

# **THE LIVED EXPERIENCES OF WOMEN DIAGNOSED WITH HIV IN THE ANTENATAL PERIOD IN A RURAL AREA**

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in the Faculty of Medicine and Health Sciences  
Stellenbosch University

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## DECLARATION

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## ABSTRACT

### Background

In South Africa women are diagnosed with HIV at antenatal clinics and simultaneously initiated on antiretroviral treatment (ART). An HIV diagnosis together with the initiation of ART have an emotional impact on the pregnant woman that may influence how she will cope with the pregnancy as well as her adherence to a treatment plan. Only a few studies in South Africa have focused on the experiences of pregnant women in rural settings who have tested HIV positive in pregnancy. The aim of the study was to explore the lived experiences of women diagnosed with HIV in the antenatal period in a rural area in the Eastern Cape province of South Africa.

### Methods

A qualitative approach with a descriptive phenomenological design was utilized to explore the lived experiences of women who were diagnosed with HIV in the antenatal period. The study applied purposive sampling to select participants from the Matatiele community clinic, in the Eastern Cape. The Health Research Ethics Committee of Stellenbosch University and the Department of Health of the Eastern Cape granted permission for conducting the study. Ten semi-structured interviews were conducted, transcribed and analysed using Colaizzi's framework. Four themes emerged from the data.

### Results

The themes that emerged were: reality hits raw, a loneliness that hurts, hope for a fractured tomorrow and support of a few. The reality of an HIV diagnosis was a life changing event. Participants experienced a painful loneliness even though they had support from a few significant people in their life. Although for some an HIV diagnosis meant a death sentence, the love and concern for the unborn child's safety provided a fractured hope for the future.

### Conclusion

An HIV diagnosis during pregnancy remains a life altering experience for women. By improving the support systems in health facilities such as counselling services and the mental health skills of midwives, the experience of pregnancy could be more positive for women who are diagnosed with HIV during pregnancy.

**Key words:** HIV, pregnancy, lived experiences, rural

# OPSOMMING

## **Agtergrond**

In Suid Afrika word vroue wat by 'n voorgeboorte kliniek tydens swangerskap met HIV gediagnoseer word, tegelykertyd met antiretrovirale behandeling begin. 'n HIV diagnose gekoppel met die inisiasie van antiretrovirale behandeling het 'n emosionele impak op 'n swanger vrou. Dit mag 'n invloed hê op hoe sy die swangerskap gaan hanteer, sowel as hoe sy die behandeling gaan volhou. Slegs enkele studies in Suid Afrika het gefokus op die ervaringe van vroue wat tydens hul swangerskap met HIV gediagnoseer is. Die doel van hierdie studie was om die lewenservaringe van vroue in landelike gebiede van die Oostelike Provinsie in Suid Afrika wat tydens hul swangerskap met HIV gediagnoseer word, te bestudeer.

## **Metode**

Die studie het gebruik gemaak van 'n kwalitatiewe benadering met 'n beskrywende fenomenologiese ontwerp ten einde die lewenservaringe van vroue wat tydens swangerskap met HIV gediagnoseer is, te ondersoek. Die studie het 'n doelgerigte steekproef gebruik om die deelnemers uit die Matatiele gemeenskapskliniek in die Oostelike Provinsie te betrek. Die Gesondheid Navorsingsetiëkkomitee van Stellenbosch Universiteit, sowel as die Departement van Gesondheid in die Oostelike Provinsie, het toestemming verleen dat die studie onderneem mag word. Tien semi-gestruktureerde onderhoude is gevoer, getranskribeer en geanaliseer deur gebruik te maak van Colaizzi se raamwerk. Vier temas het voortgespruit uit die data.

## **Resultate**

Die temas wat voortgebring is, is as volg: realiteit tref hard; eensaamheid maak seer; hoop vir 'n gefrakteurde toekoms; en die ondersteuning van 'n handjievol. Die realiteit van 'n HIV diagnose is 'n lewensveranderende gebeurtenis. Deelnemers het 'n pynlike eensaamheid ervaar alhoewel daar enkeles was wat hulle ondersteun. Terwyl 'n HIV diagnose 'n doodsvonnis vir sommige beteken, het die omgee van en deernis vir die ongeboore baba vir andere hoop op die toekoms gebied.

## **Slotsom**

'n HIV diagnose tydens swangerskap bly 'n gebeurtenis wat vroue se lewens radikaal verander. Deur ondersteuningstelsels in gesondheidsorgfasiliteite, soos byvoorbeeld beradingsdienste en geestesgesondheidsvaardighede van vroedvroue te verbeter, mag

vroue wat tydens swangerskap met HIV gediagnoseer word 'n meer positiewe ondervinding hê.

**Sleutelwoorde:** HIV, swangerskap, lewenservaring, landelik

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## **ABBREVIATIONS**

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral treatment
EMTCT	Elimination of mother to child transmission
HCT	HIV counselling and testing
HIV	Human immunodeficiency virus
MTCT	Mother to child transmission
PMTCT	Prevention of mother-to-child transmission of HIV
UNAIDS	Joint United Nations programme on HIV/AIDS
WHO	World Health Organisation

# CHAPTER 1:

## FOUNDATION OF THE STUDY

### 1.1 INTRODUCTION

At the end of 2013 there was an estimated 35 million people living with HIV globally. Twenty four million people thereof are residing in sub-Saharan Africa, which accounts for 81% of the global number of people living with HIV. South Africa accounts for half of the 81% of people living with HIV (UNAIDS, 2014:18-28). The programme for Prevention of Mother to Child Transmission (PMTCT) of HIV was implemented to reduce the mortality rates of pregnant women and infants born to HIV positive mothers. The infant mortality rate in South Africa is 41.6 deaths in every 1000 live births (Statistics South Africa, 2013:3). The World Health Organisation (WHO), in the year 2010, aimed to accomplish the following goals: (i) to reduce HIV infections in women of childbearing age, (ii) to reduce the transmission of HIV from an infected mother to her unborn child and infant, (iii) to prevent unintended pregnancies in HIV positive women and (iv) to provide support, care and treatment to HIV infected women, their children and families (WHO, 2010:6).

Since the implementation of PMTCT programmes, many women are diagnosed with HIV for the first time when they become pregnant. In South Africa women are diagnosed with HIV at antenatal clinics and simultaneously initiated on antiretroviral treatment (Department of Health South Africa, 2013:12). An HIV diagnosis together with the initiation of antiretroviral treatment (ART) have an emotional impact on the pregnant woman that may influence how she will cope with the pregnancy as well as her adherence to a treatment plan (Kasenga, Hurtig & Emmelin, 2008:31-33). Only a few studies in South Africa have focused on the experiences of pregnant women in rural settings who have tested HIV positive when they become pregnant (Nkonki, Doherty, Hill, Chopra, Schaay & Kendall, 2007:1742; Peltzer, Mosala, Dana & Fomundam 2008:450-460). Exploring what women who have tested HIV positive in pregnancy have experienced would provide nurses with the necessary insight to understanding the difficulties these women face. Nurses may then be able to adapt nursing care to meet the needs of these women and their children. PMTCT programmes could be improved resulting in the reduction of infant and maternal mortality rates.

### 1.2 SIGNIFICANCE OF THE PROBLEM

Internationally and in South Africa, the treatment and management of HIV positive pregnant women has been changed several times from 2001 to 2015. Many countries have studied the experiences of women participating in the PMTCT programmes and valuable information



has been extracted from these studies. However, very little is known about the experiences of women in rural areas in South Africa since the implementation of the new HIV guidelines. Chikonde, Sunby and Martinson (2009:146-147) found that in Malawi health facilities unintentionally disclosed the HIV status of a pregnant women in the daily health care tasks and husbands encouraged pregnant HIV infected women to exit PMTCT programmes. Liamputtong and Haritavorn (2014:3-4) also found that women in Thailand were encouraged to perform abortions when they were diagnosed as being HIV positive and the women were discouraged to have more children by health workers.

