes that women, being the vulnerable population, are affected by social norms and expectations, which shape their decisions, contributing to social isolation, discrimination, and blame (Loick, 2020; Butler, 2020). The findings showed that the participant's social and economic challenges were influenced by multiple and interrelated levels of factors, such as individual, interpersonal, organisational, community, and societal factors. They did not receive psychological interventions nor have access to any programmes at different levels to improve their health outcomes and behaviours.

There is also provision for some new insights and perspectives that are not well documented or explored in the existing literature. The findings showed that the participants faced different forms and manifestations of social and economic challenges. This includes infant feeding options as the formula was the preferred choice for the participants. However, only a few were able to afford it, except those who were working or were assisted by their partners. The findings further showed that the participants perceived breastfeeding in a negative light, as something to avoid, a challenge and a risk to their babies however due to economic constraints they had to practice it.

The findings also showed that the participants faced different consequences and impact of social and economic challenges and opportunities, such as mental, personal, interpersonal, behavioural, and attitudinal.

5.3 IMPLICATIONS OF THE STUDY

This study provided extensive insights for healthcare providers and policymakers associated with designing and implementing HIV, maternal, and infant care programmes. Understanding the psychological, emotional, social, and economic challenges faced by women diagnosed with HIV during pregnancy was essential to develop adequate interventions necessary to improve health outcomes. In this instance, it is required that healthcare providers provide tailored support services that help address the emotional and psychological concerns of women following their HIV diagnosis during pregnancy. The provision of counselling, mental health support, and educational resources may empower women to cope with depression and anxiety associated with HIV diagnosis during pregnancy (Oshosen et al., 2021). Extending counselling services to significant others and family members may also increase their involvement in providing emotional support to women with HIV, which can effectively enhance their mental wellbeing (Yousuf et al., 2020).

Policymakers are required to implement educational interventions that aim to address stigma and discrimination against pregnant women with HIV at individual and community levels (Earnshaw et al., 2020). It may help increase awareness while enhancing community engagement to provide pregnant women with a supportive environment necessary to safeguard their emotional and physical wellbeing. It may reduce the lack of disclosure prevailing among pregnant women with HIV and could inhibit the prevalence of violence and discrimination against their medical condition (Mackworth-Young et al., 2020). Furthermore, socioeconomic interventions can help address issues regarding poverty and unemployment among women. These interventions may enhance their quality of life and reduce their inclination toward transactional intercourse, which increases the risk of HIV transmission (Cavazos-Rehg et al., 2020). Economic empowerment may ensure that women have access to employment opportunities, which could increase their access to resources that safeguard their physical and mental wellbeing (Sia et al., 2020).

5.4 LIMITATIONS OF THE STUDY

This study provided insights regarding the emotional and psychological reactions and social and economic challenges faced by pregnant women with HIV, but the findings were limited to Eswatini and may not be generalised for different geographical and cultural settings. The sample size and selection process may cause bias in findings, as the participants who refused to participate in the study could have provided diverse experiences, changing the breadth of information covered in this study. The findings were significantly dependent on the participants' recollection of past experiences, which may cause the prevalence of recall bias, affecting the accuracy of responses. The subject of HIV and pregnancy is sensitive, due to which participants could have altered their responses to demonstrate their adherence to socially acceptable norms and values, which may cause social desirability bias. Also, the study focused on women aged between 19 and 35 excluding teenagers aged 18 and below yet teenage pregnancy accounts for 24% for all pregnancies in Eswatini (Dlamini, 2019), this was due to ethical considerations.

5.5 CONTRIBUTIONS OF THE STUDY

This study provides extensive insights into the emotional, psychological, social, and economic challenges and opportunities faced by pregnant women with HIV. The utilisation of a feminist phenomenological perspective helped understand the prevalence of societal norms and expectations shaping the lived experiences of pregnant women with HIV. This study has determined the significance of emotional and psychological concerns during infant HIV testing, followed by the social and economic challenges women face in coping with their health concerns while maintaining secrecy to avoid stigma and discrimination. It eventually provides a comprehensive understanding of challenges and coping mechanisms women implement to maintain adherence to their treatment. Identification of these challenges leads to the development of adequate interventions and strategies to enhance the coping mechanism for women to enhance their wellbeing and reduce the risk of vertical transmission of HIV to enhance health outcomes in the long term.

