Perceptions and experiences of HIV positive pregnant women on prevention of mother to child transmission programme in Manzini region, Swaziland

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In partial fulfilment of the requirements for the degree of

MASTER OF PUBLIC HEALTH

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DECLARATION

I, Nompilo Sibonakele Dlamini declare that “Perceptions and experiences of HIV positive pregnant women on the prevention of mother to child transmission (PMTCT) programme in Manzini region, Swaziland” is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references. It is being submitted for the degree of Master of Public Health at the Sefako Magkatho Health Sciences University. It has never been submitted before for any degree or any examination at this or any other institution.

________________________________   ________________________
SIGNATURE       DATE
Nompilo Sibonakele Dlamini
DEDICATION

I dedicate this study to my entire family, especially to my father Mr Isaac K Dlamini, my grandmother Emmelinah Dlamini and my siblings Zama, Banele and Vuyelwa.
ACKNOWLEDGEMENTS

I thank the Almighty God for making it possible for me to start and complete this study.

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- My friend Mr Sifiso Mhlanga who was tirelessly providing me with IT expertise throughout my study.
ABSTRACT

Background
Mother to child transmission (MTCT) of HIV remains a serious public health problem in sub-Saharan Africa. To combat the scourge of MTCT, a global strategy of Prevention of Mother to Child Transmission (PMTCT) was developed. How women experience PMTC has a bearing on its success.

Aim of the study
The study aimed to investigate the perceptions and experiences of HIV positive pregnant women on the PMTCT programme, in the Manzini region, Swaziland.

Method
This qualitative exploratory study used face-to-face in-depth interviews to collect data among 15 HIV positive pregnant women enrolled on a PMTCT programme in a health facility. Interviews were digitally recorded and transcribed verbatim for analysis. Data were coded, and themes emerged from the codes. Narrative organization of the themes was formulated.

Findings
The age range of participants was between 21 and 38 years. Generally, women reacted with different sad emotions after being diagnosed with HIV. Overall, all participants experienced PMTCT in a positive manner reporting it as a life saver for them and their babies. Mandatory HIV testing and same day ART initiation was perceived as being coercive. Mostly women had difficulty in disclosing their HIV to their partners. Long waiting times due to staff shortage was reported. Counselling from health care workers was found to be helpful for participants to accept HIV positive results and initiation to lifelong ART.
Conclusion
All participants in this study reported a positive experience of the PMTCT programme. However, disclosure of HIV status to partners remains a problem. Long waiting times and staff shortage created a health systems barrier in rendering PMTCT services.

Recommendation
The importance of intensified male partner involvement to facilitate disclosure is recommended. In addition, there is a need for ongoing psycho-social support services and adequate staffing in HIV care and treatment programmes including the PMTCT programme in the health facilities.
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<td>ANC</td>
<td>Antenatal Care</td>
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<td>ART</td>
<td>Anti-Retroviral Treatment</td>
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<td>AZT</td>
<td>Zidovudine</td>
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<td>CD4</td>
<td>Cluster of Differentiation 4</td>
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<td>HIV</td>
<td>Human Immune Virus</td>
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<td>MTCT</td>
<td>Mother to Child Transmission</td>
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<td>NVP</td>
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<td>PMTCT</td>
<td>Prevention of Mother to Child Transmission</td>
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<td>Swaziland Health Information Measurement Survey</td>
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<td>WHO</td>
<td>World Health Organisation</td>
</tr>
</tbody>
</table>
TABLE OF CONTENTS
DECLARATION .......................................................................................................................... ii
DEDICATION ........................................................................................................................... iii
ACKNOWLEDGEMENTS .......................................................................................................... iv
ABSTRACT ................................................................................................................................. v
  Background ........................................................................................................................... v
  Aim of the study .................................................................................................................... v
  Method ................................................................................................................................... v
  Findings .................................................................................................................................. v
  Conclusion ............................................................................................................................. vi
  Recommendation ................................................................................................................... vi
ABBREVIATIONS ................................................................................................................... vii
CHAPTER 1: INTRODUCTION AND BACKGROUND ......................................................... 1
  1.1 Introduction and Background ........................................................................................... 1
  1.2 Problem statement ............................................................................................................ 3
  1.3 Aim of the study ............................................................................................................... 4
  1.4 Research questions ......................................................................................................... 4
  1.5 Objectives ........................................................................................................................ 4
  1.6 Justification for the study ................................................................................................. 4
  1.7 Definition of terms .......................................................................................................... 4
    1.7.1 Conceptual definitions ............................................................................................... 4
    1.7.2 Operational definitions .............................................................................................. 5
CHAPTER 2: LITERATURE REVIEW .................................................................................... 6
  2.1 Introduction ...................................................................................................................... 6
  2.2 HIV prevalence among adults and children .................................................................. 6
  2.3 Description of mother to child transmission (MTCT) and prevention of mother to child transmission (PMTCT) ................................................................................................................................. 7
  2.4 PMTCT coverage in Sub Saharan Africa ....................................................................... 8
  2.5 Prongs of PMTCT .......................................................................................................... 8
  2.6 Benefits of PMTCT ........................................................................................................... 9
  2.7 PMTCT services during ANC period ......................................................................... 10
  2.8 PMTCT in Swaziland .................................................................................................... 10
  2.9 Rationale for prompt lifelong ART initiation for pregnant and lactating women in the PMTCT programme ................................................................................................................................. 11
4.2.2 HIV related data .......................................................................................................... 28
4.3 Qualitative findings ......................................................................................................... 29
4.3.1 Views about PMTCT programme ............................................................................. 29
4.3.2 Reactions after receiving HIV positive results .......................................................... 32
4.3.3 ART treatment ........................................................................................................... 35
4.3.4 Care in the PMTCT services ..................................................................................... 37
4.3.5 Views about Counselling .......................................................................................... 40
4.3.6 Partner involvement .................................................................................................. 41
4.3.7 Support ...................................................................................................................... 43
4.3.8 Stigma and discrimination ......................................................................................... 46
4.3.9 Disclosure .................................................................................................................. 47
4.3.9.1 Reasons for disclosure .............................................................................................. 51
4.4 Conclusion ...................................................................................................................... 52

CHAPTER 5: DISCUSSION, CONCLUSION, LIMITATIONS AND RECOMMENDATIONS ................................................................................................................................. 53

5.1 Introduction ..................................................................................................................... 53
5.2 Description of study participants ................................................................................... 53
5.2.1 Socio-demographic information .................................................................................. 53
5.2.2 HIV related data .......................................................................................................... 53
5.3 Views about PMTCT programme .................................................................................. 54
5.4 Reactions after receiving HIV positive results ............................................................... 55
5.5 ART treatment ................................................................................................................ 56
5.6 Care in the PMTCT services .......................................................................................... 57
5.7 Views about Counselling ................................................................................................ 58
5.8 Partner involvement ........................................................................................................ 59
5.9 Support ............................................................................................................................ 59
5.10 Stigma and discrimination ............................................................................................ 60
5.11 Disclosure ...................................................................................................................... 60
5.12 Conclusion ...................................................................................................................... 62
5.13 Recommendations ........................................................................................................ 63
5.13.1 Recommendations for education and health promotion ............................................ 63
5.13.2 Recommendation for practice/public health care ...................................................... 64
5.13.3 Recommendation for research ................................................................................... 64
5.14 Limitations .................................................................................................................... 64
REFERENCES ........................................................................................................................ 65
APPENDICES ......................................................................................................................... 75
Annexure 1A: Informed Consent (English) ............................................................................. 75
Annexure 1B: Informed Consent (SiSwati) ............................................................................. 78
Annexure 2A: Questionnaire (English) ................................................................................... 81
Annexure 2B: Questionnaire (SiSwati) ................................................................................... 83
Annexure 3A: In-Depth Interview Guide (English) ................................................................. 85
Annexure 3B: In-Depth Interview Guide (SiSwati) ................................................................. 87
Annexure 4: Letter to National Health and Review Board ...................................................... 88
Annexure 5: Ethical Clearance Certificate .............................................................................. 89
Annexure 6: SMUREC Approval ............................................................................................ 91
Annexure 7: Adverse event report form ................................................................................ 92
CHAPTER 1: INTRODUCTION AND BACKGROUND

1.1 Introduction and Background
Globally, it is estimated that about 1.5 million women who are pregnant are HIV positive, putting the lives of their newly born babies at risk of vertically acquiring HIV (UNAIDS, 2015). According to the UNAIDS (2017), in 2016, there were 160,000 new HIV infection reported among children below 15 years, and the bulk of these children were infected through mother to child transmission (MTCT) and 90% of these cases were in Sub Sahara Africa (UNAIDS, 2017).

With lack of interventions, between 20-45% of infants born to HIV infected mothers will become infected with HIV and MTCT could occur at any time during pregnancy, labour and delivery and breastfeeding period (Nolan et al., 2002; WHO, 2014).

To reduce the intensity of this problem, prevention of mother to child transmission PMTCT programme was developed in the late 1900s. PMTCT is a set of interventions used to reduce the risk of mother to child transmission (MTCT) of HIV to less than 5%. This strategy mainly includes the use of antiretroviral treatment as early as possible during pregnancy (WHO, 2014).

Although differing from country to country, PMTCT programmes operate on guidelines and policies which are regularly revised and updated in accordance with the World Health Organizations (WHO) PMTCT latest recommendations (WHO, 2014).

The National Department of Health, South Africa (2013), reported that the national HIV prevalence amongst antenatal women in 2012 was 29.5%. This meant that there was a slight decline in the HIV antenatal prevalence in 2010, which was 0.7% from 30.2%. This also suggests that the HIV antenatal prevalence in the country has been in a close range of around 29% over the past six years.

It is suggested that without receiving PMTCT services in South Arica, around 90,000 babies will be born infected with HIV every year (Department of Health Operational Plan, 2009). It has also been suggested that a comprehensive PMTCT intervention has the capacity to reduce
the newborn HIV infection rate to less than 5%, meaning that more than 75,000 babies’ lives will be saved annually (Department of Health Operational Plan, 2009). The PMTCT programme is one of numerous interventions that is used in a country to decrease the high transmission of HIV from mother to child (National Department of Health South Africa, 2011). It has also been identified as one of the leading global HIV prevention strategies (WHO, 2010).

According to the National Department of Health, South Africa (2016), approximately 95% of the South African HIV positive women went through the PMTCT programme in 2011. The UNAIDS (2012), shows that the PMTCT programme has contributed to the decline in newly diagnosed HIV infections since 2009. The Human Immune Virus testing services (HTS) uptake at ANC was at 95% and ART coverage among pregnant women was at 93% in 2015/16 (National Department of Health, South Africa, 2016). This has contributed to reduction of MTCT rate from 25-30% prior to 2001 to 1.4% in 2016.

In Swaziland, HIV prevalence amongst the population aged 15-49 years is 27% (Swaziland Health information measurement survey (SHIMS2), 2016-2017). The prevalence of HIV among pregnant women was at 41.1% and decreased to 37% in 2016 (Ministry of Health (MOH, 2017). With this prevalence, the lives of 13200 babies are at risk of MTCT of HIV each year (MOH Annual HIV Programmes Report, 2014).

In the absence of PMTCT interventions during the period of pregnancy, childbirth or breastfeeding, approximately 5200 infants would acquire HIV infection from their mothers per year (SHIMS, 2011). Prior to the introduction of PMTCT in Swaziland, the rate of MTCT of HIV was 40% and HIV infection accounted for 46% of maternal deaths and 47% of deaths among children under 5 years (MOH HIV Sero-Surveillance, 2010).

With the intention of addressing this situation, the PMTCT programme was launched and introduced in 2003 in Swaziland (MOH, 2003). Through the provision of PMTCT services by PMTCT program, Swaziland had managed to reduce the MTCT rate from 40% in 2003 to 2% in 2011 and slightly increased to 3% since 2014 (MOH annual HIV Programmes Report, 2014; MOH, 2017).
The PMTCT programme requires lifetime commitment from the pregnant women and with consistent adherence to ART and continued retention to care. There is evidence that through the PMTCT programme the baby is protected from mother’s HIV infection and the mother’s health is improved (Seenivasan et al., 2015).

However, women perceive PMTCT differently and their lived experiences during PMTCT enrolment differ. Women’s perceptions and experiences on PMTCT greatly influence PMTCT uptake and retention to care (Matheson et al., 2014). Negative perceptions and negative experiences are associated with low uptake of PMTCT and poor retention to care (Kasenga et al., 2010; Matheson et al., 2014; Tenthani et al., 2014).

Low uptake and poor retention to care on PMTCT has a negative impact in the PMTCT outcomes because there would be an increase in the HIV positivity rate among infants and may also hasten HIV progression among HIV infected mothers. This will lead to an increase in both maternal and infant mortality rate (MOH, 2014).

**1.2 Problem statement**

To achieve the crucial anticipated PMTCT outcomes, HIV positive pregnant woman have to consistently adhere to ART treatment and continuously be retained into care throughout the pregnancy and for the better part of her life (Matheson et al., 2014; Seenivasan et al., 2015).

Through decentralization of PMTCT services, uptake of ART in PMTCT is increasing in Swaziland from 50% in 2009 to 72% in 2013 and 93% in 2015 (Adler et al., 2010 and MOH, 2017). However, the overall retention to care on PMTCT has been noted to be a challenge (MOH, 2014).

Poor retention to care on PMTCT is associated with negative PMTCT outcomes mainly the increase in HIV positivity rate among infants. Women’s perceptions and experiences on PMTCT programme are some of the factors which influence retention to care (Matheson et al., 2014). In Swaziland, less attention has been given regarding women’s perceptions and experiences on PMTCT programme hence the need for the study.
1.3 Aim of the study
The purpose of this study is to investigate the perceptions and experiences of HIV positive pregnant women on PMTCT programme in clinics in the Manzini region, Swaziland

1.4 Research questions
- What are HIV positive pregnant women’s perceptions about the PMTCT programme in clinics in the Manzini region, Swaziland?
- What are HIV positive pregnant women’s experiences with the PMTCT programme in clinics in the Manzini region, Swaziland?

1.5 Objectives
- To explore HIV positive pregnant women’s perceptions about the PMTCT programme in clinics in the Manzini region, Swaziland
- To describe HIV positive pregnant women’s experiences with PMTCT programme in clinics in the Manzini region, Swaziland.

1.6 Justification for the study
Perceptions and experiences on the PMTCT programme can act as barrier or facilitating factor in accessing, adhering and retention on PMTCT services (Matheson et al., 2014). HIV positive women’s information about perceptions and experiences is very crucial to policy makers and implementers in ensuring that PMTCT services and interventions are effective, efficient and acceptable to the HIV positive women for maximum achievement of desirable outcomes of PMTCT.

1.7 Definition of terms
1.7.1 Conceptual definitions
Perception: the way in which something is regarded, understood or interpreted (Longman Dictionary of Contemporary English 2012)

Experience: instance of personally encountering or undergoing something (Longman Dictionary of Contemporary English 2012)
PMTCT programme: set of interventions designed to reduce the risk of mother to child transmission (MTCT) of HIV during period of pregnancy, labour, delivery and breastfeeding (WHO, 2014).

Antenatal Care (ANC): the care given to pregnant women from the time conception is confirmed until the beginning of labour (Fraser et al, 2014).

ART initiation: being started on three or more antiretroviral (ARV) drugs regimen (WHO, 2017).

Prompt ART initiation: starting antiretroviral treatment (ART) on the same day of HIV diagnoses or within 7 days regardless of CD4 count or WHO clinical staging (WHO, 2017).

Retention in care: being continuously connected or active in care once entered (WHO, 2017).

1.7.2 Operational definitions
Perception: personal view or understanding about PMTCT programme.

Experience: personal description of encounter or involvement in PMTCT programme.

PMTCT programme: the department in the facility which provides PMTCT services.

ART initiation: being started on triple antiretroviral drug regimen and start to take them on that very same day.

Retention in care: being continuously in care and honouring all appointments in the PMTCT programme.

Prompt ART initiation: starting antiretroviral treatment on the same day of HIV diagnoses regardless of CD4 count and clinical staging.

Antenatal care: package of clinical services given to pregnant woman at a clinic from time of conception until onset of labour.
CHAPTER 2: LITERATURE REVIEW

2.1 Introduction
This chapter presents literature on the perceptions and experiences of HIV positive pregnant women on the PMTCT programme. The first subsections discuss the definition of PMTCT, PMTCT coverage in Sub Sahara and Swaziland, benefits, coverage, enablers and barriers to PMTCT in Swaziland. The following subsection further outlines the women’s perceptions and their experiences on the PMTCT programme. This literature includes studies conducted in Swaziland, other African countries and other countries outside Africa.

2.2 HIV prevalence among adults and children
Globally, an estimated 36.7 million people were living with HIV in 2016 and 17.8 million of these people are women above the age of 15 years, the majority of which are within the reproductive age group (15-49 years) and these women have the potential of transmitting the HIV infection to their children (UNAIDS, 2017). In 2016, around 1.8 million people were newly infected with HIV, with 5000 new infections a day, of which 64% of these new infections were in Sub Saharan Africa and 43% were women (UNAIDS, 2017). Of the 36.7 million people living with HIV, 70% of them are in Sub Saharan Africa. This data indicate that Sub Saharan Africa region has a high burden of HIV.

On another note, around 2.1 million children below 15 years were living with HIV in 2016 and more than 90% of these children acquired HIV from their mothers (MTCT) during the period of pregnancy, labour, delivery and breastfeeding (UNAIDS, 2017). In 2015 alone, around 110000 AIDS related deaths were reported among the children below 15 years. This highlights the need for strengthening PMTCT interventions worldwide. In 2000, about 490000 children below 15 years were newly infected with HIV and this figure reduced to 150000 in 2015 (UNAIDS, 2016). Through PMTCT intervention, there has been a 70% significant reduction in new HIV infections among the children.