The professional nurse is accountable for providing acceptable and accessible health care to meet the needs of the clients. A study exploring the lived experiences of women diagnosed with HIV during the antenatal period of pregnancy has not been done, in the context of the Eastern Cape, with a rural community which has unique challenges. The knowledge of the lived experiences of these women will assist in nurses adapting care plans to meet the specific needs of women in rural areas who test HIV positive during pregnancy.

### **1.3 RATIONALE**

According to Statistics South Africa (2013:9), the province of the Eastern Cape has the highest fertility rate in South Africa (2.7%). The province also experienced the highest amount of migration (Statistics South Africa, 2013:12). Despite new guidelines for implementation of PMTCT, the maternal and child mortality rate is still high in South Africa. There is a very high HIV antenatal sero-prevalence in the Eastern Cape; 29.1% of the population (Massyn, 2015:2).

The researcher has observed that many women tested HIV positive for the first time in pregnancy during the antenatal period and despite counselling efforts, adherence to treatment during pregnancy was still low. Since the introduction of the new PMTCT guidelines in 2013, women are initiated on ART on the same day as receiving an HIV diagnosis, which occurs mostly in the antenatal period. It has also become apparent to the researcher that during the antenatal period nurses have more contact with HIV positive women and knowing what the experiences of these women are could assist nurses to plan care that will meet their needs. The researcher found that little was known about the experiences of pregnant women diagnosed with HIV in rural settings, as well as the experiences of women in South Africa, after the introduction of the new PMTCT guidelines. Knowledge of these experiences could help nurses motivate patients to adhere to care plans and improve maternal and child outcomes.

#### **1.4 RESEARCH PROBLEM**

The researcher worked as a professional nurse in the primary health care services of the Maluti Local Service Area, which is under the Alfred Ndzo Health District in the province of the Eastern Cape. Many of the clients who attended the primary health care services for basic antenatal care were enrolled in the PMTCT programme. Nurses went to great lengths to trace these women to return for blood results, treatment after their initial antenatal clinic visit and during the postnatal period. Mothers were often lost to follow up post-delivery, resulting in less babies being tested for HIV at six weeks and even lesser children being tested at eighteen months. Some women tested their infants for HIV and never returned to the health facility to collect results. Many mothers used formula feeding simultaneously with breastfeeding (mixed feeding), which is a practice that they are counselled against. Currently there is a lack of scientific research to guide nurses in supporting women in rural areas to improve their own health and the health of their babies. There may also be unique cultural and contextual challenges related to being diagnosed with HIV during pregnancy in the Eastern Cape that has not been explored before.

#### **1.5 RESEARCH QUESTION**

The following question guided the proposed research study: What are the lived experiences of women who are diagnosed with HIV during the antenatal period and residing in the rural Eastern Cape?

#### **1.6 RESEARCH AIM**

The aim of the proposed study was to explore the lived experiences of women who were diagnosed with HIV for the first time during the antenatal period and residing in the rural Eastern Cape.

#### **1.7 RESEARCH OBJECTIVES**

The research objectives were to:

- Understand pregnant women's lived experiences of being diagnosed with HIV during the antenatal period.
- Describe the thoughts and feelings of pregnant women about having to take antiretroviral treatment.
- Describe the influence of an HIV diagnosis on their experience of being pregnant, their self-care and relationships with significant others.

## 1.8 RESEARCH METHODOLOGY

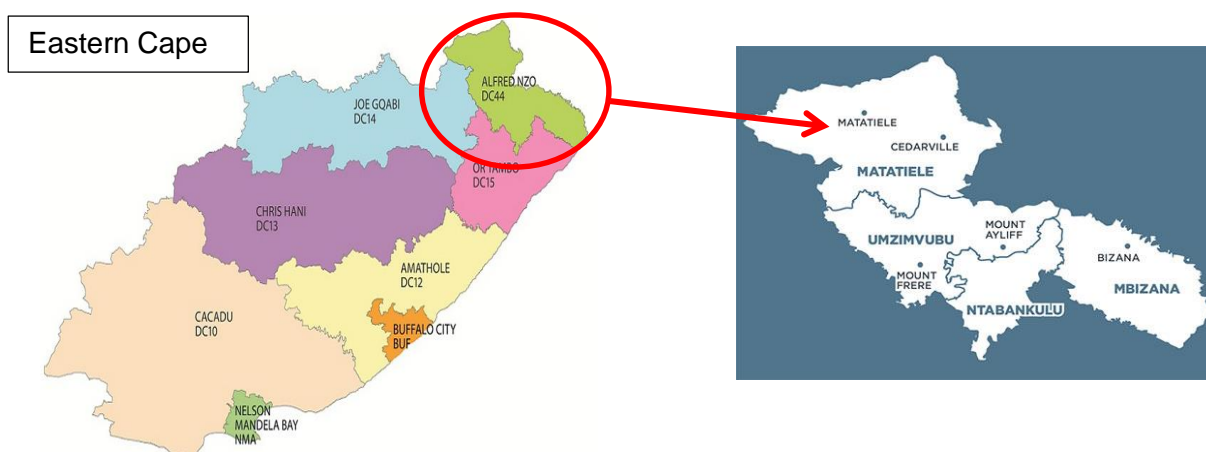
The research methodology used will be discussed briefly in this chapter, with a more detailed discussion following in chapter three.

### 1.8.1 Research design

The research study followed a qualitative design, as qualitative research focuses on the real life experiences of participants and give meaning to what the participants' experience (Burns & Grove, 2011:73). The researcher followed a descriptive phenomenological study approach, which according to Watson, Mckenna, Cowman and Keady (2008:233) is an approach that analyses and interprets the lived experiences of the participant and exposes hidden meaning behind the experiences described by the participants. To ensure that the true lived experience was captured by the researcher, the study prescribed to the Husserlian philosophy of phenomenology, using bracketing.

### 1.8.2 Study setting

The research study was conducted in the province of the Eastern Cape, in the Alfred Ndzo health district, at the Matatiele community clinic as illustrated in Figure 1.



**Figure 1.1: Geographical presentation of study setting**

### 1.8.3 Population and sampling

The study focused on the pregnant women residing in the Maluti local service area in the Eastern Cape. One hundred and nine women were diagnosed with HIV in the antenatal period from January 2015 to July 2015 and formed the study population.

The researcher purposefully sampled 10 women who were diagnosed as HIV positive for the first time during pregnancy in the Maluti Local Service Area and attended the antenatal clinic at Matatiele community clinic. These women had to be over the age of 18, diagnosed with

HIV for the first time in the antenatal period of pregnancy, been on ART for at least two months and attending the Matatiele community clinic for their antenatal or postnatal care.

Sample size in the study depended on when data saturation had been established. Data saturation was reached at the ninth interview.

#### **1.8.4 Data collection tool**

The researcher used in-depth, face to face semi-structured interviews to collect data. Semi-structured interviews allow the researcher to explore sensitive topics such as HIV/AIDS in a private environment (LoBiondo-Wood & Haber, 2010:275). The participants were encouraged to provide full descriptions of the experiences which included their feelings, images, sensations, memories as well as the situation in which their experiences occurred.

#### **1.8.5 Pilot interview**

The researcher conducted a pilot interview on one participant who met the inclusion criteria. Since the interview guide questions did not change and to ensure that the participant's voice is heard, data from this interview was included in the analysis.

#### **1.8.6 Trustworthiness**

Trustworthiness of the research study was ensured by the application of the four principles of trustworthiness described by Lincoln and Guba in Brink, van der Walt and van Rensburg, (2012:171-173): (i) credibility, (ii) dependability, (iii) transferability and (iv) confirmability.

#### **1.8.7 Data collection**

Data collection occurred through individual interviews, using a semi-structured interview guide. The professional nurse who provided antenatal care at the clinic identified and approached the HIV positive pregnant women and requested their permission to be referred to the researcher. Following the pilot study, another nine interviews were conducted by the researcher in a private room in the clinic following informed consent from participants. Follow-up interviews were conducted with three of the nine participants.