5.6 RECOMMENDATIONS

The findings of the study show that the women appreciate the health education on HIV, treatment and importance for adherence that they received at the clinic yet they still experienced distress and anxiety throughout their pregnancy due to fear of infecting their unborn babies hence the following recommendations:

- Comprehensive care for pregnant women diagnosed with HIV targeting not only medical and physical health but mental health as well.
- A multidisciplinary team is essential in meeting the needs of women negotiating pregnancy and a positive HIV status.
- Ongoing psychological support needed during pregnancy and post-natal
- Psychosocial training for HIV testing counsellors to identify and screen for psychological conditions and make referrals.
- For the women who have disclosed to partners and family to be encouraged to come together for baby appointments for routine HIV testing for emotional support.
- Support groups for women diagnosed with HIV during pregnancy.

5.7 SUGGESTIONS FOR FUTURE RESEARCH

Given the findings of this study, the following recommendations are made for future research:

- Considering covering all 4 regions of Eswatini and including teenagers.
- Identifying coping measures for mothers during routine infant HIV testing.
- Investigating women who refuse or delay ART initiation.

- Finding community perceptions of pregnant women living with HIV.
- Exploring how teenagers negotiate pregnancy and HIV diagnosis.
- Investigating the role of partners of women negotiating pregnancy and HIV diagnosis.

5.8 CONCLUSION

This research has meticulously explored the multifaceted experiences of women diagnosed with HIV during pregnancy in Eswatini. The study's in-depth interviews and qualitative analysis have unveiled the profound emotional, psychological, social, and economic dimensions that characterize the lives of these women. Emotionally and psychologically, women grapple with a spectrum of reactions from disbelief and fear to eventual acceptance, influenced significantly by their support networks and prior understanding of HIV. Socially and economically, challenges like stigma and financial insecurity are pervasive, often exacerbating the psychological burden of living with HIV. However, opportunities for empowerment through community support and tailored healthcare interventions also emerge as pivotal elements that can enhance these women's quality of life. The implications of these findings are profound for healthcare providers and policymakers. Furthermore, the study's recommendations stress the importance of inclusive care practices that consider the voices of these women in the design and implementation of HIV and maternal health services. Future research should expand this work's geographical and demographic scope, exploring the experiences of younger and more diverse populations to enhance the generalizability and impact of the findings.

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APPENDICES

Appendix A: Approval Letter

ESWATINI HEALTH AND HUMAN RESEARCH REVIEW BOARD

MBANDZENI HOUSE, 3RD FLOOR, CHURCH STREET
P.O. BOX 5, MBABANE, ESWATINI

ONE-YEAR RESEARCH PROTOCOL APPROVAL CERTIFICATE

BOARD REGISTRATION NUMBER	FWA 00026661/IRB 00011253					
PROTOCOL REFERENCE NUMBER	**EHHRRB165/2022**					
Type of review	Expedited	X	Full Board			
Name of Organization	**Masters Student**					
Title of study	Experiences of adolescent girls and young women diagnosed with HIV during pregnancy: a qualitative study in Shiselweni region, Eswatini.					
Protocol version	1.0					
Nature of application	New X	Amendment	Renewal	Extension	CTupdaccs	
List of srudy sires	Magubheleni Clinic, Gege Clinic, MabJandle Clinic, Tfokotani Clinic, SOS Clinic, Zombodze Clinic, Mkhitsini Clinic, FIJ\II Clinic, and Dwaleni Clinic					
Name of Principal Investigator	**Mrs. Munyaka Sindisiwe Simphiwe**					
Names of Co- Investigators	Prof Puleng Segalo					
Names of steering committee members in the case of clinical trials	N/A					
Names of Dara and Safety Committee members in the case of clinicaJ trials	/A					
Level of risk (rick appropriate box)	Minimal X		**More than minimal**		High	
Initial study .-\pproval information	**Approved**	X	**Study completion date**	31/12/2023	**Certificate expiry Date**	10/03/2024
	Approval date	10/03/2023				