In Swaziland, HIV prevalence amongst the population aged 15-49 years was 27% (SHIMS2, 2016-2017). The prevalence of HIV among pregnant women was at 41.1% and decreased to 37% in 2016 (MOH, 2017). With this prevalence, the lives of 13200 babies are at risk of MTCT of HIV each year (MOH Annual HIV Programmes Report, 2014).
In the absence of PMTCT interventions during the period of pregnancy or childbirth or breastfeeding, approximately 5200 infants would acquire HIV infection from their mothers per year (SHIMS, 2011). Prior to the introduction of PMTCT in Swaziland, the rate of MTCT of HIV was 40% and HIV infection accounted to 46% of maternal deaths and 47% of deaths among children under 5 years (MOH HIV Sero-Surveillance, 2010).

Through the provision of PMTCT services by PMTCT programme, Swaziland had managed to reduce MTCT transmission rate from 40% in 2003 to 2% in 2011 and slightly increased to 3% since 2014 (MOH annual HIV Programmes Report, 2014; MOH, 2017).

2.3 Description of mother to child transmission (MTCT) and prevention of mother to child transmission (PMTCT)

Mother-to-child transmission MTCT is when the woman who is HIV positive vertically transmits HIV to her baby at any time during the period of pregnancy, labour and delivery and breastfeeding (WHO, 2010). Without treatment, around 15-30% of babies born to HIV positive women will become infected with HIV during pregnancy or the delivery process, with about 5-20% becoming infected through breastfeeding (de Cock et al., 2000). The primary aim of the PMTCT programme is to decrease the number of HIV infected babies born to HIV positive mothers. It has been shown that virtual elimination of MTCT of HIV is possible (UNAIDS, 2010) especially when relevant interventions are applied and adhered to from pre-natal period until caseation of breastfeeding.

Without any interventions, the probability that an HIV positive mother transmits the HIV virus to her child is 25-40%, where breastfeeding is recommended (WHO, 2014). This means that without any interventions, between 20-45% of infants born to HIV infected mothers will become infected with HIV. Developed in the late 1900s, PMTCT is a set of interventions aimed at reducing the risk of vertical transmission of HIV from an HIV positive mother to her child which could occur during pregnancy, labour and delivery and breastfeeding to less than 5% when breastfeeding and less than 2% when not breastfeeding (WHO, 2014). The main goal of PMTCT is to reduce the risk of mother to child transmission of HIV and keep the mother healthy (WHO, 2014).
2.4 PMTCT coverage in Sub Saharan Africa

In 2015, about 77% of HIV positive pregnant women accessed PMTCT services globally (UNAIDS, 2016). The overall coverage of pregnant women receiving PMTCT treatment services in Sub Saharan Africa is 59% out of 92% of pregnant women who are HIV positive, with a range of 53-66% reflecting varying levels of implementation within each country (UNAIDS, 2012). The PMTCT programmes are being up-scaled at a national level in many Sub Saharan African countries that have a high HIV prevalence. PMTCT programmes are now being provided as a routine procedure in antenatal settings. Global commitments have also been made to tackle the challenges of HIV/AIDS and, mother-to-child transmissions of HIV for the period of 2010-2015. In 2010, WHO has recommended the following four key pillars or prongs which are a comprehensive approach to PMTCT for improved PMTCT outcomes;

a) Primary prevention of HIV among child-bearing age women.

b) Prevention of unintended pregnancies among HIV positive women.

c) Prevention of transmission of HIV from mother to child.

d) Treatment, care and support for mothers living with HIV together with their children and families.

2.5 Prongs of PMTCT

The main aim of PMTCT is to eliminate paediatric HIV infections and improve maternal, new-born and child health survival in the context of HIV. To achieve this goal, WHO devised four prongs of PMTCT as a comprehensive approach to PMTCT (WHO, 2014). The first prong is primary prevention of HIV infections among women of child bearing age. Intervention under this prong is aimed at keeping the woman HIV negative before, during and throughout the pregnancy and breastfeeding period for PMTCT of HIV. The second prong is preventing of unintended pregnancies among women living with HIV. The main interventions in this prong are aimed at addressing unmet needs of family planning to prevent unintended pregnancies among women. The third prong is preventing HIV transmission from women living with HIV to her infant. Main services provided under this prong are antiretroviral treatment (ART) services for those testing HIV positive and early infant
diagnosis for exposed babies. The forth prong is providing appropriate treatment, care and support to mothers living with HIV, their children and their families. Interventions under this prong are aimed at ensuring that HIV positive women are enrolled into ART services, retained into care to reduce morbidity and mortality. The goal of eliminating MTCT of HIV can be best achieved through intensified and improved implementation of prong 1 and prong 3 (WHO, 2014)

2.6 Benefits of PMTCT

PMTCT programmes serve as a channel for providing a multifaceted range of care, treatment and support to HIV positive mothers, infants, partners and families (Levy, 2009). Antenatal services are a critical avenue for identification of HIV-infected women for long-term HIV care and treatment. Studies suggest that women in Sub-Saharan Africa are learning about their HIV status through the PMTCT programme more frequently when they attend antenatal care (Levy, 2009). This suggests that early uptake of antenatal care services is crucial for the effectiveness of the PMTCT programme, and that each part of the programme is important. As such, a weakness in any of the programme’s aspects will impact negatively on the overall effectiveness, thereby compromising the goal of PMTCT which is to prevent mother to child transmission of HIV and keeping the mother healthy (Jackson, 2007). This will consequently lead to reduced maternal and child mortality, (WHO, 2010). The importance of HIV treatment as part of the PMTCT programme has been highlighted in that it has been shown globally that without the treatment of HIV, there is high HIV related maternal death and; multitudes of children diagnosed with HIV pass away before they turn two years of age or before they begin school (UNAIDS, 2012). In the absence of PMTCT, HIV accounts for 46% of maternal death and 47% of deaths amongst children under the age of five years (MOH HIV Sero-Surveillance, 2010).

The PMTCT package comprises of a series of interventions namely: provision of HIV counselling and testing services to pregnant women in the antenatal care settings and treatment for those women who test HIV-positive. Women are also provided with counselling on infant feeding practices, safe obstetric procedures, antiretroviral therapy and other prevention measures like safe sex practise (Levy, 2009). Another beneficial aspect of the PMTCT programme is health education. For instance, healthcare providers (HCPs) give
health talks which focus on healthy living, PMTCT, HIV and the benefits of HIV testing during pregnancy (Levy, 2009).

PMTCT programmes thus effectively allow for HIV status to be established and interventions to be provided, to prevent transmission of the infection to the infant. According to Nguyen, Oosterhoff, Ngoc, Wright and Hardon (2008), minimal PMTCT service is understood as access to HIV testing and at least receiving single ARV regimen of AZT or single dose-NVP for mother at delivery and NVP for the child post-delivery. According to WHO (2007), even in resource-constrained settings, the use of simple and less combination antiretroviral prophylactic regimes, such as short-course zidovudine (AZT) combined with single-dose Nevirapine, can reduce significantly in utero and intrapartum transmission. But in 2013, WHO recommended universal lifelong ART for HIV positive pregnant and lactating women especially in countries with high HIV prevalence and high birth rate to further reduce the chances of mother to child transmission and keep the mothers healthy (WHO, 2013).

2.7 PMTCT services during ANC period
The first step in PMTCT is testing for HIV on the first ANC attendance (WHO, 2014). HIV prevention strategies and messages are emphasized to those who test HIV negative to ensure that they stay negative; they are also tested every eight weeks so that prompt PMTCT interventions are taken in case of sero-conversion. For those who test HIV positive during pregnancy after undergoing adherence sessions and counselling, they receive a cascade of PMTCT services which include initiation on lifelong ART and genuinely adhering to the treatment for life, regular monitoring of response to treatment using CD4 and viral load test (WHO, 2014; Kim et al., 2012). Partner involvement is encouraged for emotional and psychosocial support (Kim et al., 2012). Ensuring that an HIV positive pregnant woman receives the full cascade of PMTCT intervention is crucial towards eliminating paediatric HIV infections (WHO, 2014; Kim et al., 2012).

2.8 PMTCT in Swaziland
In response to the high prevalence of HIV among pregnant women in Swaziland, PMTCT was officially launched and introduced in 2003 and it was piloted in 3 sites (MOH, 2011). Ever since the introduction of PMTCT, local guidelines have been revised and changed in
response to the WHO latest recommendation. The first guidelines in 2003 recommended the use of single dose of single antiretroviral drug of nevirapine (NVP) at the onset of labour (MOH, 2003). The second edition of guidelines released in 2006 recommended that pregnant women were to be given zidovudine (AZT) twice daily from 28 weeks gestation and 3 drug combinations of AZT+lamivudine (3TC) +NVP at onset of labour, then a tail of AZT+3TC for one week post-delivery. Women at advanced clinical disease or with CD4 cell count less than 200 were eligible for lifelong ART initiation regardless of gestational age (MOH, 2007). Again, the guidelines were revised in 2010. The 2010 guidelines recommended the use of AZT twice daily from 14 weeks gestation and all pregnant women at clinical stage 3 and 4 or with CD4 cell count less than 350 to be initiated on lifelong ART regardless of gestational age (MOH, 2010). Currently, the country is using 2015 guidelines which recommend lifelong ART for all HIV positive pregnant and breastfeeding women regardless of CD4 count and clinical stage and the women are to remain on ART for life (MOH, 2015). Through the use of this new guideline, Swaziland has managed to increase ART uptake among HIV positive pregnant women from 50% in 2012 to 93% by 2015 (MOH, 2017). The MTCT rate has also reduced from 40% in 2003 to 3% since 2014 (MOH, 2017).

2.9 Rationale for prompt lifelong ART initiation for pregnant and lactating women in the PMTCT programme

According to the Annual PMTCT report (2012), using the CD4 <350 and WHO staging eligibility criteria, only 50% of the HIV positive women eligible for lifelong ART were initiated. Delay or failure to initiate ART during pregnancy is associated with increased risk of mother to child transmission and other HIV/AIDS related maternal and child morbidity and mortality (Cohen et al., 2011; WHO, 2012). Stigma, lack of disclosure, lack of partner support, food insecurity, transportation cost and time, negative perceptions and myths about antiretrovirals (ARVs), cost of accessing treatment, inconsistency in drug availability, belief in faith and traditional healing and poor treatment of clients by health care workers are some of the reasons for delay or failure to initiate ART (Asefa et al., 2010; Fox et al., 2010; Gourlay et al., 2013, Govindasamy et al., 2012 and Johnson et al., 2013). It has been noted that HIV/AIDS related morbidity and mortality among HIV positive women during pregnancy and postnatal period is high in the group with CD4<350 (WHO 2010). Among women who are not initiated on lifelong ART, the HIV transmission rate at 6 weeks postnatally is 2-3%, and at 18 months the HIV transmission rate increases to 12-15% (Annual
PMTCT Report, 2012). The increase in transmission rate at 18 months was attributed to challenges of adhering to daily NVP prophylaxis for entire periods of breastfeeding which is required for children from mothers who are not initiated on lifelong ART (Annual PMTCT Report, 2012; Mthethwa, 2013).

Benefits of prompt lifelong ART during pregnancy include reducing risk of disease progression and mortality associated with delayed treatment, reducing risk of mother to child transmission in the current and subsequent pregnancies and reduced risk of HIV transmission to seronegative partners (Cohen et al., 2011; WHO, 2012). ART during pregnancy improves the quality of life of the women and thereby giving her healthier and longer life (WHO, 2013). In 2013 WHO recommended universal lifelong ART for HIV positive pregnant and lactating women especially in countries with high HIV prevalence and high birth rate like Swaziland (WHO, 2013). The goal of universal lifelong ART approach for pregnant and lactating women is to improve the initiation rates among this group to achieve optimal outcomes of PMTCT and prevent the negative PMTCT outcomes associated with delay or failure to initiate ART during pregnancy (Parker, 2015).

2.10 Enablers to PMTCT in Swaziland

The antenatal care (ANC) coverage of 97% and 80% hospital deliveries places the implementation of PMTCT interventions at an advantage in Swaziland (MOH, 2010). HIV testing is the entry point to PMTCT. Through the introduction of provider-initiated HIV testing and counselling (PIHTC) in 2007, HIV testing among pregnant women who have come for first ANC in health facilities has been made mandatory in Swaziland (MOH, 2011). As a result, therefore, the HTS coverage among pregnant women at ANC is at 90% in 2016 from 87% in 2011 (MOH, 2017). The number of HIV positive pregnant women who were initiated on ART improved from 50% in 2012 to about 93% in 2015 (MOH, 2017). When the PMTCT program was introduced in 2003, only 3 facilities were providing PMTCT services. The number of facilities providing PMTCT was increased to 72% in 2011 and further increased to 90.7% by 2016 (MOH, 2017). Through vigorous efforts to make PMTCT services easily accessible, PMTCT services have been decentralized and integrated in maternal and child health services and more than 90% of health facilities in Swaziland are providing PMTCT services (MOH, 2016). With a strong ambition to eliminate MTCT and keeping the mothers healthy, the government of Swaziland has made PMTCT a top priority.
Financial and technical support from the ministry of health and partners has mainly contributed towards the significant progress in the PMTCT program in the country.

Free services and drugs are some of the facilitating factors into entry and retention to care (Otieno, 2010; Laher et al., 2012). Paying for PMTCT services and drugs act as barrier in accessing PMTCT services such that some women would not be able to access PMTCT services due to lack of finances (Parker et al., 2015). In all government facilities in Swaziland, all PMTCT services are subsidized and this is one of the facilitators in acceptance and retention in the PMTCT programme. In addition, integration of other services in PMTCT services brought satisfaction to the women and it also act as facilitating factor in uptake and retention in PMTCT (Chinkonde et al., 2009; Winestone et al., 2012).

2.11 Barriers to PMTCT in Swaziland
The high prevalence of HIV among pregnant women (41.1%) places the lives of a huge number of infants (13 500) at risk who are HIV exposed each year (MOH, 2010). This shows that Swaziland is faced with a huge burden of protecting the lives of the unborn babies from HIV infection while at the same time keeping their mothers healthy. For best outcomes, PMTCT requires early ART initiation during pregnancy, consistent and continuous adherence to care and treatment. Despite high ANC attendance (97%), only 20% of the pregnant women attend ANC at first trimester and this is a barrier for favourable outcomes of the PMTCT programme (MOH, 2010). About 20% of pregnant women do not deliver in health facilities and this deprives the baby from receiving PMTCT intervention during delivery and at immediate post-partum hence increases the chances of MTCT. Even though the overall initial ANC visit and PMTCT enrolment is very high, retention to care on PMTCT is very poor in Swaziland (MOH, 2014). Experience and perception about ART treatment also act as a barrier. Fear of side effects to both the mother and the baby was reported to be one of the barriers to treatment (Katirayi et al., 2016). Feeling healthy and not in need of chronic medication was also reported as a barrier to ART treatment (Katirayi et al., 2016). In PMTCT preference of short course regimen prophylaxis over lifelong ART to avoid disclosure and stigma also acted as a barrier (Katirayi et al., 2016).
2.12 Perceptions and experiences in the PMTCT programme

2.12.1 Mandatory HIV testing

HIV testing for pregnant women seeking antenatal services has been made mandatory. With this practice, women reported that they do not consent for the test but would have to test even if they are not prepared for the implications of the results because HIV testing is considered as prerequisite for accessing the antenatal services and have the fear that refusal might impede their access to ANC services (Lassorn et al., 2012). The women feel forced to do the HIV test and initiate on ART in case they test HIV positive for them to access ANC services. However, some women view mandatory HTC as a good strategy for early diagnosis of HIV so that proper interventions are taken timely for the benefit of their own health and that of the baby (Kasenga et al., 2010; Black et al., 2014; Ngarina et al., 2014).

2.12.2 Counselling in PMTCT

Women expressed that counselling is not adequate and the time for counselling is not sufficient especially for post-test counselling following a positive HIV test result (Anderson et al., 2012; and Levy, 2009). The women also reported lack of follow up counselling after testing HIV positive, yet they need additional follow up counselling sessions after HIV diagnoses comprehension of information is compromised (Anderson et al., 2012; Stinson & Myer, 2012). Some women reported to have received quality counselling and adequate time even for asking questions; and they were content with the counselling (Anderson et al., 2012 and Stinson and Myer, 2012). They also felt that the counselling they received at the PMTCT facilities is adequate, and the information they received was clear and easy to understand (Kasenga et al, 2010; Matheson et al, 2015; Ngarina et al., 2014). In addition, the women perceived that counselling provided by lay cadre is more satisfactory and easy to understand over that from clinical personnel (Levy, 2009). However, the counselling provided tend to ignore societal and cultural issues; and more focused on clinical aspects (Stinson & Myer, 2012; and Levy, 2009).

2.12.3 Prompt lifelong ART commitment

For PMTCT, the women are required to make prompt lifelong commitment to ART. Some women would feel healthy and not in need of ART which is associated with sick people.
Because they are not given any other option and time to make the decision, this results in ART initiation of women who are not fully prepared or ready for the commitment (Matheson et al., 2015). Despite not being fully prepared for a lifelong commitment to ART, studies conducted among pregnant women enrolled on PMTCT showed that PMTCT is perceived by most women as a good government policy which is there to protect their babies from HIV and save their lives. These women valued PMTCT and perceive it not only as an opportunity to save an innocent baby from HIV infection, but also as an entry point to lifelong ART to keep them healthier and live longer and have the opportunity to raise their children, hence they were more willing to be enrolled and retention to care was very high among this group (Kasenga et al., 2010; Black et al., 2014; Ngarina et al., 2014). However, according to Nyasulu & Nyasulu P(2011), in the African culture, even if the woman clearly understands the benefits of PMTCT, approves and feels ready to make the lifelong commitment, it is the partners’ approval which is final, hence the need to intensify partner’s involvement in PMTCT programme.