#### **1.8.8 Data analysis**

Audio recordings were transcribed verbatim by the researcher. Colaizzi's seven step method, described by Mackenzie (2009:26-28) were used to guide the data analysis process.

## **1.9 ETHICAL CONSIDERATIONS**

Ethical research comprises of the following actions: (i) the protection of human rights, (ii) obtaining informed consent from research participants and (iii) submitting a research proposal for review by an institutional review board (Grove, Burns & Gray, 2013:159).

The research proposal for the study was submitted and permission to pursue the study was granted from the Health Research Ethics Committee of the University of Stellenbosch (Ethics Reference: S14/10/245) (Annexure 1). Permission for conducting the research study was also obtained from the Eastern Cape Department of Health (Annexure 2) as well as the manager of Matatiele community clinic (Annexure 2).

All participants of the research study were provided with information about the research project, individually and gave written consent for participation in the study (Annexure 3).

The human rights of participants were protected by ensuring their right to self-determination; confidentiality and anonymity; protection from discomfort and harm; and fair treatment and justice.

### **1.9.1 Right to self-determination**

The right to self-determination is based on the principle of respect for persons. An individual has the right to decide and choose how they want to conduct their lives (Grove et al., 2013: 164-168). All participants were consulted by the antenatal care nurse to request their permission to be referred to the researcher for participation in the research study. Participants were also informed and given their HIV test result prior to information regarding the research project. Thereafter consent was provided by the participants after receiving full disclosure of information regarding the research study. Participants were ensured that participation in study was voluntary, without any coercion. Participants were advised that they could exit the study at any time, although they had initially consented to participation.

### **1.9.2 Right to confidentiality and anonymity**

Women were consulted and permission requested prior to referral to the researcher, as HIV is a sensitive subject and disclosure of HIV status required permission from the individual.

Pseudonyms were used during interviews. The list of pseudonyms and corresponding personal details were kept separate from research material in a password protected file and the hard copies were stored in a locked cupboard.

Participants were informed prior to providing consent, that interviews and data obtained in the study would be shared with the research supervisor. Interviews were conducted in a

private room at the choice and discretion of the participant. Clients were consulted during antenatal visits, in the privacy of the consulting room to ensure confidentiality of their HIV status.

### **1.9.3 Right to protection from discomfort and harm**

Based on the principle of beneficence the researcher should aim to do good and avoid harm above all. Discomfort could be physiological, social, economic or emotional (Grove et al., 2013:174-175). In the study the researcher contemplated temporary discomfort such as anxiety and embarrassment as well as unusual levels of temporary discomfort such as the opening of emotional wounds and the reliving of traumatic experiences. Therefore all participants were advised that they could exit from the study at any time and they were reassured that participation in the study would have no impact on the present or future service delivery to the participant. Additionally, the researcher dressed in casual attire and not the facility uniform to avoid participants feeling intimidated.

The venue and time of the interviews were arranged at the discretion of the participants and the researcher anticipated reimbursing participants for money spent on transport fees when interviews were done on days that were separate from the participants' clinic follow-up dates. However, none of the participants were reimbursed as the interviews were done on their clinic visits. The member checking, as well as the follow-up interviews for checking of themes, by participants, were done on the clinic visits scheduled for the participants. Participants were not emotionally distressed by the interview but were given the option, by the researcher, for counselling in the event of them being emotionally distressed.

### **1.9.4 The right to fair treatment and justice**

The ethical principle of fair treatment and justice implies that each individual should receive treatment that is unprejudiced and treatment that every other person is entitled to (Grove et al., 2013: 173-174). In the study participants were identified based on the study inclusion criteria. All the pregnant, HIV positive women were allotted the opportunity to participate in the research study during the data collection process and all participants were interviewed using the same data collection tool or interview guide.

## **1.10 OPERATIONAL DEFINITIONS**

**HIV:** HIV stands for Human Immunodeficiency Virus. The HI- virus attacks the human being's immune system making the immune system weak and vulnerable to infections and diseases. The immune system functions to protect the body against viruses and diseases (Mcquoid-Mason & Dada, 2012:141).

**Pregnancy:** A state of having a young baby developing inside the body of a woman (Hornsby, 2005:1142).

**Lived experiences:** Lived refers to a way of spending one's life (Hornsby, 2005:864). Experience is a process of gaining knowledge and skill through participating in certain activities (Hornsby, 2005:513). In the context of qualitative research, lived experiences refers to first-hand accounts of human encounters and interactions that influence one's perception of knowledge and reality (Brink et al., 2012:120-122).

**Rural:** An area connected with or like the countryside (Hornsby, 2005:1285).

**Antenatal:** The period from conception until the women goes into labour to deliver a baby (Pattinson, 2007:2)

## **1.11 DURATION OF THE STUDY**

Ethical approval for the study was obtained from the Health Research Ethics Committee of Stellenbosch on 22 January 2015. Permission to conduct the research study was obtained from the Eastern Cape Department of Health on 25 March 2015. The manager of Matatiele community clinic provided permission for the study on 15 April 2015. Data collection commenced on 1 May 2015 and data saturation was achieved on 31 July 2015. Data analysis occurred concurrently with the data collection and was completed 31 September 2015. The final thesis was submitted for examination in November 2015.

## **1.12 CHAPTER OUTLINE**

### **Chapter 1: Foundation of the study**

In chapter one the background and motivation for the research study is described. A brief overview of the literature, research question, research objectives, research methodology, a definition of terms and the layout of the research study are provided.

### **Chapter 2: Literature review**

In chapter two the literature relevant to HIV and pregnancy and the experiences of pregnant women is reviewed and discussed.

### **Chapter 3: Research methodology**

Chapter three provides an in-depth description of the research methodology used to explore the experiences of women diagnosed with HIV in the antenatal period in a rural area.

### **Chapter 4: Findings**

In chapter four the results of the research study are described and interpreted.

## **Chapter 5: Discussion, conclusions and recommendations**

In chapter five there is a discussion of the results with relevance to the study objectives. The researcher concludes the research study and provides recommendations based on the scientific evidence acquired during the research study.

### **1.13 SIGNIFICANCE OF THE STUDY**

The research study provided insights into the experience of women who test HIV positive during the antenatal period of pregnancy. The information gathered in the study could be used to inform current policies and management of HIV positive pregnant women in the future, especially in the Maluti Local Service Area.

### **1.14 SUMMARY**

In this chapter, an introduction and background of the study was given. The methodology applied was briefly described. There was also an in-depth explanation of ethical considerations as well as the time taken to complete the study and the outline of the various chapters as presented in the thesis.

### **1.15 CONCLUSION**

Women may experience dramatic changes in their lives after testing HIV positive. Exploring the experiences of these pregnant women provided greater insight about challenges these women are facing besides the fact of being HIV positive. Rural living in itself comes with many challenges to women. The study explored how women lived with HIV as well as the stressful life of living in an area of low socio-economic status.



## **CHAPTER 2: LITERATURE REVIEW**

### **2.1 INTRODUCTION**

A literature review is a summary of what has been published on a specific topic or phenomenon. It is organised into themes and identifiable trends. A review of literature provides the researcher with current theoretical and scientific knowledge about a particular phenomenon. In addition a literature review provides the researcher with a synthesis of what is known and unknown about the phenomenon under study (Burns & Grove, 2011:189).

The chapter that follows provides an analysis of sources regarding the lived experiences of women diagnosed with HIV in the antenatal period.

The purpose of the literature review was to review:

- Guidelines regarding care provided to pregnant HIV positive women since the beginning of the prevention of mother to child (PMTCT) initiative.
- International trends regarding the PMTCT of HIV.
- Health care provided to HIV positive pregnant women in a South African context.
- The experiences of women who test HIV positive during pregnancy internationally, in Africa and in South Africa.