Appendix B: Participant Informed Consent Declaration

INFORMED CONSENT DECLARATION

(Participant)

The study title: "Waiting to Exhale": The Lived Experiences of Women Diagnosed HIV Positive during Pregnancy in Eswatini

This informed consent is for women aged 19 and 35 years who learnt of their positive HIV diagnosis during pregnancy.

The informed consent has two parts:

Part 1: Information sheet (to share information about the research with you).

Part 2: Certificate of consent (for signatures if you agree to take part in the study).

You will be given a copy of the informed consent form either in English or siSwati as per your choice.

Part 1: Information sheet (English)

1. Introduction

I am Simphiwe Sindisiwe Munyaka a master's student in Psychology at the University of South Africa, under the supervision of Professor Puleng Segalo. I would like to invite you to participate in this study. This information sheet presents the reasons for this study. It also discusses the implications if you agree to participate. Please take your time to ask any questions you may have regarding this study before you accept to participate. There may be some words that you do not understand. Please ask me to stop as we go through the information, and I will take time to explain. If you have questions later, you can still ask them to me.

2. Purpose of the research

Pregnancy and an HIV diagnosis can have devastating effects on an individual depending on many factors. This study aims to gain insight into how adolescent girls and young women are impacted by an HIV diagnosis during pregnancy. This study will be carried out in nine health facilities in the Shiselweni region.

3. Participant selection

If you were diagnosed HIV-positive during pregnancy while attending routine antenatal care (ANC), you are willing and comfortable to share your experience, you can express yourself in your language.

Participation in this study is voluntary. You have the option to choose to participate or decline. You may withdraw from the study at any time without giving a reason or explanation. Your decision will not result in any loss of benefits regarding accessing health care in any of the facilities where the study will be carried out. If you choose to withdraw from the study, I will not continue collecting data from you and one that has been collected already will not be used in the study but be disposed of.

4. Procedures and protocol

Routine HIV testing is compulsory for pregnant women attending antenatal care. HIV testing and counselling is done by lay counsellors trained in HTC (HIV testing and counselling) in all the facilities and it is done throughout pregnancy. When a pregnant woman is tested HIV-positive, she receives counselling and health education and is encouraged to start ART to prevent HIV infection of unborn babies. She is also encouraged to choose a family member she can trust to be her treatment supporter and is also encouraged to disclose her status to that person. They are empowered on how to disclose and how it will benefit them. All records of pregnant women who tested positive for HIV are kept in the facilities.

First and foremost, the researcher will seek and obtain ethical clearance to do the study from the University of South Africa where it is supervised and the Ministry of Health of eSwatini where it will be carried out. Once ethical clearance is granted the researcher will approach the different sisters in charge in the nine facilities to notify them about the study and assistance with contacts of relevant participants. The sisters in charge will notify relevant participants and ask for their permission to share their contact if interested in knowing more about the study. Once permission is granted the researcher will telephonically reach out to parents of potential participants and tell them about the study (encourage them to discuss with their children) and if they are interested to know more, set up an appointment during their routine clinic visits for refilling. They will be told in detail about the study.

Principles of good clinical practice such as assuring ethic principles, risk minimisation, adequate information and professionalism will be applied throughout the study. If you are willing and interested and you consent to participate in the study you will be interviewed by the researcher regarding your experience in finding out your HIV status in pregnancy. The interview will take place in the facility, in one of the counselling rooms and will recorded on a voice recorder.

5. Risks

Some risks may be associated with this study, for example. emotional problems may arise from recollection of past and ongoing events and appropriate steps will be taken to prevent and minimise the risks. The facility-trained counsellors will be on standby to offer counselling when needed. The interviewer will be as professional as possible, and all questions and how they are asked will be approved by the supervisor. There is no reimbursement of any kind in participation of this study, but should you need further counselling with a psychologist, It will be arranged with the regional psychologist, Tematima Dludlu cell no: 0026878600160.