On the contrary though, mandatory HIV testing and prompt lifelong ART initiation on initial ANC make some women view PMTCT Option B+ as a coercive programme which violates human rights of autonomy because they are not given an option and enough time to make their own decision regarding PMTCT enrolment. These women perceived that the benefits of PMTCT interventions do not surpass the demands, challenges and burdens associated with being on PMTCT (Matheson et al., 2015). It has been noted that the number of women who were lost to follow up was found to be high among healthy women initiated on ART under PMTCT as compared to those who were initiated according to clinical staging (Tenthani et al., 2014). According to the view and understanding of some women, the possibility of MTCT of HIV is very little if not impossible, so, these women perceived PMTCT as an unnecessary extra burden which adds no value to one’s life and they are less willing to be enrolled on PMTCT (Elsheikh et al., 2015).

2.12.4 Disclosure

Studies have shown that disclosure in the PMTCT programme is associated with adherence and retention to care in the PMTCT programme hence women enrolled on the PMTCT programme are encouraged to disclose their status to their partners and families mainly for support and assistance with adherence and honoring appointments so that they are retained in
care (Ngarina et al., 2014). With the hope of getting support, women disclose their status to their partners and trusted relative. To their disappointment, they are stigmatized and discriminated by their families and community. Some are abandoned by their partners, emotionally and physically abused because they are blamed for bringing the “shame” and deadly virus to the family (Katirayi et al., 2016). Due to fear of such possible negative repercussions from their male partners, some HIV positive women enrolled on the PMTCT programme choose not to disclose to their partners and or any other significant person (Anderson et al., 2012; Lassorn et al., 2012; Otieno et al., 2010; Kasenga et al., 2010; Ngarina et al., 2014). Fear of disclosure is associated with poor uptake and poor retention into care in the PMTCT programme (Otieno et al., 2010). As a result, women need to make informed decision on disclosure. However, some women reported that they received much support and encouragement from their male partners and some of their relatives and family members after disclosure (Kasenga et al., 2010; Matheson et al., 2015; Ngarina et al., 2014). Women need additional information and support on skills of how and when to disclose to minimize anxiety and negative repercussions following disclosure and the negative impact thereof (Anderson et al., 2012; Lassorn et al., 2012; Otieno et al., 2010).

2.12.5 Stigma and discrimination
HIV related stigma still exists in the world. According to Ngarina (2010), women enrolled on the PMTCT programme experienced stigmatization and discrimination from their partners, families, in laws and even health care workers. As a result of stigmatization and discrimination, some women opted to decline PMTCT enrollment or default if already enrolled. On another note, women tend to be uncomfortable in accessing services in a separate room known to be providing HIV related services because they feel discriminated and stigmatized by such settings (Chinkonde et al., 2009, Katirayi et al., 2016). Stigma and discrimination are some of the reasons for poor uptake and poor retention in care in the PMTCT programme (Ngarina, 2010; Njunga & Blystad, 2010). Fitzgerald et al., (2010) also reported that the fear of being stigmatized and discriminated is one of the reasons why people preferred to disclose to certain individual and not to others.
2.12.6 Antiretroviral Treatment

Women on the PMTCT programme perceive ART as being associated with the very sick or those with low CD4 cell count, and as such feel forced to commit to lifelong treatment when they are feeling healthy and not in need of any treatment (Stinson & Myer, 2012; Katirayi et al., 2016). Some fear that it might not be possible for them to adhere in the long run and thereby develop resistance to the drugs and other medical complications associated with poor adherence (Stinson & Myer, 2012; Katirayi et al., 2016). Also, some women fear possible side effects that might be caused by the medication (Otieno et al., 2010; Stinson & Myer 2012; Katirayi et al., 2016). For these reasons, some women prefer not to commit themselves at all. Some women had concerns about safety of the ARVs to the unborn baby. They were afraid that these drugs could cause harm to the baby (Stinson & Myer, 2012; Theilgaard et al., 2011; Katirayi et al., 2016). Moreover, some women were not comfortable about daily intake of medication which they stated that it put them at risk of accidental disclosure (Chinkonde et al., 2009). On the contrary though, some women felt that in the past, PMTCT focused mostly on the health of the infant and their own health as mothers was neglected (Levy, 2009). The lifelong ART is not only protecting their babies from acquiring HIV, but also providing them with an opportunity healthy and longer life (WHO, 2013). Despite of all the perceptions women may have and their experiences on PMTCT and ART, after gaining proper understanding of the benefits of PMTCT, most women turn to see PMTCT as a life saver and an opportunity to a better and healthier life for them, their babies and their families (Ngarina et al., 2014). Therefore, they are eager to be enrolled and they properly adhere to treatment. Most women are motivated primarily by the desire to protect their babies from HIV infection.

2.12.7 Care in the PMTCT programme

Staff shortage in facilities when seeking services has acted as a barrier in accessing and retention into care in the PMTCT programme (Theilgaard et al., 2011; Levy, 2009). Inconsistency in the availability of PMTCT services, time and travel cost associated with frequent visits to a health facility and lack of integration of other services in PMTCT departments is also another barrier in accessing and retaining women in the PMTCT programme (Levy, 2009; Chinkonde et al., 2009; Winestone et al., 2012; Tenthan, 2014). Integration of other services in PMTCT programme was associated with improved uptake and
improved retention in care (Chinkonde et al., 2009; Winestone et al., 2012). On another note, women tend to be uncomfortable in accessing services in a separate room known to be providing HIV related services because they feel discriminated and stigmatized by such settings. Women also expressed that frequent visits required in PMTCT is not only time consuming, but also comes with a financial burden; the frequent visits also put them at risk of accidental disclosure (Chinkonde et al., 2009; Ngarina et al., 2014; Elsheikh et al., 2015; Katirayi et al., 2016). Also, the need for daily taking of medication requires adjustments to their daily personal schedule and also makes them prone to accidental disclosure which exposes them to stigmatization and discrimination (Ngarina et al., 2014; Elsheikh et al., 2015).

According to Kasenga et al., (2010), the women’s experiences in their families and their communities when enrolled on PMTCT including their experiences during service provision greatly influence women’s retention to care on PMTCT programme. Some women expressed that even though they are subjected to long queues and long waiting times, most of them always felt welcomed and treated with dignity by PMTCT service providers (Elsheikh et al., 2015; Kasenga et al., 2010). Some women reported that the health care workers in the PMTCT programme showed good, none discriminatory and none judgmental care and attitudes towards them. They further expressed that the health care workers were very supportive in many ways. Their advice and encouragement motivated and kept them retained in the PMTCT programme (Larsson, 2012; Gilles et al., 2011). This is contrary to the experiences of some women who experienced unkind treatment and negative attitudes from health care workers which tend to scare them from accessing or continuing with PMTCT services. HIV positive women enrolled on the PMTCT programme reported that health care workers were discriminatory and judgmental to them and therefore, these women tended to avoid or default PMTCT services (Anderson et al., 2012; Gourlay et al., 2013, Laher et al., 2012).

2.12.8 Confidentiality

The concern that information of their positive HIV status could be leaked to third party acts as a barrier to HIV positive women in accessing PMTCT services. Some women reported that they were disappointed after discovering that information about their HIV status was leaked to a third party without their consent (Anderson et al., 2012; Gourlay et al., 2013, Laher et al.,
2012, Katirayi et al., 2016). Women were not comfortable with the settings where there are exclusive rooms or consultations designated for HIV related services because this deprived them of confidentiality. Consequently they did not access or continue with the PMTCT services in such settings (Chinkonde et al., 2009, Katirayi et al., 2016). Women were also not at ease with home visits done to PMTCT clients by community mentor mothers because their confidentiality was compromised, and chances of accidental disclosure were high (Chinkonde et al., 2009). It has been documented that fear of stigmatization and lack of trust about confidentiality has negative impact in uptake and retention into care in HIV related services (Anderson et al., 2012; Gourlay et al., 2013, Laher et al., 2012, Katirayi et al., 2016).

2.12.9 Support

Some women received support and encouragement from their partners and or other significant family members after testing HIV positive and disclosing their status. Kasenga et al., 2010; Ngarina et al., 2014; Matheson et al., 2015). Rujumba et al. (2012), also mentioned that women enrolled on PMTCT reported to have received different forms of support from the health care workers in the facilities which was very helpful to them. Some women felt that with their advice and encouragement, they felt supported and motivated and this kept them retained and committed on the PMTCT programme (Larsson, 2012; Gilles et al., 2011). According to Ngarina (2010), support has positive impact in adherence and retention to care in the PMTCT programme.

2.13 Conclusion

This chapter discussed the literature that is relevant to the study. It presented an overview of MTCT of HIV which gives a clue on the extent of the risk of MTCT without any interventions. It also presented the overview and progress of PMTCT globally, the Sub Saharan region and in Swaziland. It gave highlights on the different perceptions and experiences of HIV positive pregnant women on the PMTCT programme. However, the literature highlighted some factors which act as barriers to PMTCT in Swaziland and the negative impact it has on the PMTCT outcomes in the country. Nevertheless, the country is regularly updating and developing new PMTCT policies to ensure high coverage of PMTCT interventions among all HIV infected women in the country.
CHAPTER 3: METHODOLOGY

3.1 Introduction
This chapter focuses on the study methodology which includes study design and approach, the setting of the study, study population, sampling procedures, inclusion and exclusion criteria, data collection methods, data management and analysis. The chapter also looks at trustworthiness and ethical issues that were covered in the study.

3.2 Study design and approach
The study was explorative, descriptive qualitative using face to face in-depth interviews.

3.3 Study setting
The study was conducted in Swaziland at a clinic situated in the Manzini region, in Matsapaha under Kwaluseni constituency, about 8 kilometres from Manzini town. The facility is located in a semi urban area closer to an industrial site. The facility primarily offers comprehensive primary health care (including PMTCT services) to a catchment population of about 10900 people. PMTCT services are offered in the maternal and child health unit (antenatal and child welfare department), by a team which comprises of 1 HIV counsellor, 2 mentor mothers and 2 midwives. According to the 2016 monitoring and evaluation reports, the facility enrolls an estimate of 30 initial ANCs per month, and enrolls an average of 10 pregnant women on PMTCT programme.

3.4 Study population
The study population was all HIV positive pregnant women, enrolled on PMTCT in the ANC department at a clinic in the Manzini region during the period of the study (August 2017 to December 2017). According to the 2015 monitoring and evaluation annual report from the Ministry of Health, the facility enrolls an estimate of 10 HIV positive pregnant women on PMTCT who had come for their initial ANC visits per month.
3.5 Sample and sampling technique

A non-probability, purposive sampling was used in the study. With purposive sampling, the researcher deliberately or purposively selects informants who are knowledgeable or have experience in the area of concern to provide in-depth information about the subject studied (Varkevisser et al, 2003). The researcher purposively selected informants who were knowledgeable or had experience to provide in-depth information with regards to perceptions and experiences when enrolled on PMTCT in the area of concern. The rule of thumb recommends 15-30 participants for in-depth interviews (Luborsy & Rubinskein, 1995; Creswel, 1998). The sample size was 15 participants, but data saturation was reached at 12. Data saturation is when the data or information from the participants becomes repetitive or redundant such that there is no longer any new information given by the participants (Polit & Beck, 2008). A total of 15 participants were interviewed.

3.6 Inclusion criteria

Participants met the following criteria:

- Pregnant women at any gestational age
- Pregnant women between the age of 18-45 years
- Pregnant women who tested HIV positive and were initiated on ART at the first ANC visit
- Those who enrolled and active (not defaulted) on PMTCT programme
- Pregnant women who had been on the PMTCT programme for at least 2 months and above

3.7 Exclusion criteria

Participants who met the following criteria were excluded from the study:

- Women who had delivered (in post-partum period)
- Women who came for initial ANC already on ART or with a known HIV positive status
- Those below 18 years or above 45 years
- Those who had been on PMTCT programme for less than 2 months
- Defaulters on the PMTCT programme
3.8 Recruitment plan

Ethical clearance was obtained first from the School of Health Sciences Research Committee (SREC) followed by Sefako Makgatho Health Sciences University Research Ethics Committee and then also the National Review and Research Ethics Board of Swaziland. Permission was also obtained from the management of the clinic. After obtaining all the clearances from these authorities, the researcher went to the facility and explained the purpose of the study to the all nurses at the antenatal care (ANC) department at the clinic. After explaining the purpose of the study, its objectives and inclusion and exclusion criteria to the nurses, the nurses helped to identify potential informants for the study. When the researcher came for data collection, the nurses identified potential candidates during consultation. When they were done with their consultations in the facility, the identified potential informants were invited into a separate room in the facility where the researcher explained the purpose of the study and how data would be collected. The researcher explained that data would be collected using an interview guide and that responses will be captured using a tape recorder. Potential risks, benefits, voluntary participation and right to withdrawal were explained. Confidentiality and anonymity were assured to them. Informed consent was administered to those who agreed to participate and they were asked to sign the informed consent form.

3.9 Data collecting and tool

Data were collected through individual in-depth face to face interviews using an interview guide as a tool that was developed in English and then translated into the local language of siSwati. According to Varkevisser et al. (2003), in depth interviews are most appropriate when discussing an issue where there is limited knowledge available on the topic being discussed and when the researcher intends to get in-depth information on the participants’ experiences or personal views about particular issue. The tool had three sections. The first section was socio demographic data, the second section had questions on perceptions on PMTCT and the last section had questions on experiences on PMTCT programme. The participants who agreed to participate were ushered into the private room in the facility.
The researcher then explained the purpose and objectives of the study again to the participant. The researcher explained that data will be collected using an interview guide and that responses will be captured using a tape recorder. Potential risks, benefits, voluntary participation and the right to withdrawal were explained. Confidentiality and anonymity were assured to them. Those who agreed to participate were asked to sign the informed consent form. Informed consent was administered in the local language, (siSwati). The in-depth interview was conducted in their local language, (siSwati). The interview lasted 30-45 minutes. The researcher and research assistant were taking notes of the responses and a tape recorder was used to assist in capturing the responses. The research assistant was trained on operating the tape recorder and taking notes of the participant’s responses during the interview process. The research assistant was also trained on confidentiality of information collected during data collection. After the interview, participants were asked to complete the socio demographic data in the presence of the researcher for clarity in the questions if need be. Thereafter, each participant was provided with lunch and transport money as a way of appreciation.

3.10 Data management plan
Data collected were downloaded into a laptop immediately after data had been collected and on daily bases. All tools containing data collected in this study (laptop, notes, and tape recorder) were reviewed for completion and kept safely in a locked cabinet in a secured room within the facility which was allocated to the researcher by the facility manager. Only the researcher and research assistant had the pin code for the laptop and keys for the cabinet where data were kept.

3.11 Data analysis plan
The researcher went through the collected data from the written notes and listened to the audio recordings to obtain a greater understanding of the data. Data were transcribed and then translated into English. The transcribed and translated data were entered into Microsoft Word. The researcher would listen to the tape recorder to verify the transcribed data. The data were first coded manually and codes submitted to the supervisor. Codes were corrected and changed until the researcher and supervisor agreed on final codes. The final codes were
applied to NVivo 10 a qualitative data analysis software. After coding the researcher identified common themes from the coded data and coded data with similar or common themes were grouped under one theme. The identified common themes and codes were validated and confirmed through the assistance of the supervisor.

Through the assistance of the supervisor, a final code list was developed. Finally, the researcher interrelated and integrated these themes into a single whole describing the perceptions and experiences of the participants. Demographic data were analysed using STATA version13.0 software and NVivo version11 software was used to manage and analyse the qualitative data.

3.12 Bias
Bias is described as “an influence that produces a distortion or error in the study results thus affecting the quality of evidence in the study (Polit & Beck, 2008). The following types of bias and strategies to minimize them are discussed below:

Bias in sampling: sampling bias may occur with the use of improper sampling method or approach. It may also occur when the researcher cautiously or intentionally selects those who are known to be highly informative about the subject under study without giving everybody an equal opportunity to participate in the study (Polit & Beck, 2008). In this way, the sample might contain respondents with similar characteristics. Therefore, the sample might not be a good representation of the study population. The researcher avoided this by approaching everyone who met the inclusion criteria and agree to participate until the sample size was reached.

Bias in data collection: Bias in data collection may originate from faulty data collection tool and also from the method used in capturing the data or participants responses. The phrasing and the sequence of question in the tool might also lead to response bias from the participants (Polit & Beck, 2008). The respondents might not respond to the question asked or they may not provide genuine responses. To address this, the researcher ensured that the questions in the tool were properly phrased without ambiguity and translated into the local language to enhance understanding. To ensure that the researcher got appropriate and honest responses from the participants, the researcher clearly explained the purpose of the study; questions were arranged logically, sensitive questions asked later and in a socially acceptable manner.
**Researcher subjectivity bias:** There may also be bias if the interviewer lacks interviewing skills since the interviewer may ask questions inappropriately and may concentrate or focus on responses of her own interest and miss important information thus distorting the results in the direction of his or her own interest or expectation (Polit & Beck, 2008). To avoid this, the researcher and research assistants were trained in conducting an interview and capturing responses. A tape recorder was also used to assist in capturing all participants’ responses as they are.

### 3.13 Trustworthiness

Trustworthiness of a qualitative study is assessed by credibility, dependability, conformability and transferability. Trustworthiness will be established when the findings from the interviews reflect as closely as possible the meanings as described by the participants (Lincoln & Guba, 1985).

**Credibility:** credibility seeks to ensure that the research accurately measures what it intended to measure (Lincoln & Guba, 1985). It ensures true representation of the participant’s feelings and actions. The researcher was trained at Sefako Makgatho Health Sciences University (SMU) during winter classes in 2017 on data collection who then trained the research assistant on administering the demographic data tool and taking notes during interview. During the interview the research assistant was taking notes, and also assisting in operating the tape recorder to capture the participant’s responses as they are. After every interview, a debriefing session about the data collection tool and the data collection process was conducted by the researcher, the research assistant and the supervisor to enhance trustworthiness. During data analysis and interpretation, some of the participant’s responses were presented as direct quotations.