### **2.2 ELECTING AND REVIEWING THE LITERATURE**

The preliminary literature review was initiated prior to starting the research proposal in order to ascertain if there were any studies done before on the topic in the South African setting. In order to limit bias during the data collection process, the researcher however did not write the literature review chapter till after interviews were conducted and themes in the data emerged. The researcher also made an effort to bracket any information from the literature that could have influenced her during the data collection and analysis processes.

Search engines that were consulted during the literature review were PubMed, CINAHL as well as Google search engines. Policies and procedures developed by the Department of Health of South Africa were also consulted. Materials used in the review were published within the last ten years and were obtained from journals and books. Keywords used in the review were: HIV, pregnancy, lived experience and rural. South African and international English publications were utilised in the review.

The literature review is organised in the following manner:

- HIV as a cause of morbidity and mortality.
- Guidelines and trends for diagnosing and managing HIV in pregnancy.
- Current challenges in PMTCT programmes.
- Lived experiences of women regarding HIV and pregnancy.

## **2.3 HIV A CAUSE OF MORBIDITY AND MORTALITY**

HIV prevalence among pregnant women remains high, globally and in South-Africa. This is concerning due to the effect of HIV on the morbidity and mortality of pregnant women and their children.

### **2.3.1 Epidemiology of HIV in pregnancy**

Globally there were 900 000 pregnant women that were HIV positive and receiving antiretroviral treatment (ART) as lifelong treatment for their health or as prophylactic management for the prevention of vertical transmission, by December 2012 (UNAIDS, 2014:36).

In the year 2010 approximately 274 000 pregnant women were tested for HIV in South Africa. Of the 274 000 women, 87% were eligible for ART in 2011 contrary to 2009 when 83% of pregnant women were eligible for ART (South Africa Global Response Report, 2013:34). Approximately 5.51 million people were living with HIV in South Africa in the year 2014 compared to 4.09 million in the year 2002 (South Africa, Statistics, 2014:30). According to Statistics South Africa (2014:7), one fifth of all South African women are HIV positive in their child bearing years. In the province of the Eastern Cape, specifically the Alfred Ndzo health district there were 133 HIV positive pregnant women in 2010 and 439 pregnant HIV positive women in the year 2011. By the year 2012 the number of pregnant women diagnosed with HIV increased to 442 women (Statistics South Africa, 2014:30).

In the Province of the Eastern Cape HIV prevalence among antenatal clients is at 29.1% of the population since 2010. This is in line with the national antenatal HIV prevalence in South Africa that is at 29.5%. Of the HIV positive antenatal clients in the Eastern Cape, 79% were initiated on antiretroviral treatment in the year 2013 and 2014. However, the national target of ninety percent of antenatal clients that should be initiated on antiretroviral treatment has not been met (Massyn, 2015:2). The Alfred Ndzo health district under the Eastern Cape Department of Health has an HIV prevalence of 25.1% in 2012 among the antenatal clients, which is below the national average. Research also shows that pregnant women initiated on antiretroviral treatment has declined from 87.4% in 2012 and 2013 to 73.9% in 2013 and 2014 in the Alfred Ndzo district (Massyn, 2015:105). The Maluti sub-district under the Alfred

Ndzo health district has initiated 86.1% of HIV positive pregnant women on ART in 2013 and 2014, which is above national and district levels.

### **2.3.2 Morbidity and mortality of HIV in pregnancy**

Globally maternal mortality decreased by 45% since 1990. By 2013, the maternal mortality rate was 210 deaths per hundred thousand live births (UNAIDS, 2014:2). According to the UNAIDS (2014:24), the infant mortality rate was reduced globally from 90 to 48 deaths per every thousand live births, with the exception of sub-Saharan Africa and Oceania. Sub-Saharan Africa has the highest maternal mortality rate among developing countries, 510 in every 100 000 live births. Whereas the maternal mortality rate in developing countries is less than 100 per 100 000 live births (Millennium Development Goals Report, 2014:29). However, a decrease in AIDS related deaths is evident since the introduction of PMTCT programmes from 230 000 in 2005 to 210 000 in 2012 and new HIV infections have also declined by 44% from 2001 to 2012 (UNAIDS, 2014:35).

In South Africa, PMTCT programmes have aided in the reduction of infant mortality from 58 deaths in every 1000 live births in 2002, to 34 deaths in every 1000 live births in 2014 (South Africa, Statistics, 2014:5). Additionally, AIDS related deaths have also decreased, from 275 444 in 2002 to 171 733 in 2014 (Statistics South Africa, 2014:6).

Research performed by Canlorbe, Malheron, Mandelbrot, Oudet, Luton and Azria (2015: 241e5) found that HIV infected women displayed abnormal uterine artery doppler patterns. There was also found that HIV infection increased the risk of preterm labour especially delivery before 32 weeks and 37 weeks gestation. However, there is no evidence of vasculo-placental complications in HIV infected pregnant women such as pre-eclampsia and intra-uterine growth retardation (Canlorbe et al.,2015: 241e5). In addition a study conducted by Powis, Smeaton, Ogwu, Lockman, Dryden- Peterson, Van Widenfelt, Leidner, Makhema, Essex and Shapiro (2011:134) found that pregnant women with a CD4 cell count of less than 200, regardless of exposure to antiretroviral treatment, gave birth to infants with low birth weights and women exposed to triple drug antiretroviral drug treatment gave birth to infants with lower birth weight and lower length in comparison to infants born to mothers who were given single drug treatment of Zidovudine.

### **2.3.3 Mother to child transmission (MTCT) of HIV during pregnancy.**

MTCT is an acronym for mother to child transmission and PMTCT is the prevention of mother to child transmission of HIV (Department of Health South Africa, 2015:5).

There are three routes of mother to child transmission of HIV: in-utero, at the time of delivery and during breastfeeding.

Firstly, in-utero, the virus is passed on to the baby via the mother's placenta. However, it is a very unlikely mode of transmission from mother to child. The placental barrier becomes compromised due to various illnesses such as millitary tuberculosis or maternal syphilis which results in the integrity of the placenta becoming affected and the HIV virus is then passed on to the unborn child from an HIV infected mother. In-utero transmission of the HIV virus is also common in cases where the pregnant woman has a very high HIV viral load or a very low CD4 cell count e.g. in cases where seroconversion is taking place (Khan, Bull & Barton, 2012:2).

Secondly, mother to child transmission occurs at the time of delivery of the infant. A high maternal HIV viral load accompanied by a low CD4 cell count is also the cause of transmission during delivery. Prolonged, ruptured membranes, as well as premature birth or delivery increase the risk of MTCT during delivery. In cases where the pregnant mother's genitalia are not intact the risk of MTCT is also increased, such as lacerated vaginal walls or ulceration of the vagina. Invasive fetal monitoring and instrumental delivery also account for increasing the risk of mother to child transmission in the delivery of the infant (Khan et al., 2012: 2).

Thirdly, mother to child transmission may also occur postpartum or after delivery through breastfeeding and this mode of transmission is the cause of 40% of MTCT (Khan et al., 2012:2).

In 2013 the rate of vertical transmission had decreased globally to 16%, in comparison to 25.8 % in 2009. The number of children newly infected with HIV also declined from 350 000 in 2009 to 199 000 in 2013 (UNAIDS Gap report, 2014:5). Currently the mother to child transmission rate, in South Africa is below 2.7% (Global Response report South Africa, 2013:13).

## **2.4 GUIDELINES AND TRENDS FOR DIAGNOSING AND MANAGING HIV IN PREGNANCY**

Since the implementation of guidelines for PMTCT in the year 2000, several guideline revisions have been made based on the latest available research.