6. Confidentiality

All information collected during the study will be strictly confidential. Information that will be collected during the study will be put away and locked in a locker and no one but the researcher will have access to it. In a locker assigned and only accessible to a researcher at her place of work, Medicins Sans Frontieres (MSF). A pseudonym will be used instead of your real name. Your names or identification will not be displayed on any reports, presentations or publications resulting from this study.

7. Sharing the results

At the end of the study, if you are interested in the study outcomes, the results will be shared with you. The results will also be shared in other psychology conferences and journals. The results of this research will contribute to the knowledge base in the health sector and will also save as a starting point information essential for further research about adolescent girls and young women on the challenges they encounter with navigating pregnancy and HIV diagnoses. It can influence policy on psycho-social support for young women negotiating a pregnancy and an HIV-positive status; raise community awareness on the impact of pregnancy and HIV among young women and the role of the community as well as come up with relevant intervention strategies for pregnant HIV-positive young women.

8. Right to refuse or withdraw

You do not have to agree to take part in this study if you do not wish to. You are free to withdraw at any time or refuse to respond to any questions if you feel they will cause any discomfort, or distress or for no reason.

9. Who to contact

If you have any questions about the study or issues arising after taking part in the study, you are free to ask the researcher and her supervisor at:

Researcher: Simphiwe Munyaka Cell no:

0026878174912

Supervisor: Prof Puleng Segalo email at:

Segalpj@unisa.ac.za

Part 2: Certificate of consent

I ....have read the above information, and I confirm that the

above information has been explained to me in a language that I understand, and I am aware of this document’s contents. I have asked all questions that I wished to ask, and these have been answered to my satisfaction. I fully understand what is expected of me during the research.

I have not been pressurised in any way and I voluntarily agree to participate in the above-mentioned project.

……………………………..	…………………………..
Participant’s Signature	Date

The information sheet and consent form (Siswati Version)

Sihloko selucwaningo: “Kulindza Kuphefumula”: Loku Bantfu Labasikati Labahlangene Nako Ngesikhatsi Batfolwa Banesandvulelangculazi Ngesikhatsi Bakhulelwe Eswatini

Lifomu lesivumelwano lebantfu labangenele lelicwaningo lelibuka kabanti ngekwati ngesimo sakho se HIV ngesikhatsi ukhulelwe.

Lelifomu lesivumelwano lineticephu letimbili:

Sicephu sekucala: umniningwane lotokwatisa ngelucwaningo.

Sicephu sesibili: lifomu lesivumelwano lapho khona utosayina uma uvuma kuba yincenye yalolucwaningo.

Utawuniketwa lifomu lesivumelwano lelitawuba ngesingisi nobe ngesiswati, kutawukhetsa wena.

Sicephu sekucala: umniningwane welucwaningo.

1. Singeniso

Libito lami ngingu Simphiwe Munyaka ngenta lucwaningo ngekwati ngesimo sakho sengati uma ukhulelwe. Ngitokunika umniningwane ngiphindze ngikumeme kutsi ube yincenye yalolucwaningo. Ungabese uyakhetsa kutsi uyafuna nobe awufuni kuba yincenye yalolucwaningo. Ngitsandza kukumema kutsi ube yincenye yalelicwaningo. Ukhululekile kutsi ukhetse kulungenela nobe ungalungeneli lolucwaningo ekubeni sewucabangisisile. Tsatsa sikhatsi sakho ungajaki kutsatsa sincumo. Kungenteka kube nemagama longawacondzisisi nobe tintfo lofuna ngitichaze kabanti. Ngicela ungimise nobe kunini ngisazama kukuchazela nganaku lokulandzelako.

2. Injongo yalelucwaningo

Injongo yalelucwaningo kucondzisisa kabanti kutsi timo tini bantfu labakhulelewe futsi batfolakale kutsi baneligciwane le HIV labahlangabetana nato.