**Dependability:** Dependability measures whether the study can yield the same results if repeated almost at a similar setting (Lincoln & Guba, 1985). The data collection tool was translated into local language for easy understanding of the participants. The demographic data of the participants were taken as quantitative data for triangulation and participants’ description of their perceptions and experiences were taken as qualitative data. On everyday basis, the researcher went through the collected data on the written notes and audio recordings to get more understanding of the data and assess if the tool addressed the intentions of the study.
Transferability: This is the extent to which the study results can be generalized or applied into another similar setting (Lincoln & Guba, 1985). The researcher used relevant literature to support implementation, analysis and interpretation of the study.

3.14 Ethical considerations
According to Polit and Beck (2008), before a study is implemented, the research proposal will have to be reviewed by different research ethics committees to ensure that human rights will be protected from the study. The proposal was first submitted to the School of Health Sciences Research Committee (SREC). From the SREC, the proposal was reviewed by Sefako Makgatho Health Sciences University Research Ethics Committee and also the National Review and Research Ethics Board of Swaziland where study was submitted in order to get ethical approval to conduct the study. Once the study was approved by the ethics committee, the researcher then got permission from the operational managers from the site where the study was conducted.

The participants were assured about confidentiality of the information given and data collected. The data were kept in a locked cabinet and only the researcher and the supervisor had access to the data to maintain confidentiality. Participants were requested not to provide their real names for anonymity to ensure that information obtained cannot be linked to the participants. There was no risk of harm for participating in the study. Participants were informed that participating in the study is voluntary and they will not be any penalty or loss of benefits for refusing to participate. All those who agreed to participate were requested to sign an informed consent form which was written and explained by the researcher in the local language, siSwati. Participants were informed that they have the right to withdraw from the study at any time of the study.

3.15 Conclusion
This chapter explained how the research design guided the whole research process from selection of study participants, data collection up to data analysis and results discussion. It also highlighted the ethical considerations that were undertaken in this research. Furthermore,
this chapter also discussed the various measures that were taken to ensure trustworthiness of the data and discussion of findings.
4.1 Introduction

This chapter presents findings of the study including the demographic characteristics of the participants, themes and sub themes of the findings. Demographic data were obtained using a tool developed by the researcher. Qualitative data were obtained in siSwati using an interview guide developed by the researcher. The data were then transcribed and translated into English prior to analysis. The transcribed and translated data were entered into Microsoft Word. The data were first coded manually and codes applied using NVivo 10 software. After coding the researcher identified common themes from the coded data; coded data with similar or common themes were grouped under one theme. Nine (9) themes emerged from the data.

4.2 Description of study participants

4.2.1 Socio-demographic information

The study sample of the study was HIV positive pregnant women enrolled on the PMTCT programme. There were 15 participants who participated in the study. Most (n=9, 60%) of the participants were living with their partner and (n=6, 40%) were living in an extended family set up. Their age group ranged from 21 to 38 years and the mean age was 28.6 years. Most of them (n=11, 73.3%) were aged between 21 -30 years, while (n=4, 26.7%) were aged between 31-38 years. Among the participants 7(46.7%) were single, while (n=5, 33.3%) were married and (n=3, 20%) were cohabiting. On educational level, most (n=9, 60%) had reached high school education, only (n=2, 13.3%) had tertiary education and none had never been to school. The employment status of the participants showed that (n=8, 53.3%) were employed, while (n=6, 40%) were unemployed and (n=1, 6.6%) was self-employed.

4.2.2 HIV related data

With regards to HIV diagnosis, most (n=12, 80%) of the participants were diagnosed as HIV positive in the current pregnancy during their first ANC visit. (n=3, 20%) knew their HIV status before they came for their first ANC visit. Out of the 15 participants, (n=13, 86.7%) had disclosed to their partners who were responsible for the pregnancy, while (n=2, 13.3%) did not disclose to their partners. The majority of them (n=13, 86.7%) of the participants
started ART on the day of HIV diagnoses while (n=2, 13.3%) did not start ART on the day of diagnoses (delayed starting ART). It was also found that (n=7, 46.7%) did not know their partners HIV status, and (n=8, 53.3%) knew their partners HIV status. Worth noting is that (n=6, 40%) reported that their partners were HIV positive and (n=2, 13.3%) had HIV negative partners. The gestational age of the participants ranged from 8 to 38 weeks and the mean gestational age being 24 weeks. More than two thirds of the participants (n=10, 66.7%) had been on PMTCT programme for 2-3 months and (n=5, 33.3%) had been on PMTCT programme for 5-8 months.

4.3 Qualitative findings
The study findings are presented in the form of themes and sub-themes. Themes under the two main areas of focus perceptions and experiences were identified. The following nine (9) themes emerged from the findings. These themes are discussed below.

4.3.1 Views about PMTCT programme
When asked about their perception on PMTCT, most participants expressed a positive view about PMTCT and felt that PMTCT is a good programme with a number of benefits seen such as bringing life and hope to HIV positive pregnant women. They also felt that the programme preserves their life and that of their babies. The following statements reflects their perceptions.

_I can say PMTCT is a very good programme. It is a programme that has brought life to us HIV positive women even if we had lost hope about life. It just raised our hopes about life in a way that even the babies we are carrying are safe and we do not have fear or doubt that we might both die. But because we know that the baby is protected and because I am taking the tablets I am also protected. …. Actually I can say we are getting to a point whereby the HIV mother to child transmission will be at zero because the next coming generation will not have the virus, it will only end with us. So those are the good results of the PMTCT programme, because if this programme was not there, maybe we would continue dying…children…parents…everyone. (30 years old participant)_
Eish it’s a very good programme. It advocates for the innocent souls. I can say it’s the voice of the babies who cannot talk for themselves. As for the baby, if I didn’t do this enrolling in the PMTCT programme, I wouldn’t be able to protect her or him from getting HIV. Now when I do blood test they would tell me that the virus is suppressed. This makes me very happy. I am sure I will give birth to a negative baby (28 years old participant)

They further highlighted the benefits of the PMTCT programme suggesting that it is a good programme for them. The major benefits highlighted were that of protecting the baby from acquiring HIV from the HIV infected mother and PMTCT also gave them an opportunity to know their HIV status early and start treatment early before they get sick.

It is an opportunity for you to know your HIV status early and you start the medication when you are healthy and fit, no one will go around pointing at you that you are like this..., you are on ARVs. You just don’t show any signs that you are on treatment because you start them when the body is still healthy and strong and you are still able to walk unassisted. No matter how much is my CD4, they will just initiate me on treatment, unlike starting treatment when I am bed ridden. (30 years old participant)

Ok! What is brought by this programme which is good is for us to give birth to healthy babies who do not have the virus at the end of it all. Also is that you are able to deliver your baby in healthy condition and when you are still able to walk by yourself. You give birth as a healthy woman and when you are still able to do things for yourself and you continue living as a healthy woman and be able to take care of your baby. (30 years old participant)

Some participants expressed negative feelings about mandatory HIV testing and prompt ART initiation in the PMTCT programme. They viewed this component of the programme as being coercive and not giving them time to accept the HIV positive results, report to their partners and make their own decisions regarding treatment. Generally, they felt they were not ready to start ART following HIV positive results.

So when I came they explained that today as I am pregnant and came for my first ANC, they explained that they will test me for HIV. If I am found to be HIV positive, I start treatment there and there. I should not go and think about it because I am protecting this baby I am carrying. Actually I was not prepared for testing because I
had not ever tested in my life, let alone starting ART for life. This surprised me when I got into this facility when they told me that just because I am pregnant, I have to do an HIV test. They tested me and said I am HIV positive. I didn’t even know where to from here with the containers they gave me. I even thought of discarding them along the way because I was not ready for them…….. We should go back to the criteria of using CD4 count. Because the thought of coming and taking medication on first day, it is not going well with us (37 years old participant)

What I have found not good about this programme is that today they tell me my HIV status that I am positive. And also today evening they tell me I will be starting drinking my medication yet I have not accepted on my own. I want to go and think about it thoroughly. But the nurses would not agree to that. They just say take everything today and go with the tablets, there is no time for thinking (27 years old participant)

What is bad is that the health care workers feel like if they test you and you are positive, then you need to start on the ARVs same day yet it is not always the case where you have accepted. So I think everyone...every pregnant woman who tested positive should be given some time to go home and think and accept the situation then come back. This thing of starting the medication same day Ayyy! I am not comfortable with it because I would be having this stress of having tested positive (22 years old participant)

Data also revealed that because they were not given time to accept and tell their partners, participants would take the ART home but kept them for some time while trying to accept and disclose to their partners.

The counsellor counselled me and told me that now that I have been found to be HIV positive and pregnant at the same time, they will not even negotiate with me. They will initiate me on treatment even if I have more than 1000 soldiers..... I was not ready...I was so worried such that even after they have given me the tablet, when I left the clinic, I just put it aside, and did not drink it on that day but took it the following day because I was trying to accept. (30 years old participant)

But when I tested here I couldn’t take the tablets such that when I came for 2 weeks review in the clinic to check on how I’m doing with medication, I had not taken them.
Yes I didn’t take them. When I reached home I couldn’t take them because I was afraid of my husband. I couldn’t tell him about this. (37 years old participant)

The decision to accept treatment even though they felt they were not ready was propelled by wanting to protect their babies from getting HIV infection. Some participants even feared that refusal to test for HIV and start ART if found to be HIV positive would lead to being refused antenatal services in the facility.

I was not ready. But it was this situation that now I am pregnant and I should test to protect my baby as I was taught……. They do not give you opportunity to go and think. They just tell you to test, take tablets and start drinking. But because you are protecting the baby, there is nothing you can do…….. Yes protecting our babies is the main goal, otherwise without the baby I was not going to accept this, it is was going to be difficult, very difficult (28 years old participant)

Eyyyy what is not good is that you do not have time to accept. And they don’t say go and think because before they would do your CD4……so now the way it is some people find it difficult. Like me, I found that it was difficult for me to start the tablets. But because I wanted to protect my baby, there was nothing I could do. I had no choice (37 years old participant)

4.3.2 Reactions after receiving HIV positive results

Participants expressed different sad emotions after receiving HIV positive results. These emotions included anger, pain, loss mind, confusion and fear of disclosing, fear death, concern about lifetime commitment to ART etc. Some participants were still emotional when they recalled this day although they would emphasize that they had accepted being diagnosed as HIV positive.

It was very painful …..it is my first pregnancy and now I am positive. Ey so it was painful. I just cried. I felt like dying (21 years old participant).

It is because one didn’t know. It is difficult that now you will have to live on tablets for the rest of your life. The thought of taking the tablet every day…..! It is something that I was not used to. So it is those problems. Another thing is that most people were
dying before. So I had no hope that I will continue to live…… 30 years old participant).

Eyyy. It was difficult... it was difficult I don’t want to lie...I just cried..... I even thought of killing myself (32 years old participant).

Yiihhhh! Yahh! It was not easy to accept it. It was difficult. It was like I am losing my mind. I felt like I will die. Something like that....... I had no hope that I will continue to live. (38 years old participant).

Denial was also one of the reactions described by participants because according to them they did not show any signs of being HIV positive. So, it was difficult for them to accept or believe that they were HIV positive. They expressed that they could not believe the results such that they needed to confirm it in another facility.

It was difficult for me. I first went back to the house. It took me days to think about it. I first tested that side and then went to the other side to test again.... I disappeared for days after testing positive. I felt like maybe it is going to change. After some time I came back to start the treatment. But when I came back I found that nothing has changed. (30 years old participant).

No I was expecting an HIV negative result. I did not think I had HIV because I was healthy. But then they said I am HIV positive. I did not believe them. I had to go to another clinic to do a second test again. But they told me the same thing. I accepted the status after the second test in another clinic. But I still couldn’t understand how and where I got it from. I was hurting but I had to accept...... It was not easy to accept it. It was difficult. It was like I am losing my mind. I felt like I will die. Something like that. (38 years old participant).

Participants reported that they had lots of questions on where and how they would have got infected with HIV because they perceived themselves as not at risk of getting HIV since they were faithful to their partners. As a result, they feared that they might be the ones blamed for bringing HIV infection at home and be accused of not being unfaithful to their partners and hence they acquired HIV infection.

I asked myself where I got it from then because I only sleep with my husband. (32 years old participant).
It is because I was living a decent and faithful life. I was not a reckless person with my life. So I asked myself how? How did I get the virus? What really happened? In his mind he will tell himself that maybe I am not faithful to my marriage……. He might shift the blame on me. (38 years old participant).

Data also showed that some participants were suspicious that their partners were also HIV positive but kept hiding their status from them; hence they were the ones who infected them with HIV. This brought anger, hurt and disappointment to the women.

I felt anger because in my mind I knew he infected me with this virus. What hurt me most was that this person did not want to come to the clinic with me yet he knew how he is pertaining his HIV status……. I recalled that when I met him he didn’t look well or healthy but after sometime he gained weight. I was surprised that why all of a sudden (22 years old participant)

The person I was in love with or let me say the father of the baby…because I was staying with the father of the baby. He was a problem. When I told him that let us use condom he would totally refuse. eish he always shunned away from topic of HIV testing. Actually at times he would get angry when you talk about HIV related topics. So …….. One would see that he really doesn’t want anything to do with HIV and I didn’t know why….but I was suspicious. So after discovering that he is like this…..I was hurt. It didn’t go down well with me (28 years old participant)

On the other hand, data revealed that some participants did not have any sad emotions after testing HIV positive. It was easy for them to accept their situation mainly because they had relatives living with HIV and who are healthy; and they could not be identified as having been infected with HIV and on ARVs.

It was not a very difficult thing. Yes it was painful but it was for short time. It just took few days because I then accepted……….. I just felt like even at home there are people with it. And most people are also taking this medication without any problem and they are living. You will not tell by mere looking that this one is taking tablets, this one is not. They are just humans like me. (23 years old participant).

Yes they would teach about it. Then I would get the information that it is important to test early if you are pregnant and the baby gets protected if you are taking the medication. Then I stood up, went to clinic and tested. They told me I have it. I didn’t
get sad or what because I knew my mother is taking the medication so what can hinder me. I didn’t get angry. Yes it was easy to me, I just accepted. (25 years old participant).

4.3.3 ART treatment

Participants describe their experiences with the ART treatment. Some participants delayed the initial intake of ART mainly because they still had not accepted the fact that they are HIV positive and had to start lifelong ART. Besides not being ready personally, non-disclosure to a partner was also a stated reason for delaying in starting ART.

They told me that they are giving me 15 tablets because they want to see how the medication will treat me, I will come back after 2 weeks. I came back without taking the medication. I did not take them. When I reached home I couldn’t take them because I was afraid of my husband. So I came back and explained that the biggest challenge is that even the time they gave me ey...I have to take the medication when I go to bed. The man...my partner would already be in the house, so I am afraid....im afraid how will I explain to him about the story of these tablets? (37 years old participant).

Yes I kept them for a whole week....thinking on how I will disclose the issue of the medication to my husband... Sister, my husband takes alcohol....so it was difficult...It is difficult...It was difficult to tell him such things. I couldn’t take them. I was waiting to disclose to him first. (32 years old participant).

Another reason for the delay in starting ART was fear and of myths about ART. They were sceptical about ART because of the negative comments they had heard about ARV drugs.

Ok another thing is that lot of people who are taking these medication are saying a lot of things....they are saying different things... some say they make you shapeless, they were saying your body will be shapeless, they will cause you to be sick and bed ridden.....they cause horrible night mares.....just things like that. So I was afraid of these thoughts. Those fears in general. They just raise lot of fears...It is like when you go to deliver for first time people will tell you that you will experience this and that.....so it was like that even to me. People were talking saying the tablets cause
this…and that …and that… so I had those fears of side effects. That it may happen to me. (28 years old participant).

It was because I was afraid that many people think that once you are diagnosed with HIV you are going to die. They said the tablet sometimes cause you to bed ridden…your hips and bums would disappear and you will be shapeless. (27 years old participant).

Participants mentioned that the ARV drug is big and difficult to swallow. They were also not comfortable about the container of the ARV drug which was described to be big and making noise thus exposing them to accidental disclosure.

The tablet is actually big. It doesn’t go down the throat... when you have just been initiated... I don’t want to lie to you....its big. They are two; there is also this other white one cotrime, the one they give us to drink with plenty of water. They are almost same size, it is difficult. The situation was actually difficult. (32 years old participant).

I suggest that they reduce the size of the tablet and be size of panado. It shouldn’t be this big. It should change the shape and be bit small... it is too big...the way it was shaped, it is too big. They should just reduce it, it shouldn’t be this big. Our throats are not the same size. Mine is small, but my husband is not complaining of the size he just swallows it. Mine is small. (27 years old participant).

When they started on the ARVs treatment, they experienced side effects. However, they mentioned that they were informed about these possible side effects when they were given the drugs. These side effects last for few days then resolve. Common side effects mentioned were dizziness, vomiting and hot flushes.

It was when I started. I felt like I should remove my stomach because after taking them I would feel burning sensation on my abdomen, and then feel hot flushes all over my body such that I would want to go outside. At that moment I would feel like vomiting. I vomited once. Even the hot flushes lasted for some days but eventually it was better. (30 years old participant).

It was just dizziness and vomiting for few days. Just 3 days. But thereafter I was fine. But I was not worried because they had told me about the possible side effects. (28 years old participant).
However, some participants reported that they experienced improvement in their health after starting the ART. They revealed that they were having some persistent and recurring ailments which could not respond to other treatment. But ever since they started ART, they noted some great improvement in their health.