### **2.4.1 History of PMTCT programmes**

The World Health Organization (WHO) released the first recommendations for PMTCT in the year 2000. WHO initially recommended that all pregnant women with a CD4 count of less

than 200/mm<sup>3</sup> regardless of WHO clinical staging be initiated on life-long ART, whereas women with WHO clinical staging of one and two and a CD4 count of more than 200/mm<sup>3</sup> were provided with prophylactic treatment of a single dose nevirapine (NVP) at the onset of labour and combination of Zidovudine (AZT) and lamivudine (3TC) during labour at 3 hour intervals and 7 days post-delivery. Pregnant women also received prophylactic treatment with AZT from 28 weeks gestation, in all cases, not eligible for lifelong ART. Infants exposed to HIV were provided with AZT syrup for 7 days post-delivery and infants were tested for HIV at 6 weeks (WHO, 2007:6-9).

In South Africa the PMTCT programme received scaling up efforts since 2004. In 2010 there was the introduction of dual antiretroviral treatment. Dual treatment included a single dose of nevirapine at the onset of labour and zidovudine twice daily from twenty eight weeks gestation in pregnancy, for all women with a CD4 above 200. Women with a CD4 less than 200 were initiated on lifelong antiretroviral treatment (Department of Health South Africa, 2013:34).

However, in 2010 new guidelines were issued for the management of HIV positive pregnant women as another attempt at improving PMTCT programmes. HIV positive pregnant women were initiated on antiretroviral treatment from 14 weeks gestation as a prophylactic measure, which included single dose nevirapine at the onset of labour and zidovudine twice a day until delivery. During labour and delivery the HIV positive, pregnant woman received zidovudine every three hours until delivery and a single dose truvada (tenofovir and emtracitabine), post-delivery (Department of Health South Africa, 2010:25). This was followed by nevirapine syrup as prophylactic treatment to the infant post-delivery up to six weeks, if the infant was not breastfeeding, or until one week post cessation of breastfeeding in infants who were breastfed (Global response Report South Africa, 2013:34).

Thereafter, South Africa introduced option B in the year 2013. The guidelines for managing HIV positive pregnant women required that all pregnant women routinely be provided with HIV counselling and testing at the first antenatal care visit (Department of Health South Africa, 2013:5). After an HIV diagnosis the women were issued with a fixed dose combination drug consisting of triple antiretroviral drug treatment for seven days, if they had no history of psychiatric illnesses or renal illnesses (Department of Health South Africa, 2013:5-6). If women had a history of psychiatric illnesses or renal illnesses, they received zidovudine single drug treatment instead. Women were reviewed after seven days of treatment. If the women had a serum creatinine level of more than or equal to 85 µmol/l and a CD4 cell count of less than or equal to 350mm<sup>3</sup> or WHO staging of three or four, the women would receive ART in the form of a fixed dose combination life-long. In women with

CD4 cell counts of more than 350mm<sup>3</sup>, WHO staging of one and two, prophylactic ART was provided in the form of fixed dose combination for the duration of pregnancy, labour, and post-delivery until one week post-cessation of exclusive breastfeeding (WHO, 2013:8).

South Africa has since adopted World Health organization Option B plus, as announced by the Minister of Health in July 2014. Option B plus was implemented on the first of January 2015 (Department of Health South Africa, 2014:7). Option B plus prescribes that a woman who is diagnosed as HIV positive during pregnancy is automatically enrolled on life-long antiretroviral treatment regardless of the woman's health needs or CD4 cell count (Department of Health South Africa, 2014:14). Infants born to HIV positive women are given nevirapine syrup as prophylaxis for an extended twelve week period if the mother is not virally suppressed (Department of Health South Africa, 2014:15). To improve adherence and success of PMTCT programmes pregnant women are also linked to the MomConnect programme at the first antenatal care visit (Department of Health South Africa, 2014:15). MomConnect is an initiative introduced by the National Department of Health of South Africa, to use cellphone technology such as sms to register every pregnant woman in South Africa. Once the pregnant women has been registered on MomConnect the system sends the woman updates and support messages, via sms on her cellphone, for every stage of her pregnancy, during childbirth and then up to the first birthday of the child (Reducing mother and child mortality South Africa, 2014:1).

The United Nations in 2011 called for the virtual elimination of vertical transmission of HIV by 2015, therefore stating that no child born from an HIV infected woman should test HIV positive by the year 2015. This changes PMTCT to the elimination of MTCT or EMTCT (Mnyani, 2012:10). For complete eradication of mother to child transmission of HIV, 90% of women should receive ART as per WHO guidelines, the incidence of HIV infection should be decreased by 50%, there should be no unmet need for family planning and breastfeeding should be restricted to a maximum of 12 months (Mnyani, 2012:12).

In an attempt to achieve the elimination of vertical transmission, option B and B plus have proven to be beneficial as these options ensure that women's health is optimal throughout pregnancy and delivery as well as breastfeeding since ART initiation does not depend of CD4 cell count results. Additionally, there is simplicity in HIV management, whereby women remain on the same treatment they started at antenatal care (WHO, 2012:5).

#### **2.4.2 Routine HCT during pregnancy**

HIV counselling and testing (HCT) should be offered to all pregnant women at the first antenatal clinic visit and at every follow up antenatal care visit if not done at the initial visit.

Initially information about HIV and HIV testing and counselling is given in the form of a group health education session to all pregnant women (Department of Health South Africa, 2013:15). Thereafter, individual counselling and testing sessions are given to each pregnant woman who attends the clinic either for the first time or at a follow-up visit. Counselling can be done by a midwife, a trained HIV counsellor or a nurse. In the individual counselling session women are provided with information regarding the HIV testing procedure and women are provided an opportunity to pose questions (Department of Health South Africa, 2013:15). Information is followed by the offering of an HIV test and the woman is asked for written consent for the performing of the rapid HIV antibody test. Women are given the opportunity to decline or refuse the performance of an HIV test and the refusal is called opt-out option (Department of Health South Africa, 2013:15). Following an opt-out option women are given pre-test counselling, not as a means of coercion for the pregnant woman into providing consent or undergoing an HIV test, but to clarify misconceptions and provide more clarity on information given in group counselling sessions (Department of Health South Africa, 2013:15). When a pregnant woman declines or refuses HIV testing, the women should be offered an HIV test at every consequent antenatal visit (Department of Health South Africa, 2013:15). In the event of a pregnant women agreeing to an HIV test and providing consent, an HIV test is performed. When an HIV test gives a positive result, a second HIV test is performed as a confirmatory test. The confirmatory test should be from another manufacturer. Two positive test results then confirm an HIV positive result (Department of Health South Africa, 2013: 15). Women, who are diagnosed and confirmed as HIV positive, also receive post-test counselling (Department of Health South Africa, 2013:15).

### **2.4.3 Antiretroviral treatment for PMTCT in pregnancy**

According to South African guidelines on management of HIV positive pregnant women, the drugs used are tenofovir, emtricitabine and efavirenz as the first line regimen. Zidovudine can be used in cases where tenofovir is contraindicated. Children born to women that are HIV positive are given nevirapine syrup and or zidovudine syrup as prophylaxis (Department of Health South Africa, 2015:45-46).

Drug toxicities accompanied by the current first line ART regimen is indicated in Table 2.1. The most common side effects are nausea, hepatitis, peripheral neuropathy and skin rashes. However in a study conducted to examine antiretroviral treatment used in HIV prevention programmes, severe adverse events in clients on highly active combination antiretroviral treatment (HAART), was absent. The unexpected drug toxicities related to antiretroviral



treatment were absent as well (Tonwe-Gold, Ekouevi, Amani-Bosse, Toure, Coffie, Rouet, Becquet, Leroy, El-Sadr, Abrams & Dabis, 2007: 1369-1370).

**Table 2.1: Drugs used in pregnancy and potential side effects**

(Department of Health South Africa, 2015:84-85).