3. Kungenela lolucwaningo

Wati kutsi uneligciwane le HIV ngesikhatsi ukhulelwe. Ngako ke uyamenywa kutsi ungenele lolucwaningo. Akukameli ulungenele lucwaningo uma ungafuni. Kukuwe kutsi uyalingenela noma cha. Uma ukhetsa kungalungeneli kulungile kute lokutoshintja. Utochubeka usebentise sibhedlela njengenhlalayenteka. Nobe ungatsi uyavuma nyalo bese ushintja umcondvo esikhatsini lesitako, naloko solo kulungile. Uma sewukhetsa kuyekela kuba yincenye yelucwaningo emkhatsini, ngeke siyisebentise iminingwane yakho uma sekuhlatiwa imiphumela yelucwaningo. Naka kutsi uyacondzisisa yini: uma ukhetsa kungalungeneli lolucwaningo, solo kulungile. Akukamele kutsi ulungenele lolucwaningo uma ungafuni. Kukhona yini imibuto?

4. Imigomo nemibandzela: kutokwentekalani kimi?

Utokuta emtfolampilo ngelilanga lakho lekukala sisu noma umntfwana noma utolandza emaphilisi.

Sitococisana khona lapho singeke siphatamiseke khona. Ngitokubuta imibuto ngiyitsebule.

5. Bungoti lobungabakhona Kimi

Kesengenteka kutsi sisacocisana kuvuke imicabango nemizwa lebuhlungu. Uma kwenteka loko bakhona beluleki na Songcondvongcondvo batokusita bakululeke. Uma kukhona lokwenteka kuwe sisacocisana utongatisa kumele ukhululeke ungishayele noma nini uma kukhona lokhatsateke ngako nobe uma unemubuto.Uma kwenteka udzinge kwelulekwa usangele lolucwaningo utobona Songcondvongcondvo longu Tematima Dludlu, inombolo yakhe:0026878600160

6. Kugcinwa kwetimfihlo

Umnininingwane lotawukolekwa kusachubeka lucwaningo utawugcinwa uyimfihlo. Libito lakho nobe matisi wakho angeke kuvele ndzawo kutetfulo telucwaningo. Ngitawucinisekisa kutsi kute umnininingwane lotokufaka engotini yekutsi kwembuleleke bunguwe bakho. Ekupheleni kwelucwaningo, Ngitawugcina umnininingwane wakho, onkhe emafomu, tivumelwane letisayiniwe kanye nato tonkhe timphepha talolucwaningo kuphephile iminyaka lesihlanu emahhovisini aboDokotela labangenamncele e Nhlangano ngaphansi kwalobuke liphiko lebacwaningi, lapho ngisebentela khona.

7. Tetfulo telucwaningo/kwabelana ngemiphumela

Uma seliphelile lucwaningo uvumelekile kutsi umphumela walo uwutfole uma ufisa. Imiphumela yalo lucwaningo itawutfulwa etigungwini letehlukene letifaka lihlangotsi laboSongcondvongcondvo, lababukete tindzaba te HIV/AIDS. Imiphumela yalo licwaningo itongeta lwati kabanti mayelana nensha letfola kwati ngesimo sabo se HIV uma bakhulelelwe, kuventa tingcinamba labahlangabetana nato.

8. Lilungelo lekwala nobe uphume kulelicwaningo

Kukuwe kutinikela kulelicwaningo, ungala uma utsandza futsi usengawushintja umcondvo uma ungasafuni kuchubeka. Kute inchazelo lekutofuneka uyisho. Phindze uvumelekile kutsi ungaphendvuli imibuto lobutwa yona mawungafuni kuphedvula, kungaba kutsi ayikuphatsi kahle noma kute sizatfu.