*Before I started on the treatment, I was having frequent episodes of headache most of the time. Even on my body I would have those rashes, having lot of itchy things. When I finish bathing the body will be itchy. But ever since I started on the tablets, all those things are disappearing in my body. I am now heathier. (27 years old participant).*

*Now that I have started the tablets I am no longer sickly person. I am now a healthy person. No one goes around pointing fingers at me that ey this person is sick. I am now beautiful, my bums are now big and even the hips. I am just beautiful. I am doing fine with the tablets. (22 years old participant).*

*Ay no I am no longer a sickly person. It helped me because I was diagnosed with meningitis couple of times and I would be sick and admitted in hospital. I am ok now. I no longer get those flue attacks. (28 years old participant).*

### 4.3.4 Care in the PMTCT services

Participants reported that generally the attitude of health care workers as being good and they felt they took good care of them. They mentioned that health care workers are caring, encouraging and supportive such that they are given time to freely ventilate their concerns with them and they would get good advice from the health care workers. They also reported to be receiving a warm welcome from the health care workers when they came for their first visit in the facility or in the PMTCT programme.

*They are treating us well. I don’t want to lie. They are treating us well. Even if you ask, they do respond. They give you time even inside the consultation room, they don’t rush to finish the que, they give each one of us enough time. They also examine us well with tender care such that we can’t hide anything. You just talk freely. (28 years old participant).*

*Their attitude is very good. When you come to the clinic for the first time, you do not get lost, they would notice that you don’t know the clinic and they would then show*
you that you start from here then next you go there. They are very supportive. They just help you and they don’t get tired even if you ask them questions. So you go home satisfied and happy all the time. (22 years old participant).

On the other hand, it was also highlighted that some health care workers do not have a good attitude and they are not treating them well. Some further highlighted that even though the attitude of health care workers was not good when they started on PMTCT, they noted some improvement with regards to their attitude as they continued coming for PMTCT services.

Their attitude is good and but I can also say it is bad because when they are at work like everywhere else we are not the same. Someone might just be naturally mean to people and do not welcome people well, but on other days you will find that there is someone else. They say they rotate. On other visits you will find this nurse whom you will be able to report all your problems but somebody else like I have said on other days they are short staffed, when you want to report the nurse will tell you that you should mind the long que outside, you should give the others opportunity to also get the services they came for. (38 years old participant).

So far I can say nurses have now been taught on how to treat patients. But before, their attitude was not good. They would not even have your time. But now I can see the improvement. They are basically taking good care of us. It is just the waiting when they have not yet started working. (38 years old participant).

It differs because at times you find that the nurses if last month you were attended by this one, the following month when you come you will find another nurse whom will have bad attitude you see those things. At times I have to ask what I should do she would just respond that way. So they differ. We do not see same nurses every visit. Some are good, some are bad. (37 years old participant).

Due to high catchment area of the facility and staff shortage, the waiting time is long. Some reported that it depends on the queue you will find. As a result therefore, participants have decided to come early so that they don’t find a long queue.

At times they tell us that there is one nurse, so we have to wait for the nurse working that side in the other departments until she comes back to work here at the ANC (27 years old participant)
I can say waiting time is good and is bad. That is what I can say. When I say it is good and its bad I mean it happens that there is no nurse who will attend to us when we come from Egumeni, (a room where PMTCT women would have health education and counselling sessions with mentor mothers and expert clients) they would tell us they are short staffed and we have to wait for long time. But then when the nurse is available, when we come from Egumeni we get service fast. (38 years old participant)

The problem with this clinic is that it is usually full of many patients. It usually takes lot of time before you get help... At times you come in the morning around 8am but you will find that you go back home around 12 noon. You just stay and find that you are hungry and tired yet even here there are still lot of patients in the que before you. (22 years old participant)

No it’s because of the ques....It is just the ques. You wait for long time. Eish! We wait for long time before we get services. I do not know how government can help us we pregnant women because eish! We just want our things to be done fast so that we go back home to rest (30 years old participant)

Participants reported that PMTCT services in the facility are always available. At times they will find that there is shortage of blood supplements but the ARV drugs are always available.

Services are always available. I have not encountered situation whereby they don’t provide some services. It is only once where I came and they said .....I have come on Thursday for my ARV refill and I was due for blood tests. So they told me to come Tuesday for the bloods. When I came on that Tuesday, they told me that they forgot to tell me that they do not have test tubes for collecting blood. I should remind them when I come back again so that I take the blood tests. (21 years old participant)

Ever since I started, I usually get services I have come for. It has never happened to me that they deny me some services for some reason. Ever since I started, I get the help I need. (23 years old participant)

The main challenge reported is that there were stipulated times for the PMTCT services. Late comers are turned away and told to return for services the next day.
At 9:30 am, they stop doing ANC. After that time they won’t attend you. So we always try to be on time to get services. …….at one point in time; they turned us back with my husband. They just told us to go back and come following day because ours is not an emergency. (37 years old participant)

At times you would come and you won’t get that service. Let us say maybe they say some tablets are out of stock or maybe you have come late for PMTCT services and they turn you back. It does happen that you do not get all the services you have come for. (38 years old participant)

Participants receive all the health services they need in one room; they do not have to move from one room to another. Other health services are integrated in the PMTCT department.

Even if you are sick, you just report your sickness to that nurse and you get treated in the same room. There is no need to go to another room for prescription; everything is done in the same room. (38 years old participant)

We just get into one room. One cannot notice that you are pregnant and you have come to refill medication. So the nurse, who will attend you, is the nurse who will also do refill for you and give you other services you may need. You do not move from one door to the next and you do not queue on different door because you are positive. You just get into one consultation room and the nurse will do ANC services and give you your ARVs and other services you need in one room (27 years old participant).

4.3.5 Views about Counselling

The counselling they receive in the facility is satisfactory. They found the counselling to be helping them to accept and cope with their HIV positive status. Different cadres were said to be providing them with satisfactory counselling which helped them to cope and accept their HIV positive status.

I was helped by coming frequently to the clinic to attend support groups to get health education and counselling. They would teach us and counsel us. And I would also see that I am not the only one HIV positive. We are many. I would then get courage, that so and so is living with it, so and so is living with it. (30 years old participant).
I continued to get counselling here in the clinic. I came back even if I was not my appointment date, I would come and they would talk to me. I would tell them that I have not accepted yet….. I continued even to read myself, I would ask for pamphlets and books from the clinic and would read and read a lot. I then realized that I will leave there is nothing wrong with this medication. So I was helped a lot by being truthful to the staff, getting counselling and reading. (28 years old participant).

The nurse and the counsellor who tested me and the women at Egumeni they helped me to understand that I should not focus on who infected me or how I got infected, when. (38 years old participant).

Data also showed that the participants perceived counselling to have helped their partners to accept them and their HIV positive status.

They gave him the letter of invitation that he should come. When he came they counselled him about my condition. Soo they found that hawwuu! He is accepting me. Life became nice after that, it was nice. He started accepting me such that when its 8 he reminds me that it is time for taking medication. (37 years old participant).

I was helped by the HTS counsellor. She is the one who counselled me. No she really helped me. If she was not there...because I even thought of killing myself but she told me, life goes on...this is not the end of the road...there is no permanent situation....It is just temporally. I will get over it. He even invited my husband and explained to him. She also helped in counselling him. We are now fine. Otherwise, it was difficult. (32 years old participant).

4.3.6 Partner involvement

Worth noting is that, efforts are made to involve male partners through invitation letters given to the women to invite their partners to come with them to the clinic. When they come to the facility, the male partners would also be offered HIV counselling and testing, and some would also test HIV positive. Upon finding that they are also HIV positive, they would accept their women and support each other with their ART.

He accepted after he also came for the test and tested positive too, then he accepted. Otherwise before he tested, he did not accept. Even for him to go for testing, I told
him they are calling you at the clinic, the baby is not positioned well in the stomach. That is when he followed me to clinic. When we reached the facility, they talk to him, they talk to him and referred him to testing room. They talk to him and he tested. I was not there with him he tested and found that he is also positive. He then accepted the situation. (30 years old participant).

Then the health care provider asked me to come with my husband next visit as I have explained before that they would give us invitation letters to give to our men. I went back with the letter and gave it to my husband. We then came together to the clinic one day. When the health care provider tried to explain to him, my husband was able to understand that being HIV positive does not mean you were loose. So he then also tested for HIV and was found to be HIV positive too. And that is when he accepted me. When we got home he was able to talk to his parents and share with them what he has learnt in the clinic. (30 years old participant).

Efforts are made by health care workers to involve partners by inviting them to come over through invitation letters but usually partners would not honour those invitations. Common reasons stated were that they are busy at work.

*They give us invitation letter to give to our partners....... Yes they give us short letters to give to our partners so that the health care workers have an opportunity to talk to our partners and also test them. But my partner always said he is busy at work* (38 years old participant).

*They do involve them it is just that most men do not like coming to the clinic. They do encourage us to encourage our man to come with us to also come and test, and also to get more information in order to support us. They tell us to invite them by giving us invitation letters.* (22 years old participant).

When one comes with her partner in the facility for PMTCT services, they are fast tracked. This is a strategy to involve more male partners in the PMTCT programme, for them to be tested for HIV and to support their women. In this way, the male partners are encouraged to accompany their spouses to the facility.

*In this facility what is good is that if you have come with your partner, you do not que, everything is done fast for you. This is a way of encouraging the men to come to the*
clinic. So if I have come for ANC, my partner goes with me in all the departments. We just stand by the door, and ushered in. (22 years old participant).

In this facility I just found that if you come as couple, you get special treatment. You do not que, you just don’t join ques... they just escort you from registration from door to door and they tell the health care worker inside that there is couple outside, you just don’t wait, they treat you like an egg.....when you have come with your partner..!!? I wish even after I have delivered...It is just that work may not permit, but I wish my husband would continue accompanying me all the time to avoid hearing noise of crying children in the benches. Even now he does accompany me. (22 years old participant).

4.3.7 Support

Participants expressed that they receive forms of support from their partners, families and health care workers in the facility.

The support they receive from their family or relatives mainly include being reminded to take medication, being encouraged and supported with food.

My mother has backyard vegetable garden she would say if your husband has financial challenges you should freely come to get vegetables. Even in the house we eating balanced diet because they have taught us in the clinic that we should eat balanced diet. We are now taking our medication in same facility with my husband. We accompany each other. (32 years old participant).

My mother! She is very fine. She sometimes reminds me about time because I told him the time for taking my tablets. So at times she would buzz me and I would see that Ohh! She is now reminding me that it is my time I have to take the medication.... she shows me love all the time. She gives herself time to be with me and support me with food; even emotionally she is there to support me... My partner is someone who is able to take care of myself even with food. Even in the house he buys clothes. He supports me in every way I would want from him. (22 years old participant).
Partner support also included being reminded to take medication, financial support, and emotional support. Furthermore, their partners would support them by ensuring that they have protected sex to protect the baby from being infected with HIV.

He supports me by ensuring that we protect ourselves always because we are in this situation, he ensures that we always use condom so that we don’t infect the baby.... he also gives me money for going to the clinic. And encourages me that I should make sure that I go to the clinic so that I know that we are both healthy and fine. (38 years old participant).

He is the one who came with the idea of accompanying me to my clinic. He got transfer from his facility and came to my facility and we taking ART in same facility now. He would even refill for me if I am held up at work. He is very supportive. (32 years old participant).

Health care workers in the facility supported them through continuous health education, counselling, a positive attitude of health care workers, and non-discriminatory care.

The nurses....the nurses are very supportive. Each time I come to the facility, the nurse would ask how I am doing with the medication...yes she ask. Then I would respond. Like me when I started I would vomit, I had nausea. Then the nurse told me to first drink a glass of water, then take the tablet, then drink water again. I did that and I never vomited again, I never. (32 years old participant).

As I came again and again in this facility for my ANC visits they would counsel me and ask me how am I doing with my tablets. They would ask me if I had any problems. The nurses and the counsellors were very supportive and encouraging. I then realized that these people care a lot about me. (30 years old participant).

Ever since I came to the facility, they are taking good care of me. Just because we are positive, they do not treat us that way. They are very supportive, a lot. Even now I had missed my appointment for coming here..... But I explained to them and all went well, they welcome me and told me that there is no problem as you have explained. They continued supporting me. If you have missed your appointment, they always make means to follow up on you so that you do not default. (25 years old participant).
Data showed that facilities also support them through establishment of support groups for women enrolled on PMTCT in facilities. The support group serves as a platform for receiving more health education, encouragement and support which helps them to accept their HIV positive status and continue living positively.

In the facility at Egumeni they have established support group for us where we can freely ventilate our feelings and concerns and help each other. I can just say that is where we are able to ventilate because you find that there are others who are taking the medication yet they have not disclosed to their partners yet they are staying together. But we share with them on how we disclosed. On the next support group meeting, you find that they have also managed to disclose. At times they would even come with the partner in the support group. And this is the good thing about it. (32 years old participant).

During month end, we usually have a programme whereby pregnant women meet. This is a platform where we meet and discuss how we are treated in the facility and where we want then to improve. So, this helps us a lot. So, they usually give us whatever they can as refreshments but that’s not always the case, days are not the same. (22 years old participant).

In the support groups, they also share ideas on income generating projects and this assist them to generate income so that they are able to generate income to cater for themselves and their families rather than being fully dependent on the partners.

In the support group they usually call us every month end we pregnant women and those with children 0-2 years. They help us and teach us on income generating projects. As I speak I have my fabric softer in the house that I make. I was taught in this support group. So that we make a living and be able to buy spinach if you want it and do not complain that my food is not balanced diet. (32 years old participant).

But month end they would invite us to support group where we pregnant women we come and get information on how we can make living. So, they would teach us on income generating projects. This happens every month and we come and get ideas on how we can make living. (38 years old participant).
4.3.8 Stigma and discrimination

Being stigmatized and discriminated against by the people they had disclosed to, was another reaction some participants. Some were made to use separate dishes and cutlery and were not allowed to share with the rest of the family members, while some were made to drink their medication outside the house especially when there are guests in the home.

*I was very close to my sister before but after I have told her I noticed that when I am at home where she stays, she would not get closer to me, we used to eat together but you would find that she doesn’t want to do that anymore, she would dish separate plates. We didn’t eat together anymore. Even when we talk, she was not as open as she was before I told her about my HIV status.* (38 years old participant).

*She told her son not to use plates that I use, and spoons… they would buy me plastic spoons and they would use the metal one. They bought me plastic spoons. Even if I am in her kitchen, she would tell me not to wash her dishes, I should only wash my dishes and those of my children. I was living that kind of difficult life, yet I was pregnant and living such difficult life.* (30 years old participant).

*Let me say when we were together and it was time for me to take medication and maybe we are having visitors. I will see that my boyfriend is not happy, he is not at ease. At times he would take the bag with the tablets and go outside, then call me outside and tell me to drink my medication outside……. Even at times when it is both of us he would say your things are making noise here, why don’t you change the containers because it is drawing lot of attention to visitors. He eventually left me.* (28 years old participant).

Participants did not disclose to their neighbours or community members because they feared that they might be stigmatized and discriminated.

*I have not disclosed to them. I cannot disclose to strangers because they might go around and tell everyone. Yes, even if you can come to ask for salt she would say there she comes with her virus to infect us because you would find that that person is not educated about HIV and this can make your life difficult.* (32 years old participant).
You shouldn’t go around telling people your stories…people talk….they talk a lot. So, I didn’t want them to go around pointing figure at me. I only told my partner. (30 years old participant).

4.3.9 Disclosure

Participants expressed that it was difficult to disclose especially to their partners due to fear of partners’ reaction after disclosing. Fear of how to introduce this issue to the partner made participants to delay disclosure to their partners.

Eish! He always shunned away from topic of HIV testing. Actually, at times he would get angry when you talk about HIV related topics. So ……. One would see that he really doesn’t want anything to do with HIV and I don’t know why. So, I had that anxiety that maybe he will do something to me if I discover that I am like this. I was so stressed because I asked myself how I will enter the house with this news…with these containers. How will I tell him? I even thought of throwing them away along the way. (28 years old participant).

It is very difficult to come back to your man and tell him that you are pregnant, let alone telling him that you are HIV positive. It was difficult for me to tell him that I am HIV positive, because I didn’t know what will happen thereafter when we go back home. So, I wanted to know his status to know if he also have the virus because you may find that I have it and he does not have it then this was going to cause problems. (27 years old participant).

It took some time. Yah! It took some time. I was still trying to find ways on how I will tell him. It was difficult to tell him there and there. (38 years old participant).

As a result of the fear of disclosing to their partners, some participants hid their medication and took them in secret or waited until they managed to disclose their status to their partners.

It was very difficult to disclose. It was very difficult to disclose to anyone. I just stayed and locked myself in the house. Even the father of my children when he came back he asked how did I go in the clinic, he thought maybe I had some pains in my body as pregnant woman, I just told him that it went well at the clinic. I hid all the cards. I hid
all the tablets. I would always wait for him to just disappear maybe to the toilet so that I take my medication. It was difficult. (30 years old participant).

For the tablets it was not a problem because I had chosen to take them at 6, by this time he would still be at work, not yet in the house. So, I hid them in the house and drank them before he came back from work. (27 years old participant).

Due to the fear of disclosure to partner, some participants preferred to disclose their status to other relatives first before they could inform their partners.

What I thought of was to go home to my mother to disclose to her because my man was a lion when you talked about HIV things. So I went back home to my mother to disclose my status to her. (27 years old participant).

But then I thought of calling my mother. I told her what happened and what I was thinking to do and she said I should think about the baby in my stomach because the baby cannot talk for him or herself. If he chases you away you are more than welcome to come back home to be able to take your medication well and protect the baby.... when I went out of the clinic, I just called my mother and told her. She said there is no problem sis. Go and take your medication but if they give you problem where you stay, please come back home. (28 years old participant).

Participants reported different reactions from the people they disclosed to during and after disclosure. Some were easily accepted by the people they had disclosed to. Data revealed that the participants were easily accepted by their other relatives other than their partners. These relatives would further encourage them to adhere to all advices given to them in the facilities so that they continue to live a healthy life.