<b>Drug</b>	<b>Common side- effects</b>
<b>Tenofovir</b>	Flatulence, diarrhoea, abdominal discomfort,
<b>Efivarenz</b>	Central nervous toxicity such as: abnormal dreams, depression or mental confusion.
<b>Nevirapine</b>	Hepatotoxicity. In severe cases Steven Johnson syndrome as well as convulsions.
<b>Lamivudine</b>	Headaches and dry mouth.
<b>Zidovudine</b>	Anaemia , lipoatrophy or liphodystrophy
<b>Emtricitabine</b>	Severe skin reactions, hyperpigmentation of the palms and soles.

Research shows that women who were treated with triple drug treatment as aforementioned and were stopped at delivery or women who received a single dose nevirapine and stopped at delivery had a high probability for a decline in CD4 cell count after cessation of the antiretroviral treatment. Prophylactic antiretroviral treatment was found to result in a decline in the CD4 cell count of women within the first 24 months post-delivery and often the decline resulted in women becoming eligible for life-long ART (Ekouevi, Abrams, Schlesinger, Myer, Phanuphak, Carter & Rosalind, 2012:e43750).

Tonwe-Gold et al. (2007: 1369-1370) also found that pregnant women developed adverse events such as rashes, and liver toxicity after using nevirapine and anaemia after prolonged use of zidovudine. However, there were no fatalities among the pregnant women due to the use of ART and changing the women from one regimen causing toxicity to another regimen resulted in health improvement of the affected women. In the infants born to women taking ART there was a high probability for low birth weight (Tonwe-Gold et al., 2007:1369-1370). Additionally Tonwe-Gold et al. (2007:1369-1370) reported lower rates of mother to child transmission of HIV in the peri-partum stage as well as lower HIV transmission rates in women post-delivery and women who had short periods of breast feeding while on ART. A study in South Africa found birth defects among babies born to mothers using efivarenz for prevention of mother to child transmission. Birth defects included arachnoid cysts, facial asymmetry, overlapping fingers, bilateral club feet and umbilical hernias (Bera, McCausland,



Nonkwelo, Mgudlwa, Chacko & Majeke, 2010: 286). However, a study conducted by Ford, Mofenson, Shubber, Calmy, Andrieux-Meyer, Shaffer, Victoria and Renaud (2014:126) found that the use of efavirenz in the first trimester of pregnancy yielded no difference in the risk of possible congenital abnormalities compared to cases in which efavirenz was not used. Hence, in South Africa, efavirenz is currently used as a first line drug for antiretroviral treatment for HIV positive women regardless of the gestational age.

## **2.5 CURRENT CHALLENGES IN PMTCT PROGRAMMES**

In Eastern and central Europe targets of PMTCT have been met and they have reached the 90% target of PMTCT coverage. However, countries such as Asia, Pacific and the Middle East and North Africa have coverage of less than 20% in PMTCT. Twenty one of the countries in sub-Saharan Africa also have PMTCT coverage between 57% and 70% in PMTCT coverage (UNAIDS, 2013:39-40). Of the infants infected with HIV through mother to child transmission, 49% are infected during breastfeeding and 62% during pregnancy. The global report published by United Nations also reports that globally the pace at which new HIV infections are decreasing is becoming slower since 2008, and in some countries there has been no decrease in the number of new HIV infections in women of childbearing age. Additionally, 10 priority countries still show less than 50% in the initiation of pregnant women on antiretroviral treatment with a CD4 cell count less than 350 (UNAIDS, 2013:43-45).

Despite global attempts at improving access to HIV counselling and testing, only 44% of women of low- and middle income countries received HIV counselling and testing in 2013 (UNAIDS Gap Report, 2014:7). In addition, only three out of every ten pregnant women, globally had received antiretroviral treatment in 2013, even though all HIV pregnant women were eligible for ART regardless of CD4 cell count from 2013 (UNAIDS Gap Report, 2014:8).

Although Option B plus is considered optimal it still comes with challenges such as women who decline initiation of ART in pregnancy and women being lost to follow up once they have delivered (Mnyani, 2012:21). Another challenge in relation to Option B plus is the high drop-out rates of women on ART from PMTCT programmes after the delivery of the infant. More research is needed to address the concerns of multi-drug resistance in women who displayed poor drug treatment adherence while on antiretroviral treatment (WHO, 2012:5).

## **2.6 THE EXPERIENCES OF WOMEN REGARDING HIV AND PREGNANCY**

Pregnancy may be a life-altering and emotional period for many women. The body of the mother undergoes changes and for many women support (emotionally, physically and financially) becomes imperative (Lau, Wong, Wang, Kwong & Wang, 2014:307-310).

### **2.6.1 HIV diagnosis during pregnancy**

In a study in Vietnam, HIV testing of pregnant woman was done as a routine procedure. Women were tested and results issued back to the women through a district health system (Hardon, Oosterhoff, Imelda, Anh & Hidayana, 2009:840). Women had no insight into why they were tested for HIV or the benefits of having an HIV test done (Hardon et al., 2009:840). In Thailand, women most often learned about their HIV status during antenatal care. After an HIV diagnosis women would opt for an abortion as soon as possible, fearing the possibility that the baby would be HIV positive and that an HIV positive individual did not live long after diagnosis. Many women chose to deliver their babies at facilities away from their hometown to ensure anonymity and protect themselves from unintended disclosure of their HIV status (Liamputtong et al., 2014:3-4).

In the United Kingdom, women diagnosed with HIV, in pregnancy, felt that the negative publicity and information provided in the media, worsened their fear and added to stigmatization of people living with HIV. Many women felt that being diagnosed with HIV was a punishment from God and sought religious practices as a means of atoning for the perceived transgression (Treisman, Jones & Shaw, 2014:148-149).

HIV positive women in Ireland felt that being diagnosed with HIV in pregnancy took away the emphasis on pregnancy and HIV overshadowed the whole pregnancy experience (Kelly, Alderdice, Lohan & Spence, 2011: 135). D'Auria, Christian and Miles (2006:14), found that women took steps to identify legal guardians for the children after an HIV diagnosis as they would die, while others feared that their children would not remember them and therefore felt the urgency to nurture and develop a close relationship with their children. Women also expressed concern about the opinion their children would have about them after the children were to find out that they were HIV positive (D'Auria et al., 2006:14). In Connecticut women had conflicting emotions after an HIV positive test. Some women felt their lives were over, others mourned for a return to their lives prior to an HIV diagnosis, while others felt that the test acted as a lifesaving intervention for their unborn child (Simpson & Forsyth, 2007:40). Women in Connecticut displayed various levels of depression as well as suicidal thoughts post-diagnosis, while other women stated that they took on extra work to keep busy in an effort to cope with their diagnosis of HIV (Simpson & Forsyth, 2007:40).

In Malawi, women saw having an HIV test is a means of confirming a long suspicion of being HIV infected and that it may protect them and their unborn children. HIV screening was seen as an empowering tool (Kasenga et al.,2008:31). In another study, Levy (2009:157) found that women showed that the primary motive for testing was to benefit their own health; concern for the risk their HIV status would have on the infant was secondary and was only

considered or became a reality once the mother was found to be HIV positive. In a study performed in Zambia, HIV testing was seen as a governmental law developed for the protection of women and children, therefore women tested because of a desire to obey the law (Shroufi, Mafara, Saint-Sauveur, Taziwa & Vinales, 2013: 4). Women reported feeling shock, loss of control and disbelief on receiving an HIV positive result which was followed by a lot of reflection on an HIV positive result (Kasenga et al., 2008:32). Many women focused on the health of the infant rather than that of her own on receiving a positive result (Levy, 2009:156).