9. Ungachumana nabani

Uma unembuto ngelucwaningo nobe lokuvukako ekubeni ungenele lucwaningo, uvumelekile kubuta umcwaningi nobe sisebenti setemphilo lesitabe sikusita uma ubuyela esibhedlela, futsi ungashayela nayi inombolo nobe kunini;

Lobuke lucwaningo: Simphiwe
munyaka Inombolo:
00268 78174912

Tsatsa sikhatsi sakho ubute yonkhe imibuto lonayo uphindze ucinisekise kutsi iphendvulekile, uphindze ucondzisise kutsi kusho kutsini kungenela lolucwaningo. Uma uvuma kuba yincenye yelucwaningo, sisebenti setemphilo sitawucela kutsi usayine nobe ufake sitfupha efomini lesivumelwano. Lokusayina nobe lesitfupha sisho kutsi uyawucondzisisa umniningwane loniketwe wona kanye nekutsi imvume yakho usinike ngaphandle kwekukucindzetelwa.

Sicephu II: Sitifiketi sesivumelwano

Sihloko selucwaningo: “Kulindza Kuphefumula”: Loku Bantfu Labasikati Labahlangene Nako Ngesikhatsi Batfolwa Banesandvulelangculazi Ngesikhatsi Bakhulelwe Eswatini

Umbiko lochamuka kulongenela lucwaningo

Ngiwufundzile umnininingwane longenhla nobe ngifundzelwe. Ngilitfolile litfuba lekubuta imibuto kantsi futsi imibuto yami iphendvulwe ngenetiseka. Ngiyicondzisile injongo Kanye nenhloso yalolucwaningo kanye nalokungaba yingoti kanye nalokungaba yinzuzo kimi ngekungenela lolucwaningo. Ngekutinikela kwami ngiyavuma kuba yincenye yelucwaningo kantsi futsi ngiyacondzisisa kutsi ngingayekela nobe kunini kuba yincenye ngaphandle kwekunika tizatfu kantsi futsi loko angeke kutsikamete kwelashwa kwami. Ngiyavuma kutsi umcwaningi angicocise kabanti ngekukhulelwa kwami nangekwati ngesimo sami sengati. Ngiyavuma kungenela lolucwaningo kute longiphocelelako.

Kusayina longenela lucwaningo:_________________

___________________________ Libito lalongenela lucwaningo:_________________

____

Lusuku: ___________________________(Lusuku/inyanga/umnyaka)

Uma ungakhoni kufundza,

Uma lomuntfu longenela lolucwaningo angakhoni kufundza nobe kucondzisisa umnininingwane welucwaningo ngekwakhe, umcwaningi nobe sisebenti setemphilo sitakufundzela siphindze sikuchazele kabanti ngalomnininingwane sicinisekise kutsi uyawucondzisisa.

Appendix C: Questionnaire (English)

1. Biographic Information

Pseudonym ______________________

Age

____

____

____

Education

____

____

____

Marital status

____

Number of children

____

____

Occupation

____

____

____

2. Main question: What does it mean to be pregnant and HIV-positive? How did an HIV-positive diagnosis in pregnancy affect your life?

What challenges did you face living with HIV and being pregnant?

Follow-up questions:

Who did you open up to about your status?

What is it that you do to cope with living with HIV daily?

What can you say to healthcare workers working with mothers living with HIV?

1. Biographic Information

Ligama

mbumbulu_______________________

____

____

Umnyaka________________________

____

Libanga

lemfundvo_______________________

____

____

Sigaba sekwendza

____

____

Bantfwana lonabo_______________

Usebentani_______________________

2. **Umbuto logcamile**: coca kabanti ngesimo sekwati ngesimo sakho sengati ngesikhatsi ukukhulelwe, HIV Yini lowahlangabetana nako usaphila neligciwane phindze utetfwele?

Imibuto lengalandzela:

Ngubani lowambhobokela ngesimo sakho

sengati Umntfwana unjani yena?

Yini lokwentako emihleni lokwenta kutsi uphile kancono

naleligciwane? Ngubani lokusingatsile wena nemntfwanakho?

Ngekucabanga kwakho yini longeluleka ngako betemtfolampilo labasebenta nabo make labakhulelwe phindze labaphila neligciwane le HIV.