My mother didn’t take it bad. She just told me to go to the clinic and take every instruction and advice the doctors give me. She didn’t have that much knowledge about HIV but she did advise me to follow all the instructions from health care workers in the clinic so that my baby comes out without the virus (22 years old participant).

My mother felt a lot of pain. But then she became a mother because she was able to cope in that situation and she managed to support me in all possible ways. She sat down with me and told me that this is not the end of the world. She knows some
relatives who have gone through the same so if I can just follow all advises they give me in the clinic and take my medication well, and if the father of my baby can also be supportive, she doesn’t foresee any problem or challenges. (22 years old participant).

When I got home, I disclosed to my mother. I told her. ..... She just accepted me. Luckily, in the community, they educated about PMTCT. So she already knew about it. It was not difficult. (32 years old participant).

It was also found that acceptance by the people to whom they have disclosed to was not easy at first. However, data revealed that these participants would eventually find acceptance as time goes on.

At times if he has come to visit me where I stay, he would pretend. He would not act the way he used to. Like when we talked or laughing he would ..... Yes you could see that he is not in that good mood. At times he would tell me that the thing you told me is eish............! But when he continued to come back he eventually told me that Hhayi! I have accepted this. Yes! (24 years old participant).

What made me see that it is difficult is because on the day I told him he kept quiet and told me that he does not have words to respond to what I have just told him. So I saw that ....yah it was just my thoughts that maybe it is difficult for him to accept. But maybe let me give him some time..... So it was difficult at first but I told him let me give you time to think about this. Then it will be up to you on whether we continue or not. But I am telling you because I want you to also go to the clinic. I think I gave him a week. He called me and said, there is no problem xxxx. Come let us talk. I am grateful that you told me the truth because these girls today they don’t tell the truth in this matter. Even now he would have come with me but it is just that he has gone to work. (23 years old participant).

At first he ignored me and sort of left me. But after sometime he came back and we sat down and talk. He said, “I don’t know why I am running away because if you are like this, I also have to go and test”. (21 years old participant).

On the other hand, some participants suffered desertion by their partners or being chased away from their marital homes after disclosure of HIV status, mainly because they were being blamed for bringing HIV infection or getting themselves HIV infect. In some instances, they were scolded by their own family.
The day I managed to tell him that this is what they gave me at the clinic, he told his mother the news. They chased me from his house. His mother blamed me for bringing deadly disease to the home to infect her son because her son did not have this disease. She said I was the one who brought the death at her home.....I was so hurt. (38 years old participant).

Eyyy it was difficult. Such that my mother had this saying of ...you see....I told you about your behavior and lifestyle.....your lifestyle is not good... I told you with your behaviour you are heading to such things...you see now you are even pregnant and all those things you have now Yooohhhh! But eventually she accepted me. All is well now. (37 years old participant).

At times when we are just seated, talking about it, I would see that this thing does not go down well with him. He was always quiet. He always said I still owe him an explanation on where I got this thing. I should tell him who infected me..... He eventually left me...So I think that was the reason we separated. (28 years old participant).

On another note, it was found that participants’ disclosure led to partners disclosing their own HIV positive status to them.

On that day he also told me the truth and showed me his booklet. It means he was also attending another facility, but he was scared to tell me that he is also like this. So I knew when he had been on treatment for 2 years...then I knew now that he is also taking the tablets. It did not go down well with me because I was faithful to him, and I was healthy, I didn’t have the virus. It really pained me a lot. At the same time, I was also grateful that he did not continue with hiding the status but eventually told me the truth at the end of it all. We accepted each other. (22 years old participant).

He had a problem in disclosing to me. He had started the ART 2 months ago, he started first and I later. He then told me that he also went for HIV test and they started him on ART. He was storing them outside in chicken shed. He then showed me his refill booklet and said this is where I take my medication. I also went to clinic to test and they started me on this medication..... Yes we accepted each other. (32 years old participant).
4.3.9.1 Reasons for disclosure

Participants stated different reasons for disclosing to their partners and/or relatives. The reasons stated for partner disclosure was to be able to take medication freely and also to encourage their partner to seek HIV testing.

The reason I disclosed to him was that I would go to my parental home to my parents. I just thought the first person to disclose to was the one I stay with, the one who will see me when taking the tablets. Even if I had told them at my home, I don’t go there often, most of the time I am with my husband. When he sees me taking tablets he should know what they are for. (38 years old participant).

With my husband, I wouldn’t be able to take my medication because we stay together, he would also want to see my ANC card. So, I would know maybe the nurses have written in the card….maybe he knows and he will see in the card. So I had to tell him so that he goes and test and we are able to continue living. (32 years old participant).

It was important for me to tell him so that he stands up and go for testing because we need to trust each other. So if I start hiding something from him it might not be a good thing. Life should continue so I have to tell him. He had to know. I also wanted to be able to take my medication well and freely without hiding them. (38 years old participant).

Another reason stated was that they disclosed their status because they wanted to be supported in adhering to the medication or in case they get sick.

I thought it is better to disclose to them because they will be able to support me even if I can get sick or admitted in hospital I should not be afraid that it is time for medication. They should be able to know and give me. As for my spouse it is because I stay with him, I cannot manage to take medication if he doesn’t know about them. (37 years old participant).

Another reason I disclosed to him is that I wanted or I thought he will support me as his wife as I take the medication because in the facility they had explained that there might be side effects from the medication, so I had to have someone who will support me as I take them. (38 years old participant).
4.4 Conclusion

This chapter focused on data analysis and interpretation which highlights the findings of the study. Findings on the participants’ perceptions and experiences on the PMTCT programme were expressed through themes. This is a narrative that has been organized to communicate the participant’s perceptions and experiences on the PMTCT programme.
5.1 Introduction
This chapter presents the discussions of the main findings of the study. Firstly, it presents the demographics of the participants, then the discussion of the themes that emerged from the study on the perceptions and experiences of HIV positive pregnant women on the PMTCT programme. The conclusions, limitations and recommendations of the study follow thereafter.

5.2 Description of study participants
5.2.1 Socio-demographic information
The sample for the study comprised of fifteen HIV positive pregnant women enrolled on the PMTCT programme. Most participants (n=9, 60%) lived with their partners, whilst the rest lived with their extended family. Participants’ age ranged from 21 to 38 years with a mean age of 28.6 years. The majority of the participants were single (n=7, 46.7%), while 33.3% (n=5) were married and 20% (n=3) were cohabiting. Sixty percent (n=9) had a high school education, and only 13.3% (n=2) had a tertiary education. The employment status of the participants showed that 53.3% (n=8) were employed, while 40% (n=6) were unemployed and 6.6% (n=1) was self-employed.

5.2.2 HIV related data
Majority (n=12, 80%) of the participants were diagnosed as HIV positive in the current pregnancy during their first ANC visit. About 20% (n=3) knew their HIV status before this pregnancy. An overwhelming majority of 86.7% (n=13) of the participants had disclosed to their partners and started ART on the day of HIV diagnoses while 2, (13.3%) did not start ART on the day of diagnoses (delayed starting ART). It was also found that 46.7%, (n=7) did not know their partners HIV status, and 53.3%, (n=8) knew their partners HIV status. Worth noting is that 40% (n=6) reported that their partners were HIV positive and 13.3% (n=2) had HIV negative partners. The gestational age of the participants ranged from 8 to 38 weeks and mean gestational age being 24 weeks. More than two thirds of the participants (n=10, 66.7%)
had been on PMTCT programme for 2-3 months and 33.3% (n=5) had been on PMTCT programme for 5-8 months.

5.3 Views about PMTCT programme

When asked about their perceptions on the PMTCT programme, most participants expressed a positive view about PMTCT and felt that PMTCT is a good programme which has brought life and hope to HIV positive pregnant women. They felt that the programme preserves their life and that of their babies. They further highlighted the benefits of the PMTCT programme which makes it to be a good programme to them. The major benefits highlighted were that of protecting the baby from acquiring HIV from the HIV infected mother. PMTCT also provided them with an opportunity to know their HIV status early and start treatment early before they became sick. Similar studies also revealed that PMTCT is perceived by most women as a good government programme which protects their babies from HIV and also provides them with an opportunity to know their HIV status early. It is also viewed as an entry point to lifelong ART to keep them healthier and live longer and have the opportunity to raise their children (Kasenga et al., 2010; Black et al., 2014; Ngarina et al., 2014).

On the contrary though, some participants expressed negative feelings about mandatory HIV testing and prompt ART initiation in the PMTCT programme. They viewed this component of the programme as being coercive and not giving them time to accept the HIV positive results, report to their partners and make their own decision regarding treatment. They were also not given any other option; they were just tested and initiated there and there. Generally, they felt that they were not ready to start ART following HIV positive results. Black et al. (2014); Lettow et al. (2014); Matheson et al. (2015) reported similar findings in their studies which reported that women on PMTCT felt that the PMTCT programme violates human rights to autonomy because they are not given an option and enough time to make their own decision regarding PMTCT enrolment; hence they viewed PMTCT as coercive programme.

The decision to accept treatment even though they felt they were not ready was propelled by wanting to protect their babies from being infected with HIV. Some participants even feared that refusal to test for HIV and start ART if found to be HIV positive would lead to being refused antenatal services in the facility. These findings are similar to recent studies showing that HIV positive pregnant women’s desire to protect their babies was the main reason which
drove the women to enrol on PMTCT programme (Tenthani et al, 2014; Elsheikh et al, 2015; Matheson et al, 2015).

5.4 Reactions after receiving HIV positive results
Participants expressed different emotions after receiving HIV positive results. Some participants were still emotional when they recalled this day although they would emphasize that they had accepted the diagnosis. Similarly, Rujumba et al. (2013) reported that women experienced feelings of disappointment and sad emotions upon receiving HIV positive results. Furthermore, Nakimuli-Mpungu et al. (2013), in their study stated that some people who are diagnosed with HIV suffer from undiagnosed depression and this has a negative impact on adherence and retention to care in HIV care programme. This places the need for continuous psychosocial support across all HIV care programmes including the PMTCT programme.

On the other hand, data revealed that some participants did not have any sad emotions after testing HIV positive. It was easy for them to accept mainly because they had relatives living with HIV and who are healthy; and no one could tell that they are on ARVs. These participants mentioned that they had been acting as treatment supporters or taking care of their relatives living with HIV, and they have seen them living healthily. This made it easier for them to accept that they are HIV positive.

Denial was also one of the reactions described by participants because according to them they did not show any signs of being HIV positive. So, it was difficult for them to accept or believe that they were HIV positive. They expressed that they could not believe the results such that they needed to confirm it in another facility. As a result, it was not easy for them to accept lifelong ART. Painter et al. (2004) in their studies also reported that denial of an HIV positive test was one of the reasons women would not accept antiretroviral prophylaxis for PMTCT of HIV. This increased the risk of MTCT of HIV to their babies.

Participants reported that they had many questions on where and how they would have become infected with HIV because they perceived themselves as not at risk of getting HIV since they were faithful to their partners. As a result, they feared that they might be the ones blamed for bringing HIV infection to their home and be accused of not being faithful to their partners.
Similar findings were previously reported by Kasenga et al. (2010), Rujumba et al (2012) and Ngarina et al. (2014) who argue that upon being diagnosed to be HIV positive, pregnant women were concerned that they might be blamed by their partners or relatives for being infected with HIV and exposing their partners and relatives to HIV. The fear of being blamed for bringing HIV to the family would make them to hesitate to disclose their status especially to their partners. Ngarina et al. (2014) also state that women who were diagnosed with HIV in the PMTCT programme were blamed for bringing the virus home by their partners or their in laws. Being the first one to find out that you are HIV positive was associated with being the one who brings HIV at home to infect your partner. As a result, women in the study suggested testing as a couple in the PMTCT programme to reduce the chances of being blamed.

Data also showed that some participants were suspicious that their partners were also HIV positive but hid their status from them; hence they were the ones who infected them with HIV. They felt that their partners deliberately infected them with HIV and further kept their HIV status a secret. This brought anger, hurt and disappointment to the women. This is similar to findings of Mary et al. (2009) who reported that their male partners were hiding their HIV positive status. The women reported feelings of anger, betrayal and disappointment because they felt their partners deliberately infected them.

5.5 ART treatment

Participants described their different experiences with the ART treatment. Some participants delayed starting ART mainly because they still had not accepted the fact that they are HIV positive and had to start lifelong ART. Some delayed starting ART because they perceived themselves as healthy and felt no need for chronic medication. This concurs with the finding of Stinson and Myer (2012); and Katirayi et al. (2016), who reported that some women felt not ready for lifelong ART commitment because they perceived themselves as healthy and did not see the need for starting ARV medication.

Another reason for the delay in starting ART was perceptions and myths about ART side effects. Some women reported that they were concerned about the safety of the baby from the daily ART drug intake. This is congruent to the findings of Otieno et al. (2010), Theilgaard et al. (2011), Stinson and Myer (2012) and Katirayi et al. (2016) who found that the fear of
possible harmful side effects to both herself and the baby made women reluctant to commit themselves to ART.

Some women appreciated the prompt initiation to ART to protect the baby and also for their own health. These findings are echoed by Levy (2009) in his study who reported that women would be grateful of the prompt ART initiation because they felt the medication is not only beneficiary to the babies but also to their own health yet in the past, the PMTCT programme would only focus to the health of the baby, and their health was somehow neglected.

When they started RVs, they experienced side effects but these side effects did not interfere with their adherence mainly because they were informed about these possible side effects when they were given the drugs. These side effects were bearable and would last for a few days then resolve on its own. Common side effects mentioned were dizziness, vomiting and hot flushes. Tweya et al. (2014) and Katirayi et al. (2016) in their studies found that ARV side effects were one of the reasons why some women stopped taking ART or did not start ART. Therefore, clients should receive constant counselling on ARV side effects and these side effects should be closely monitored so that they do not impact on uptake, adherence and retention to care.

Participants reported that they experienced improvement in their health after starting the ART. They revealed that they experienced some persistent and recurring ailments which did not respond to other treatment. But having started ART, they noted some great improvement in their health.

5.6 Care in the PMTCT services

A good attitude of health care workers is associated with high uptake and good retention to care in the PMTCT programme (Larsson, 2012; Gilles et al., 2011). Data showed that participants believed that the attitude of the health care workers differed. However, in general data showed that participants felt that the attitude of health care workers is good and they were well taken care of.

They mentioned that health care workers are caring, encouraging and supportive to them such that they could freely ventilate their concerns with them and they would receive good advice from the health care workers. Kasenga et al., (2010) and Elsheikh et al., (2015) in their studies also found that women reported that they received dignified, non-discriminatory and
non-judgmental care from the health care workers. On the other hand, it was also highlighted that some health care workers do not have a good attitude and they are not treating them well. Some further highlighted that even though the attitude of health care workers was not good when they started on the PMTCT programme, they noted some improvement with regards to their attitude as they continued attending for PMTCT services. This is in line with previous studies indicating that women experience unkind treatment and negative attitudes from health care workers which tended to scare them from accessing or continuing with PMTCT services (Anderson et al, 2012; Laher et al, 2012; Gourlay et al, 2013).

In this study, long waiting times when coming for PMTCT services due to staff shortages was a common experience reported by the participants. Levy (2009) and Theilgaard et al.,(2011) argue that staff shortage in facilities when seeking services acts as a barrier in accessing and retention into care in the PMTCT programme.

Participants reported that PMTCT services in the facility are always available. Even though at times they would find that there was shortage of blood supplements, but the ARV drugs were always available. The main challenge reported were that there were stipulated times for the provision of PMTCT services such that arriving after the stated time resulted in denial of services and informed to return the following day for the services.

Participants receive all health services they need in one room; they do not have to move from one room to another. Other health services are integrated in the PMTCT department and they were satisfied with their intervals between visits. Other studies reported that inconsistency in the availability of PMTCT services, time and travel cost associated with frequent visits to the health facility. Lack of services integration in the PMTCT department is also another barrier in accessing and retaining women in the PMTCT programme (Chinkonde et al, 2009; Levy, 2009; Winestone et al, 2012; Tenthan, 2014).

5.7 Views about Counselling

Data revealed that the counselling they receive in the facility was satisfactory. They found counselling to be helpful to them in order to accept and cope with their HIV positive status. Different cadres were said to be giving them satisfactory counselling which helped them to cope and accept their HIV positive status. The findings are consistent with other studies reporting that the counselling that women receive at the PMTCT facilities is adequate, and the information they received was clear and easy to understand (Kasenga et al, 2010; Matheson et al, 2015; Ngarina et al, 2014). Contrary to the researchers’ findings, Stinson and
Myer (2012) and Levy (2009) found that women expressed that the counselling they received ignored societal and cultural issues and focused more on the clinical aspect. In addition, the time for post-test counselling following HIV positive results is not sufficient. Participant also reported a lack of follow up counselling following HIV positive results, yet according to them follow up counselling was of high priority to help them cope and accept the situation.

5.8 Partner involvement

Data showed that efforts are made by health care workers to involve partners by inviting the through invitation letters; but usually partners would not honour those invitations. Common reasons stated were that they are busy at work. Even though interventions like invitation cards are made to encourage more male partners to participate in the PMTCT programme, some male partners would still not attend in PMTCT programme. This is similar to other studies that reported on a reluctance by men to attend the PMTCT programme due to unwelcoming services and cultural beliefs (Brittain et al, 2015; Cucoa et al, 2016).

To encourage men to join their partners in the PMTCT programme, couples are fast tracked and get quicker services in the PMTCT programme. This is a strategy to invite more male partners to become involved in the PMTCT programme, so that they may also be tested for HIV and support their women in HIV care.