In South Africa, women were eager to be tested but were not able to, due to lack of HIV counsellors or a lack of HIV testing kits. A minority neglected to do an HIV test due to fear of having an HIV positive result (Nkonki, Doherty, Hill, Chopra, Schaay & Kendall, 2007:3-4). In a study conducted in a poor resource setting in South Africa, a health worker failed to identify and issue a HIV positive result to a pregnant woman who had visited the health facility numerous times and had undergone an HIV test at the same facility. A number of women also did not accept their HIV positive result when given results (Nkonki et al., 2007: 3-4). Women received positive results fairly close to delivery and many women were not ready to accept their HIV status (Nkonki et al., 2007:3-4). Women in South Africa showed decreased insight into the risk of transmission to their baby as many were provided nevirapine as a prophylactic treatment and forgot to take the single dose prior to delivery for numerous reasons such as lost dose, intensity of labour pains and lack of information from the health care worker (Nkonki et al., 2007:3- 4). Consequently, the risk of in utero transmission of HIV was increased. Horwood, Butler, Haskins, Phakathi and Rollins (2013:e74568), found that adult mothers were more ready to undergo HIV testing in pregnancy than adolescents.

### **2.6.2 Disclosure**

Research found that, in Africa, disclosure of an HIV positive result to a sexual partner was a continuous stress factor for pregnant women. Women were constantly weighing the benefits against the risks of disclosure (Rujumba, Neema, Byamugisha, Tylleskar, Tumwine & Heggenhougen, 2012: 4). The benefits of disclosing would be receiving support and care from the partner, whereas the risks would be possible abandonment, the woman being labelled as a prostitute and bringing a fatal disease into the family or “killing” her husband. Many women deferred from disclosing claiming that they did not want to add stress onto their partners (Rujumba et al., 2012:6). In another study women feared that disclosing their HIV status would result in them being perceived as having poor social morals and this fear was a barrier to disclosure (Chivonivoni, Ehlers & Roos, 2008:1621).

Women found it easier to disclose their HIV positive status to their mother or to a close friend or relative, as these aforementioned individuals were a greater source of support. Mothers are seen as dependable confidantes to the women (Kasenga et al., 2008:33). Husbands were found unreliable and were reluctant to test even after a woman disclosed her own HIV positive status (Kasenga et al., 2008:33). Rujumba et al. (2012:7) found that women who were of an older age, disclosed easier than younger women. Another study found that women were less likely to disclose their HIV status to their spouses if the women lived with their own family and not the mother-in-law. Women were also less willing to disclose their HIV positive status if there was another spouse (Brou, Djohan, Becquet, Allou, Ekouevi, Viho, Leroy, Degrees-du-Lou & ANRS Ditrane Plus Study Group, 2007:1915- 1916). Disclosure was easier when the woman and husband lived on their own and was also motivated by the feeding choice opted by the woman. If the woman opted for exclusive formula feeding she would disclose so as to obtain money to buy formula. Women were found to disclose their HIV status to spouses before delivery, if they chose formula feeding or between delivery and resuming of sexual activity (Brou et al., 2007: 1915-1916).

In relationships where disclosure was done, Kalembo, Zgambo, Mulaga, Yukai and Ahmed (2013:5-6) found that there was greater condom use, a better response of the women to PMTCT programmes and follow-up visits as well as an increase in hospital deliveries. There were also positive responses by spouses to women disclosing their HIV positive status. Some women found support and a deeper emotional relationship with their spouses (Kasenga et al., 2008: 33). In contrast, disclosure for other women resulted in violence against the HIV positive pregnant woman, loss of financial support and also the disbelief of being HIV positive (Kalembo et al., 2013:5-6). Disclosure for some women led to the women finding out that her partner had been HIV positive for a period of time and receiving antiretroviral treatment without her knowledge (Rujumba et al., 2012:6).

### **2.6.3 Treatment**

Health care workers in Thailand did not discuss the option of antiretroviral treatment for the wellbeing of the mother or the infant. Most healthcare workers promoted and educated HIV pregnant mothers on sterilization after delivery or after an abortion. Women stated that they were made to understand that because of their HIV positive status they were not to have any more children as the children would be born infected and there would be no one to raise their children after the mothers had died (Liamputtong et al., 2014:3-4). HIV positive women in New York were concerned that antiretroviral treatment would be harmful to the infants and many postponed to take antiretroviral treatment (Sanders, 2008:51).

Women in Connecticut described the taking of antiretroviral treatment as mandatory in an effort to save their unborn babies. They took treatment because it had to be done, and many became obsessed with taking the treatment and would become distraught when they have forgotten a dose. Even though they continued the treatment, mothers silently feared the effects that the treatment would have on the children when they were born (Simpson & Forsyth, 2007:39-40).

In a study performed in Tanzania, women declined the use of antiretroviral treatment pre-delivery because of socio-economic factors. Women who were initiated on ART did not maintain adherence and claimed family responsibilities and economic factors made it difficult to adhere. Women also stated that healthcare workers provided wrong doses of medication and neglected to dispense ART and also failed to document return dates to collect treatment after initial initiation on treatment (Kirsten, Sewangi, Kunz, Dugange, Ziske, Jordan Harder, Harms & Theuring, 2011:e21020). Kirsten et al. (2011:e21020) also found that women who disclosed to family members and significant loved ones would more likely adhere to antiretroviral treatment as well as PMTCT programmes.

In KwaZulu-Natal, South Africa, research found that women often opted for maternal antiretroviral treatment (i.e. where the pregnant or lactating mother takes the drug instead of the infant) as they desired the potential benefits that ART offered to the infant. The women also felt that the potential risks that were involved in taking the ART should rather be experienced by the mother rather than the infant (Chavula, Long, Mzembe, Kayira, Chasela, et al., 2012:58). Horwood et al. (2013:e74568), found that a higher proportion of adult mothers were on ART for their own health than adolescent mothers and a greater number of adult mothers received the full PMTCT regimen than adolescent mothers.

#### **2.6.4 Women's preferences to ART options**

Option B (i.e. maternal ART during pregnancy and breastfeeding) was welcomed by some women due to the fear of HIV related stigma. Women felt giving a healthy infant medication would lead to the community and family members becoming suspicious of the mother's HIV status (Ngarina, Tarimo, Naburi, Kilewo, Mwanyika- Sando, Chalamilla, Biberfeld & Ekstrom, 2014:5-6). Additionally Option B allows for safe breastfeeding of the exposed infant without the HIV positive women having to disclose her HIV status to family members. Infants born to HIV positive women were also protected against possible side effects of drugs and perceived complications later in life. Many women also stated that the infants were too innocent to take antiretroviral treatment (Ngarina et al., 2014:5-6).

Option B plus (lifelong ART) also appealed to HIV positive women as they saw the possibilities of prolonging their lives and having a longer chance at raising their children (Ngarina et al., 2014:6).

### **2.6.5 Health facilities and staff**

Women want to feel accepted by healthcare workers, as well as to be given respect and be treated with dignity (Treisman et al., 2014:148-149).

In the United Kingdom, some women felt marginalized and discriminated against by healthcare workers who refused to consult women, once they were diagnosed as HIV positive. In contrast, other women received support and encouragement from healthcare workers (Treisman et al., 2014:148). Similarly, in Northern Ireland, HIV positive women were distressed by gestures and actions displayed by midwives while attending to them, as the midwives were uneasy to acknowledge the HIV status of the women. In some health facilities midwives placed bio-hazard stickers on the refuse bins in the rooms of HIV positive women. Women also experienced lack of communication and continuity of care among healthcare workers (Kelly et al., 2011:135). A few women in Thailand reported support and encouragement from doctors and reassurance regarding treatment such as ART to promote well-being and prolong the life of the HIV positive woman (Liamputtong et al., 2014: 3- 4).

A study in Malawi, further found that mothers who received information in counselling sessions held at the health facilities and who had open communication with health care workers were more informed about PMTCT programmes (Kasenga et al., 2008:31). Levy (2009:154) also found that in Malawi, even in facilities where PMTCT programmes were conducted by non- governmental organisations and antenatal care was provided by the government facilities, the pregnant women were well informed about PMTCT and were actively involved in participation of PMTCT programmes.