Appendix D: Ethical Clearance

COLLEGE OF HUMAN SCIENCES RESEARCH ETHICS REVIEW COMMITTEE

07 June 2022

Dear Simphiwe Sindisiwe Munyaka

NHREC Registration # :
Rec-240816-052
CREC Reference # :
11397993_CREC_CHS_2022

Decision:
Ethics Approval from 07 June 2022 to 07 June 2025

Researcher(s): **Name: Mrs SS Munyuka**
Contact details: **11397993@mylife.unisa.ac.za** **Supervisor(s):** **Name: Prof. P. Segalo**
Contact details: Segalpj@unisa.ac.za

Title: Experiences of adolescent girls and young women diagnosed with HIV during pregnancy: A qualitative study of Shiselweni Region, eSwatini

Degree Purpose: MA Psychology

Thank you for the application for research ethics clearance by the Unisa

The ***low risk application*** *was reviewed by* College of Human Sciences Research Ethics Committee, in compliance with the Unisa Policy on Research Ethics and the Standard Operating Procedure on Research Ethics Risk Assessment.

The proposed research may now commence with the provisions that:

1. The researcher(s) will ensure that the research project adheres to the values and principles expressed in the UNISA Policy on Research Ethics.
2. Any adverse circumstance arising in the undertaking of the research project that is relevant to the ethicality of the study should be communicated in writing to the College Ethics Review Committee.
3. The researcher(s) will conduct the study according to the methods and procedures set out in the approved application.
4. Any changes that can affect the study-related risks for the research participants,

College of Human Science Ethics Committee. Ethics approval is granted for three years.

confidentiality of the data should be reported to the Committee in writing, accompanied by a progress report.

5. The researcher will ensure that the research project adheres to any applicable national legislation, professional codes of conduct, institutional guidelines and scientific standards relevant to the specific field of study. Adherence to the following South African legislation is important, if applicable: Protection of Personal Information Act, no 4 of 2013; Children's Act no 38 of 2005 and the National Health Act, no 61 of 2003.
6. Only de-identified research data may be used for secondary research purposes in future on condition that the research objectives are similar to those of the original research. Secondary use of identifiable human research data requires additional ethics clearance.
7. No fieldwork activities may continue after the expiry date **(07 June 2025).** Submission of a completed research ethics progress report will constitute an application for renewal of Ethics Research Committee approval.

Note:

*The reference number **11397993_CREC_CHS_2022** should be indicated on all forms of communication with the intended research participants, as well as with the Committee.*

Khan

Yours sincerely,

Signature:

Prof. KB Khan
CHS Research Ethics Committee Chairperson
Email: khankb@unisa.ac.za
masemk@unisa.ac.za
Tel: (012) 429 8210

Signature: PP

Prof K. Masemola
Exécutive Dean: CHS
E-mail:

Tel: (012) 429 2298

Appendix E: Permission Letter

Telephone: (22078362)
Email: nhohealthojJJice@gmail.com
OFFICE

REGIONAL HEALTH

P.O. BOX 58
NHLANGANO
ESWATINI

THE KINGDOM OF ESWATINI

11th April 2023

Ms. Simphiwe Sindisiwe Munyaka

<u>YOU'RE REF: PERMISSION TO CONDUCT A STUDY</u>

Dear Madam,

Management hereby permits you to conduct a study at the above-mentioned facility to meet your academic expectations.

We wish you all the best in your endeavour.

Yours faithfully

MFANAW
REGION **<u>ENKHOSI MASEKO</u>**

AL PUBLIC HEALTH MATRON

Cc.

1. **Sr. Thabsile Zwane -----------Nhlangano Pu**

2. Sr. Themba Dlamini-----------Dwaleni Clinic
3. Sr. Jabu Hlophe----------------Mahlandle Clinic
4. Sr. Phumzile Myeza-----------FTM 2
5. S/N Nomvula Dlamini--------- Community & Textile Clinic
6. S/N Welcome Mdluli --------- Mashobeni Clinic
7. Staff/N Cebsile Dube-------------SOSClinic