5.9 Support

Participants expressed that they received forms of support from their partners, families and health care workers in the facility. They reported that they were reminded by their partners and or family members to take their medication. Continuous health education and counselling, a good attitude of health care workers, non-discriminatory care and the establishment of support groups in facilities are other forms of support they receive in the facilities. Kasenga et al., (2010); Ngarina et al., (2014); Matheson et al., (2015) in their studies also found that some women received more support and encouragement from their partners and or other significant family members after disclosing their status. Rujumba et al., (2012) also found that women enrolled on PMTCT programme reported to have received different forms of support from the health care workers in the facilities which was very helpful to them. Participants found attendance of support groups as being helpful to them.
because it provided a platform where they encouraged each other and shared ideas on how to live positively. This assisted them in accepting their status. Nattabi et al., (2011) supported these findings in their study which reported that support groups serve as good supportive environments for people living with HIV. Researchers argue that support has a positive impact on adherence and retention to care in the PMTCT programme (Ngarina et al, 2014).

5.10 Stigma and discrimination
Being stigmatized and discriminated by the people they have disclosed to, was another reaction some participants received. Participants did not disclose to their neighbours or community members because they feared that they might be stigmatized and discriminated against. Fitzgerald et al., (2010) in their findings reported that, fear of stigmatization and discrimination is one of the reasons why people preferred to disclose to certain individuals and not to others. In line with this, Ngarina et al., (2014) reported that women enrolled on the PMTCT programme experienced some form of stigmatization and discrimination from either their partners, their in-laws or even from the health care workers.

5.11 Disclosure
In the study it was found that all the participants have at least disclosed to someone, none had not disclosed to anyone. According to Ngarina et al., (2014), disclosure to a partner or any other family member is associated with improved support, adherence to ART and retention to care on the PMTCT programme; hence women enrolled on the PMTCT programme are encouraged to disclose.

Worth noting is that participants preferred to disclose to their close relatives whom they trust and their partners. They were not comfortable with disclosing to their neighbours and/or other community members due to fear of being stigmatized and discriminated against or judged. Similar findings have been reported by Fitzgerald et al., (2010) where the fear of being ridiculed or rejected was one of their findings.

Whilst participants chose to disclose their status, it was also found that they found it difficult to do so especially to their partners due to concerns of the partner’s reaction after disclosure. Due to fear of disclosure to partner, some participants preferred to disclose to other relatives
first before they could disclose to their partners. As a result, the women would delay or keep postponing the disclosure and keep their HIV status a secret whilst they tried some other means on how they would disclose to their partners. In this period, they would hide their medication and take them in secret or decide not to take them until they had managed to disclose. This was supported by Kasenga et al. (2010), Otieno et al. (2010), Anderson et al. (2012), Lassorn et al. (2012) and Ngarina et al. (2014) who reported that due to fear of possible negative repercussions from their male partners, some HIV positive women enrolled on the PMTCT programme choose not to disclose to their partners and or any other significant person. Data showed that eventually, participants would manage to disclose by themselves, but some were assisted by nurses in the clinic to disclose to their partners. Otieno et al. (2010) is of the view that none disclosure is associated with poor adherence and poor retention in care in the PMTCT programme.

Participants reported different reactions from the people they disclosed to during and after disclosure. Some were easily accepted by the people they had disclosed to. Some were not easily accepted by the people they disclosed to at first. However, data revealed that these participants would eventually gain acceptance as time went on. After being accepted these relatives and their partners would be supportive to them in ensuring that they adhere to all advice and instructions given to them in the facilities so that the baby is protected and they also remain healthy. This is in line with the findings of Kasenga et al. (2010), Ngarina et al. (2014) and Matheson et al, (2015) who found that some women received much support and encouragement from their partners and or other significant family members after disclosing their status. Support has a positive impact in adherence and retention to care in the PMTCT programme (Ngarina et al, 2014).

On the other hand, some participants said they were deserted and chased away after disclosing and were blamed for bringing HIV infection to the family. These findings are consistent with previous data showing that after disclosing their HIV positive status some participants were abandoned by their partners, emotionally and physically abused because they are blamed for bringing the “shame” and deadly virus to the family (Njunga & Blystad, 2010; Otieno et al, 2010; Theilgaard et al, 2011; Anderson et al 2012; Lassorn et al, 2012; Stinson & Myer, 2012; Ngarina et al, 2014; Katirayi et al, 2016).

Participants stated different reasons for disclosing to their partners and or relatives. Being free to take medication without hiding was one of the reasons stated for disclosure.
Participants also mentioned that they disclosed to their partners so that they would also go for HIV testing to know their HIV status. Another reason stated was that they disclosed because they wanted to be supported in adhering to the medication or in case they get sick. Ngarina et al. (2014) also found that women enrolled on the PMTCT programme disclosed their status mainly for support and encouragement during their lifetime. Participants also mentioned that they disclosed because they were encouraged by health care workers who emphasised that it was very important to disclose especially to your partner.

Worth noting is that through invitation letters given to women to invite their partners to attend the clinic, some male partners would accompany their partners to the clinic in the next visit where they would also be counselled and tested for HIV. Upon finding that they are also HIV positive, they would then accept their women and support each other. On another note, it was found that upon disclosing, some participants reported that their male partners also revealed to them that they are also HIV positive but they could not disclose. Rujumba et al. (2012) also reported that after women have disclosed their HIV status to their partners, some men also went for HIV testing and some men who were already receiving HIV treatment would also disclose their own status. They would then support and encourage each other in their HIV treatment.

5.12 Conclusion

This chapter focused on the discussion of the findings of the study. It first presented the description of the demographics of the participants and then detailed narrative discussion of the themes on the participants’ perceptions and experiences on the PMTCT programme. Women enrolled on the PMTCT programme had different perceptions and experiences on the PMTCT programme. Literature to support the findings was also discussed.

Being diagnosed with HIV was associated with sad emotions among the women who reported that regular counselling they received from the health care workers helped them to cope and accept. This highlights the need for continuous psychosocial support to the women following HIV positive result.

The findings of the study also highlighted that women had both negative and positive perceptions about the PMTCT programme. Some perceived it as a life saver to both them and their babies, whereas others viewed it as being a coercive programme because of mandatory
HIV testing and prompt ART initiation. As a result, some women would resort to take ART home but delay to ingest it until they felt ready. Fear of side effects and non-disclosure to partners were also some of the reasons highlighted for delay in ART initiation.

Disclosure especially to their partners was also found to be a challenge among the women such that some women preferred to disclose to other relatives first other than their partners. Some women encountered rejection, stigma and discrimination from the people they disclosed to. Others were accepted and supported by the people they disclosed to. The good attitude and none discriminatory care from health care workers made the women feel encouraged and supported.

Information on women’s perceptions and experiences in PMTCT programme is very critical in development and amendment of PMTCT policies which would be feasible and acceptable to both the users and implementers. This will lead to achievement of optimal PMTCT programme outcomes hence reduce HIV related maternal and child morbidity and mortality.

5.13 Recommendations

5.13.1 Recommendations for education and health promotion

The study revealed that disclosure to a partner was the most challenging part for women who tested HIV positive in the PMTCT programme. The major reason was that their partners they have less knowledge on the importance of PMTCT. As a result, some women would decide not to take their medication until they managed to disclose their status. Therefore, couple testing should be strengthened and promoted to enable mutual disclosure of HIV status and reduce the burden of anxiety and depression associated with finding ways on how to disclose. Male involvement on the PMTCT programme should be intensified so that the males have a clear understanding of PMTCT in order to support their partners who are enrolled on the programme.

Women reported different attitudes from health care workers which tend to be influencing their adherence and retention in the PMTCT programme. This highlights the need for more education and capacity strengthening of the health care workers on the importance of treating each client with dignity; and providing equal and none discriminatory care to all clients at all times.
5.13.2 Recommendation for practice or public health care
In addition to the existing policy of universal ART initiation for all HIV positive pregnant
women, it is crucial to avail other options of PMTCT prophylaxis for women who test HIV
positive. Results from this study showed that some women would delay in starting the ART
at home due to issues of not being ready for various reasons. This, places the life of the baby
at higher risk of acquiring HIV. The existence of this other options will ensure that the right
to autonomy of these women is respected, other than being deprived of their right to decide or
choose.

Staff shortages on the PMTCT programme was the main cause for long waiting times for
clients when accessing PMTCT services. Ensuring that the PMTCT programme department is
well staffed is also important as this would reduce the waiting time of the clients in the
PMTCT programme department.

5.13.3 Recommendation for research
Findings revealed that women have different perceptions and experiences in the PMTCT
programme which have a high influence in the uptake, adherence and retention in care in the
PMTCT programme. HIV positive women’s information about their perceptions and
experiences in the PMTCT programme is crucial to policy makers and implementers in
ensuring that PMTCT services and interventions are effective, efficient and acceptable to the
HIV positive women for maximum achievement of desirable outcomes of PMTCT. This
places the need for more research to be conducted under this area.

5.14 Limitations
The study only focused on women who were currently still active on the PMTCT programme
whereas even those who had defaulted or refused to be enrolled on the PMTCT programme
would have given information on their perceptions and experiences on the PMTCT
programme. The perceptions and experiences on those who defaulted or denied enrolment on
the PMTCT programme would also have yielded useful information in the study. Moreover,
findings cannot be generalized to the whole region or clinics.
REFERENCES


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Swaziland Demographic Health Survey (2007). Ministry of Health, Mbabane.


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Annexure 1A: Informed Consent (English)

SEFAKO MAKGATHO HEALTH SCIENCES UNIVERSITY ENGLISH CONSENT FORM

PERCEPTIONS AND EXPERIENCES OF HIV POSITIVE PREGNANT WOMEN ON PREVENTION OF MOTHER TO CHILD TRANSMISSION (PMTCT) PROGRAM IN MANZINI REGION, SWAZILAND.

Introduction

I am Nompilo Dlamini, a student at Sefako Makgato University in South Africa and I am pursuing Masters in Public Health. I am conducting a study on “Perceptions and Experiences of HIV positive pregnant women on the PMTCT programme”. As one of the HIV positive pregnant women who are enrolled on the PMTCT programme, you are invited to partake in the study to understand about your perceptions and experiences with the PMTCT programme. This consent form may contain 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 are welcome to ask me or the research assistant.

Purpose of the study

PMTCT programme is a set of interventions aimed at protecting babies from acquiring HIV from their mothers during the period of pregnancy, labour, delivery and breastfeeding as well as keeping the mothers healthy. The study is interested in finding out what are the perceptions and experiences of HIV positive pregnant women with the PMTCT programme.

Types of interventions

An in-depth interview will be conducted with you if you agree to participate in the study. The interview will take about 30-45 minutes. During the interview, the interviewer will ask questions and the research assistant will take notes of the responses. A tape recorder will also be used to assist in capturing information during the interview.

Participant selection

You are invited to participate because you are one of the HIV positive pregnant women who are enrolled on the PMTCT programme and therefore we want to understand about your perceptions and experiences with the PMTCT programme.

Voluntary participation

Your participation in the study is entirely voluntary and even after consenting you have the right to withdraw from the study at any time. There is no penalty or loss of benefits for refusing to participate; you will continue to receive the services in the facility without any change.

Procedures
The interview will take about 30-45 minutes. During the interview, I and the research assistant will sit down with you in a comfortable place in the facility. If you are not comfortable in answering any of the questions during the interview, you may say so and the interviewer will move on to the next question. A tape recorder will be used to capture the entire discussion. The recorded information will be kept confidential and anonymity will be used to ensure that responses are not linked to participant. No one except me Nompilo Dlamini and my supervisor Dr Busi Ntuli will access the information documented during your interview. The tapes and documents will be kept in a locked cabinet and will be destroyed after 12 months.

**Risks**

There is no risk of partaking in this study. If you are not comfortable in answering any of the questions during the interview, you may say so and the interviewer will move on to the next question or stop the interview.

**Benefits**

There will be no direct or personal benefit for participating in this study. The information gained may help the ministry of health in improving the service delivery on the PMTCT programme in the future.

**Reimbursement**

You will not be provided any incentive to take part in the research. However, you will be provided with lunch after the interview.

**Confidentiality**

If you agree to participate in the study, all your responses will be kept confidential. Your name will not be written on the questionnaire and it will not be used in any way to link your responses. Instead of your name an interview number will be used which will have no link to your name and no one will know that you were part of the study.

All information about the study will not be known by the people who work in this facility. The documents and tapes will be kept in a locked cabinet and will be destroyed after 12 months. No one except me Nompilo Dlamini and my supervisor Dr Busi Ntuli will access the information documented during your interview.

**Who to contact**

If you have any questions, you can ask them now or later. If you wish to ask questions later, you may contact any of the following:

Nompilo Dlamini
The Researcher
Cell: 76631799
Statement by the Participant:

I have read and heard the information on the aims and objectives of the proposed study and was provided the opportunity to ask questions and given adequate time to rethink the issue. The aim and objectives of the study are sufficiently clear to me. I have not been pressurized to participate in any way.

I know that sound recordings will be taken of me. I am aware that this material may be used in scientific publications which will be electronically available throughout the world. I consent to this provided that my name and hospital number is not revealed.

I understand that participation in this Study is completely voluntary and that I may withdraw from it at any time and without providing reasons. This will have no influence on the regular treatment that holds for my condition neither will it influence the care that I receive from my regular doctor or nurse.

I know that this Study has been approved by the Sefako Makgatho University Research Ethics Committee (SMUREC), Sefako Makgatho Health Sciences University / Dr George Mukhari Hospital and National Review and Research Ethics Board of Swaziland. I am fully aware that the results of this Study will be used for scientific purposes and may be published. I agree to this, provided my privacy is guaranteed.

I hereby give consent to participate in this Study:

............................................................          ........................................................
Name of patient/volunteer                                      Signature of patient/volunteer

........................................
Place                             Date                                               Witness

Statement by the Researcher:

I provided verbal and or written information regarding this study.
I agree to answer any future questions concerning the study as best as I am able.
I will adhere to the approved protocol.

.......................................    ....................................    ...............……       ………………….
Name of Researcher                  Signature                              Date                         Place
Annexure 1B: Informed Consent (SiSwati)

SEFAKO MAKGATHO HEALTH SCIENCES UNIVERSITY ENGLISH CONSENT FORM

PERCEPTIONS AND EXPERIENCES OF HIV POSITIVE PREGNANT WOMEN ON PREVENTION OF MOTHER TO CHILD TRANSMISSION (PMTCT) PROGRAM IN MANZININI REGION, SWAZILAND.

Singeniso

Libito lami ngingu Nompilo Dlamini longumfundzi weMasters wase Sefako Makghato University eSouth Africa ngenta lucwaningo le injongo yalo kutfola imivo yabomake labatetfwele labaphila neligciwane le HIV mayelana neluhlelo lwekuvikela kutsi bomake labaphila neligciwane le HIV bangalendululiseli kubantfwana (PMTCT), kanye nekuva timo bomake labendlula kuto basengenele loluhlelo.

Nhengoba ungumake lotetfwele loku loluhlelo lwPMTCT uyamenywa kutsi ungenele lolucwaningo kutokuvu kabanti ngemivo yakho ngaloluhlelo kanye netimo londlude kuto usengenele loluhlelo. Uma ngabe kwenteka kuba nalongakuvu kahle noma lokungacaci sisafundza lesivumelwano, ungangimisa ngitochaza kabanti noma sesicedzile umangabe solo unemibito ukhululeke uwubute nami futsi ngitotama kukuphendvula ngalokuphulelele.

Inhloso Yalolucwaningo?

Lulhlelo lwPMTCT luyikhatsa yetinsita tekuvikela kutsi umnfwana angalitfoli ligciwane lembualave kunina makasatetfwele, ngesikhatsi semuhelo, makabelekwa noma amunya umntfwana. Letinsita tiphindze tente kutsi make lonaleligciwane aphephe. Inhloso yalolucwaningo kwati kabanti ngemivo kanye netimo bomake labendlula kuto basengenele loluhlelo.

Yini lekumele uyente uma uvuma kubayincenye yalo lucwaningo?

Uma uvuma kuba kulolucwaningo, utawubutwa imibuto lejulile ngaloluhlelo lwakaPMTCT ikakhulu ngemivo yakho kanye netimo londlude kuto usesekuloluhlelo. Lencoco itawutsatsa sikhatsi lesingange mizuzu lemashumi lamatsatfu kuya kulamane nesihlanu (30-45 minutes). Isentiwa lengcoco kutaba nemsiti lotabe abhala timphendvulo kanye nemshini wekutsebula emavi lotosita kutsi kube bete lokusalela ngephandle kutotiphendvulo.

Ukhetfwe njani kutsi ube kulolucwaningo?

Uyamenywa kutsi ube yincenye yalo lucwaningo ngoba ungumake lotetfwele lophila neligciwane lembulalave lokuloluhlelo lwakaPMTCT.

Kungenela lulucwaningo uyatikhetsela?

Sincumo sakho sekutsi ulingenele noma ungulungeneni lulucwaningo angeke kutsikabete tinsita lotitfolako kulomtfolamphilo. Noma sewusisayinile sivumelwano sekuba yincenye yalo lucwaningo unalo lilungelo lekuphuma kulelcwaningo.

Yini imigomo letolandzelwa kulelcwaningo?
Lengcoco yalulucwaningo itawutsatsa sikhatsi lesingange mizuzu lemashumi lamatsatfu kuya kulumane nesihlanu (30-45 minutes). Legcogco itawentelwa endzaweni lesitsele emtfolaphilo lapho kutaba nami umcwaningi kanye nelisekela lami. Leminye yalemibuto ingakwenta utive ungakhululeki, awukaphoceleleki kutsi uphendvule imibuto lekwenta utiva ngaleyo ndlela.


**Yini bungoti bekungenela lolucwaningo?**

Kute bungoti bekungenela lolucwaningo. Awukaphoceleleki kutsi uphendvule imibuto lekwenta utive ungakhululeki futsi ungamtjela umcwaningi awece lowombuto noma umise lengcoco uma uva kungatsi awusakhululeki.

**Yini tinzuzo tekungenela lolucwaningo?**

Kute inzuzo lecondzene nawe lotayitfola ngekuba yincenye yalulucwaningo kodvwa imininigwane lotasinika yona itawusita litiko letemphilo kutsi litutfukise tinhlelo takaPMTCT tibe secophelelweni ngalokutako.

**Kukhona yini lengtawunikwa kona ngekungenela lolucwaningo?**

Kute lotakutfola lokuyimbadalo ngekungenela lolucwaningo, kepha ke utawuphiwa sidlo sasemini emvakwengcoco.

**Kugcineka kwemininingwane yakho iyimfihlo?**

Uma uvuma kungenela lolucwaningo, timphendvulo takho titawugcinwa tiyimfihlo. Libito lakho angeke libhalwe kulamafumu alolucwaningo futsi angeke lisentjetiswe ndzawo kuchumanisa lositjele kona. Esikhundleni selibito sitosebentisa inombolo yengcoco lete budlelwane nelibito lakho.


**Ngubani lengingamtsints sa nangabe ngnembuto?**

Umangabe unemubuto ungabuta manje noma mangabe awukhoni kubuta nyalo ungashayela natinombolo letilandzelako:

- Nomphilo Dlamini
- Umcwaningi walulucwaningo
- Lucingo: 76631799
SEFAKO MAKGATHO HEALTH SCIENCES UNIVERSITY SISWATI CONSENT FORM

Sitatimenti macondzana nekungenela kulolucwaningo

Ligama laloluCwangingo

Kubuketa imivo Kanye netimo bomake labatetfwele labendlula kuto mabangenele luhlelo lwukukukhala kwendluliselisa ligciwane le HIV kubantfwana, esifundzeni saka Manzini, eSwatini

Perceptions and experiences of HIV positive pregnant women on the prevention of mother to child transmission programme, in the Manzini Region Swaziland

Ngilufundzile lwati, ngivile tinhloyo netinjongo futsi ngeniketwa litfuba lekubuta imibuto nesikhathile lesekelo kuti ngicabangisise ngekungenela lolucwaningo. Inhluso nenjongo yalo lalolucwaningo kucaciswe ngalo kwemimo kumi. Angikacindzetelwa nanomanganguyiphile indlela kutsi ngibe yincenye yalo lalolucwaningo.


Ngiyathi kutsi lolucwaningo lugunyatwe yi Sefako Makgatho University Research Ethics Committee (SMUREC), Sefako Makgatho Health Sciences University / Dr George Mukhari Hospital Kanye ne National Review and Research Ethics Board of Swaziland. Ngiyathi ngalokuphelele kutsi imiphumela yakulolucwaningo itosetjentiselwa tinhloyo tesayensi futsi ingashicilelelwa. Ngiyakuvuma konkhe loku, uma nje lingasense lami litawucinisekiswa.

Lapha nginkelana imvume yekungenela lolucwaningo

............................................................       ....................................................
Ligama lelivolontiya                                              kusayina kwelivolontiya.

................................     ....................................      ................................................
Indzawo.           Lusuku.                                  Fakazi

Sitatimenti seMcwaningi


........................................    ................................      ...................................
Ligama leMcwaningi      kusayina kwengcwaningi    Lusuku            Indzawo
**Introduction:**

The objective of the study is to investigate the perceptions of HIV positive pregnant women on PMTCT and describe their experiences on PMTCT. Consenting to participate in the study is voluntary and even after consenting one has a right to withdraw from the study at any time. There is no penalty or loss of benefits for refusing to participate. Face to face interviews will be conducted with those who agree to participate. Each interview takes about 30 minutes. During the interview, the interviewer and research assistant will be taking notes of the responses. A tape recorder will be used to assist in capturing information during the interview. All information obtained will be kept confidential and anonymity will be used to ensure that responses are not linked to participants.

### PART A: DEMOGRAPHICS

<table>
<thead>
<tr>
<th>1. How old are you?</th>
<th>Age: _____________</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(years)</td>
</tr>
<tr>
<td>2. What is your marital status?</td>
<td>□ Single</td>
</tr>
<tr>
<td></td>
<td>□ Married</td>
</tr>
<tr>
<td></td>
<td>□ Divorced</td>
</tr>
<tr>
<td></td>
<td>□ Separated</td>
</tr>
<tr>
<td></td>
<td>□ Cohabitating</td>
</tr>
<tr>
<td></td>
<td>□ Widowed</td>
</tr>
<tr>
<td>3. Who do you live with?</td>
<td>□ Partner only</td>
</tr>
<tr>
<td></td>
<td>□ Partner and children</td>
</tr>
<tr>
<td></td>
<td>□ Children only</td>
</tr>
<tr>
<td></td>
<td>□ Siblings only</td>
</tr>
<tr>
<td></td>
<td>□ Parents and siblings</td>
</tr>
<tr>
<td></td>
<td>□ Other relatives</td>
</tr>
<tr>
<td>Question</td>
<td>Options</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------</td>
</tr>
<tr>
<td>4. What is your highest level of education?</td>
<td>☐ No formal education</td>
</tr>
<tr>
<td></td>
<td>☐ Primary education</td>
</tr>
<tr>
<td></td>
<td>☐ High school education</td>
</tr>
<tr>
<td></td>
<td>☐ Tertiary education</td>
</tr>
<tr>
<td>5. What is your employment status?</td>
<td>☐ Employed.</td>
</tr>
<tr>
<td></td>
<td>☐ Self-employed.</td>
</tr>
<tr>
<td></td>
<td>☐ Unemployed.</td>
</tr>
<tr>
<td><strong>Parity</strong></td>
<td></td>
</tr>
<tr>
<td>6. Is this your first Pregnancy? (If Yes, Skip question 8)</td>
<td>☐ Yes</td>
</tr>
<tr>
<td></td>
<td>☐ No</td>
</tr>
<tr>
<td>7. If no, including this pregnancy, how many times have you been pregnant?</td>
<td>Number of Pregnancies: __________</td>
</tr>
<tr>
<td>8. Gestational Age in weeks</td>
<td>--------------------------weeks</td>
</tr>
<tr>
<td><strong>PMTCT</strong></td>
<td></td>
</tr>
<tr>
<td>9. When did you first learn that you are HIV positive?</td>
<td>☐ Before this pregnancy</td>
</tr>
<tr>
<td></td>
<td>☐ On this pregnancy</td>
</tr>
<tr>
<td>10. Were you initiated on ART the same day of HIV diagnoses?</td>
<td>☐ Yes</td>
</tr>
<tr>
<td></td>
<td>☐ No</td>
</tr>
<tr>
<td>11. How long have you been on PMTCT?</td>
<td>Month/s: __________</td>
</tr>
<tr>
<td>12. Have you disclosed your status to your partner/s?</td>
<td>☐ Yes</td>
</tr>
<tr>
<td></td>
<td>☐ No</td>
</tr>
<tr>
<td>13. What is the HIV status of your partner?</td>
<td>☐ HIV positive--</td>
</tr>
<tr>
<td></td>
<td>☐ HIV negative--</td>
</tr>
<tr>
<td></td>
<td>☐ Do not know--</td>
</tr>
</tbody>
</table>
**Annexure 2B: Questionnaire (SiSwati)**

**Singeniso:**


**SEHLUKO A: DEMOGRAPHICS**

<table>
<thead>
<tr>
<th>1. Iminyaka yakho mingakhi?</th>
<th>Umnyaka: _____________</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>2. Ngabe ushadile yini (ngesihlungu noma ngesiSwati) noma kukhona yini lovana naye?</th>
<th>Chake angikashadi</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Ngishadile</td>
</tr>
<tr>
<td></td>
<td>Ngafola sehukana</td>
</tr>
<tr>
<td></td>
<td>Sehukana</td>
</tr>
<tr>
<td></td>
<td>Nginalenhlahlisana naye</td>
</tr>
<tr>
<td></td>
<td>Ngingumfelokati</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3. Uhlala nabani?</th>
<th>Nalotsanze naye</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Nalotsanze naye kanye nebatchana</td>
</tr>
<tr>
<td></td>
<td>Nebatchana</td>
</tr>
<tr>
<td></td>
<td>Nebantfwana</td>
</tr>
<tr>
<td></td>
<td>Nebantfwabakini</td>
</tr>
<tr>
<td></td>
<td>Nebatali kakhono kanye nebatchana bakini</td>
</tr>
<tr>
<td></td>
<td>Naletinye tihlolo</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>4. Wagcina kabani esikolweni?</th>
<th>Angitange ngike ngiyi esikolweni</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Efundvweni lephansi</td>
</tr>
</tbody>
</table>
| 5. Uyasebenta yini? | □ Efundvweni lephakeme  
□ Ngiyasebenta.  
□ Ngiyatisebenta.  
□ Angisebenti. |
|---------------------|------------------------------------------------|
| 6. Ngesekucala yin lesisu lonaso? (mangabe sisekucala, yeca umbuto 5) | □ Yebo  
□ Cha |
| 7. Uma singesiso sekucala lesisu, ngesesingaphi? | Emahlandla ekumitsa: _________ |
| 8. Semangakhi emaviki utetfwele? | ________________ weeks |

**PARITY**

| 9. Ingabe wati nini kwekucala kutsi soneligciwani leHIV? | □ Ngaphambi kwalokutitfwala loku  
□ Kulokutitfwala loku |
|--------------------------------------------------------|------------------------------------------------|
| 10. Ingabe lamaphilisi ekundzindzibalisa ligciwane le HIV wawacala ngalelolanga litfolakala ligciwane engatini yakho yini? | □ Yebo  
□ Cha |
| 11. Sewunesikhatsi leisinganani ungenile kuloluhlelo lwaka PMTCT? | Inyanga/Tinyanga: _________ |
| 12. Ingabe babe wemntfwana sombhobokele yini ngesimo sakho sengati? | □ Yebo  
□ Cha |
| 13. Sinjani simo sengati sababe wemntfwana? | □ Unalo ligciwane leHIV  
□ Ute ligciwane leHIV  
□ Angisati |
PART B: INTERVIEW GUIDE

1. How did you come to know about your HIV status?
   - When was that?
   - What was the occasion?
   - How did you react when they told you that you are HIV positive?

2. How did you come to know about the PMTCT programme?
   - What do you know about it?
   - Where did you get the information?
   - When was that?

3. Now that you are on PMTCT, what is your view about this PMTCT programme?
   - How can you describe it?
   - What can you say are the good things about it?
   - What can you say are the bad things about it?
   - What are your fears about being on PMTCT programme?
   - What do you think should be changed in PMTCT?

4. Who did you tell about your HIV status?
   - Why did you choose to tell this particular person/s?
   - How long did it take to tell this person?
   - How did that person take it?
   - Have you disclosed to your partner?
   - How have been your relationship with the person/s you have disclosed your status to?
   - What kind of support have you receive from the people you have disclosed to?

5. Tell me about the care you receive in the PMTCT programme?
   - Waiting time?
   - Frequency of visits?
   - How is the attitude from service providers?
   - Are the counselling messages clearly explained and easy to understand?
   - Consistency in availability of health services?
   - Integration of other services in PMTCT department?
   - Partner involvement?
   - The kind of support you receiving from the facility?
   - What do you think can be done to improve the care in PMTCT programme?

6. Please narrate the most challenging times of being on PMTCT programme?
   - In relation to your treatment
   - In your relationship
   - In your family
What do you think can be done to avoid such challenges?

7. Is there anything else you would like to share with regards to the PMTCT programme?

Thank you for agreeing to participate in the study!!!
Annexure 3B: In-Depth Interview Guide (SiSwati)

SEHLUKO B: INTERVIEW GUIDE

1. Ingabe wati kanjani ngesimo sakho sengani?
   ➢ Bekukunini?
   ➢ Futsi bekwentenjani?
   ➢ Kwakuphatsa kanjani mabakutjela kutsi unalo leligciwane le HIV?

2. Ingabe wati kanjani ngaloluhlelo lwaka PMTCT?
   ➢ Watinini ngalo?
   ➢ Walutfolaphi lolwati ngalo?
   ➢ Nini nje?

3. Loku sewulungenele loluhlelo ingabe yini umuvo wakho ngalo?
   ➢ Ungachaza utsini nje ngaloluhlelo?
   ➢ Yini locabanga kutsi kuhle ngalo?
   ➢ Yini locabanga kutsi kubi ngalo?
   ➢ Yini lokusabako ngalo?
   ➢ Yini longafisa kutsi kushintje ngalo?

5. Ngubani lowambhobokela ngalesimo sakho sengati?
   ➢ Yini lokwakwenta wakhetsa kubhobokela yena?
   ➢ Kwakutsatsa sikhatsi lesingakanani kumbhobokela?
   ➢ Wakutsatsa kajani?
   ➢ Sombhobokele yini lolotsandzana naye?
   ➢ Ingabe bube njani budlelwane benu kusukela wambhoboakele?
   ➢ Ingabe ngutiphile thandlele tekusekeleka lotitfolako kulabo lobabhoboakele?

6. Yini tingcinamba lohlangene nato usangele loluhlelo lwPMCT?
   ➢ Emaphilisini eHIV lowanatsako?
   ➢ Ebudlelwaneni bakho nalotsandzana naye?
   ➢ Emndenini wakho?
   ➢ Yini locabanga kutsi kungenteka kugwema letingcinamba?

7. Kukhona yini lesingakakhulumi ngako mayelana naloluhlelo longafisha kukungenta noma kukusho?

Siyabonga kutsi uvume kuba yincenye yalolucwaning nekubambisana!!!
Annexure 4: Letter to National Health and Review Board

Nompilo Dlamini
P.O Box 8892
Mbabane
06 June 2017

The Chairperson
National Health and Review Board
P. O. Box 35
Mbabane

Dear Sir/Madam

RE: Application for review and Ethical approval of research proposal

I am a student pursuing Masters in Public Health at Sefako Makgatho Health Sciences University in South Africa. I am kindly applying for review and approval of my research proposal entitled: Perceptions and Experiences of HIV positive pregnant women on the PMTCT programme, in the Manzini region, Swaziland.

The main aim of the study is investigating the perceptions and the experiences of HIV positive pregnant women in the PMTCT programme. Such information is crucial in planning and implementation of PMTCT services in order to achieve improved outcomes of the PMTCT programme.

PMTCT is among the priority areas of the research agenda. All data collected will be true reflection of participants’ responses and confidentiality will be maintained throughout the study.

Yours Faithfully

Nompilo Dlamini
(+268 76631799)
Annexure 5: Ethical Clearance Certificate

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<td>Name of Principal Investigator</td>
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<td>Names of Co- Investigators</td>
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<td>Names of Data and Safety Committee members in the case of clinical trials</td>
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<td>Secretariat Contact Details</td>
<td>Name of contact officer</td>
<td>Ms Simanini Nkhatha</td>
</tr>
<tr>
<td>Email address</td>
<td><a href="mailto:kluamasi@gmail.com">kluamasi@gmail.com</a></td>
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<tr>
<td>Telephone no.</td>
<td>(00268) 24040565/24044905</td>
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### Approval Conditions

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<td>Submission of end of project report (Hard copy)</td>
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<td>2</td>
<td>Cover letter</td>
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<td>3</td>
<td>Evidence of administrative permission to conduct the research by involved institutions/sites (where applicable)</td>
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<td>4</td>
<td>Detailed current resume or curriculum vitae of Principal Investigator/s including Principal Investigators declaration</td>
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<td>5</td>
<td>Summary resume or biography for other investigator(s)</td>
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<td>Evidence of approval/rejection by other Ethics Committees, including comments and requested alterations to the protocol, where appropriate.</td>
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<td>7</td>
<td>Research protocol (see outline in Annex 1)</td>
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<tr>
<td>8</td>
<td>Questionnaires and interview guides (with back-translated versions where applicable)</td>
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<td>9</td>
<td>Case report forms (CRFs), abstraction forms and other data collection tools</td>
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<tr>
<td>10</td>
<td>Participant/subjects Information Statement(s) (where applicable)</td>
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<td>11</td>
<td>Informed consent form(s) including photographic and electronic media consent statements.</td>
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<td>12</td>
<td>Advertisements relevant to the study (where applicable)</td>
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<td>Source of funding and detailed budget breakdown including material and incentives to participants if applicable</td>
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<td>Notification form for adverse effects/events.</td>
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ANNEXURE 6: SMUREC APPROVAL

Sefako Makgatho Health Sciences University
Research & Postgraduate Studies Directorate
Sefako Makgatho University Research Ethics Committee (SMUREC)

Molotlegi Street, Ga-Rankuwa 0208
Tel: (012) 521 5617/3698 | fax: (012) 521 3749
Email: lorato.phiri@amu.ac.za
P.O. Box 183 Medunsa 0204

APPROVAL NOTICE - NEW APPLICATION

06 April 2017
Ms NS Dlamini
Department of Public Health
P.O. Box 215
Medunsa, 0204

MEETING:
03/2017

SMUREC Ethics Reference Number:
SMUREC/170/2017: PG

The New Application received on 18 January 2017, was reviewed by members of Sefako Makgatho University Research Ethics Committee 02 February 2017 and was approved on 06 April 2017.

Title:
Perceptions and experiences of HIV positive pregnant women on the prevention of mother-to-child transmission programme, in the Manzini Region Swaziland.

Researcher:
Ms NS Dlamini

Supervisor:
Ms B Ntuli

Department:
Public Health

School:
Health Care Sciences

Degree:
MPH

Please note the following information about your approved research protocol:

Protocol Approval Period:
06 April 2017 – 06 April 2018

Please remember to use your protocol number (SMUREC/170/2017: PG) on any documents or correspondence with the REC concerning your research protocol.

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

After Ethical Review: Please note a template of the progress report is obtainable in the Research Office and should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit. Translation of the consent document in the language applicable to the study participants should be submitted.

International Organisation (ORG0008891), Institutional Review Board (IB000101386) Expiry date: 09 December 2018,
Federal Wides Assurance (FWA000023843) Expiry date: 31 August 2017 and NHREC No: REC 210408-003

Sincerely,

PROF C BAKER
DEPUTY CHAIRPERSON SMUREC

Date: 06/04/2017
Annexure 7: Adverse event report form

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