In a study in New York, women felt that their HIV status was also unintentionally disclosed as HIV positive women were all referred to a specific health care provider, and HIV negative women were not (Sanders, 2008:50). Some women in Zambia also felt that health facilities encouraged stigmatization and unintended disclosure of HIV status in the routine caring and procedures practiced in the facilities (Shroufi et al., 2013: 4). The physical layout of the facility caused difficulties for some women and the home visits provided by health workers was seen as a means of unintended disclosure (Chikonde, Sunby & Martinson, 2009:146-147). Spouses or partners blamed healthcare workers for providing conflicting HIV information and influencing their wives or partners. Husbands did not believe that their

partners were infected with the HIV virus and encouraged the partners to leave the HIV programmes offered at health facilities (Chikonde et al., 2009:147-148).

### **2.6.6 Self-care**

Women who tested HIV positive in the United Kingdom began to realize that HIV is not only an African disease but that it could touch anyone, anywhere. Women believed that displaying a good self-image would assist in society not identifying them as being HIV positive and living healthy lifestyles would improve their health and provide them with a longer life span to care for their children (Treisman et al., 2014:149). For other HIV infected pregnant women the baby gave them a sense of purpose for their lives. They felt an appreciation for the present and thereafter lived each day at a time. Women then lived each day to love and nurture their infants and also developed a reason to take care of themselves (D'Auria et al., 2006:14-15).

### **2.6.7 Relationships with others**

Although many women expected rejection and abandonment from significant loved ones, when faced with acceptance and positivity from loved ones the women felt improved self-esteem and hope for the future (Treisman et al., 2014:151). Women in Connecticut declared that their relationship with spouses and partners became strained after disclosure of their status and some spouses developed suspicion against their wives (Simpson & Forsyth, 2007:40). Women felt anger and resentment towards their partners after being diagnosed with HIV. Many of the women also feared that the relationship with their children would be affected negatively once they had to disclose to their children (Simpson et al., 2007:39-40).

## **2.7 SUMMARY**

In chapter 2 a review of literature regarding an HIV diagnosis in pregnancy was presented. There was an exploration of HIV as a cause of morbidity and mortality, the guidelines and trends used in the diagnosis and management of HIV in pregnancy as well as the current challenges in PMTCT programmes. The lived experiences of women who are HIV positive and pregnant were also examined and presented.

## **2.8 CONCLUSION**

Eliminating vertical transmission is at the forefront of ensuring a HIV free generation. There is a need for a therapeutic relationship between pregnant women and the healthcare worker. If this relationship is not established and maintained the fight against vertical transmission is lost. As seen in the chapter, women diagnosed with HIV endure countless challenges.



Health workers are the driving force behind the PMTCT programmes, regardless of the changes and global recommendations the two parties that bring PMTCT into reality is the pregnant woman or mother and the health worker.

The chapter that follows provides a description of the research methodology used to explore the lived experiences of women who are diagnosed as HIV positive during pregnancy in the rural Eastern Cape.



## **CHAPTER 3:**

# **RESEARCH METHODOLOGY**

### **3.1 INTRODUCTION**

In chapters one and two, the background of the study was described as well as the existing knowledge about the lived experiences of pregnant women who test HIV positive for the first time in pregnancy. The purpose of this chapter is to describe the research methodology that was used to explore the lived experiences of women who test HIV positive in the antenatal period in a rural area.

### **3.2 AIM AND OBJECTIVES**

The aim of the proposed study was to explore the lived experiences of women who were diagnosed with HIV for the first time during the antenatal period and residing in the rural Eastern Cape. The objectives were to:

- Understand pregnant women's lived experiences of being diagnosed with HIV during the antenatal period.
- Describe the thoughts and feelings of pregnant women about having to take antiretroviral treatment.
- Describe the influence of an HIV diagnosis on their experience of being pregnant, their self-care and relationships with significant others.

### **3.3 STUDY SETTING**

The setting is the location where the study is performed. A setting could be: (i) natural or uncontrolled for example in a real life situation or setting, (ii) partially controlled where the researcher modifies the location to a certain extent or (iii) highly controlled where the location resembles the real life situation but the location is completely unreal (Grove et al., 2013:373).

The research setting in the study was natural as it occurred in a real life setting, in the community where the participants were living and attending the antenatal or postnatal clinic. The study was limited to the Matatiele community clinic. The researcher observed that a high number of pregnant women from the health district were attending antenatal care at the facility and a large number of women tested HIV positive for the first time when they came for their antenatal booking visit. The Matatiele community clinic is central to the community and attends to 500 to 600 pregnant women per month of which 60 to 80 women are new antenatal clients (Matatiele clinic, monthly statistics 2015:1).

### 3.4 RESEARCH DESIGN

Research design is defined by Grove et al. (2013:49) as a blueprint for how a study is conducted. It ensures that maximum control is emphasized over possible factors that could affect the desired outcome of the study.

A qualitative research design was used in the study, as the researcher wanted to focus on the real life experiences of participants. Qualitative design is described by Burns and Grove (2011: 73) as an approach to research in which life experiences of participants are described and meaning is given to the real life experiences of participants. It explores human experience through the viewpoint of the participant in the context in which the actions take place (Brink et al., 2012:121).

The researcher also followed a descriptive phenomenological study approach, which according to Smythe (2012:6) is an approach that analyses and interprets the lived experiences of the participant and exposes hidden meaning behind the experiences as described by the participants. Phenomenologists believe that the world around the person shapes and defines the person and the person then shapes the world. Phenomenology allows for the understanding of an individual as a unique being, how an individual interacts with others, how the individual attaches meaning to different occurrences and how the individual interacts within a specific environment (Finlay, 2009:9-11). Phenomenology is subjective as it explores an occurrence from the perspective of the individual who is experiencing the phenomenon. Therefore in phenomenology the human or the participant is seen to be the most knowledgeable about the phenomenon (Finlay, 2009:9-11).

To ensure that the true lived experience is captured by the researcher, the study prescribed to the Husserlian philosophy of phenomenology, using bracketing. Husserlian philosophy implies that the human experience, as understood by the human is valuable and should be studied, scientifically. In seeking to understand what motivates human actions and behavior, Husserl believed that one should explore the subjective information provided by the human experiencing the phenomena and what an individual perceives as reality will direct the individual behavior (Finlay, 2009:12-13).

For a researcher to obtain the essential and true lived experience of the participant the researcher has to shed or put aside, what he or she perceived as reality about a phenomena as well as any personal knowledge about the phenomena, defined as bracketing (Grove et al., 2013:284). This process of bracketing is a continuous process to ensure that the true experience under study is not influenced (Grove et al., 2013:284). In this study the researcher made a list of her preconceived ideas such as: (i) the opinion that public

awareness of HIV has been promoted since the year 2000, therefore everyone has accepted that HIV is a reality, (ii) women are empowered by the media and are not afraid to disclose their status, (iii) women are not rejected because of their HIV status, (iv) HIV is openly discussed in families as it has been around for a decade already. The researcher also listed the comments she had heard from clients she had consulted prior to the study, as well as the statistics of women who defaulted from PMTCT programmes and the in-service training the researcher received. The researcher set the preconceived ideas and assumptions in this list aside as a conscious action to exclude previous knowledge and preconceptions and focused on what the participants were describing. The researcher also did not do any review of the literature during the data collection and part of the data analysis period, up to the development of themes, to ensure that the experiences of the participants were reflected. This process allowed for the true lived experiences of the women to be identified from the interviews.

The philosophical assumption of phenomenology is that true understanding is dependent on how the individual interprets a phenomena or occurrence. The way in which an individual understands any experience is unique to the particular individual person and understanding is only achieved by our experiences of a phenomenon or occurrence. To explore the experience and understanding of someone else, I therefore needed to identify and be open to my own bias as a unique being (Smythe, 2012:6).

### **3.5 POPULATION AND SAMPLING**

Population refers to the distinctive group of people on which the intended research study focuses (Grove et al., 2013:351). The study took place in the Eastern Cape Province. The province of the Eastern Cape is divided into seven health districts namely: Oliver Tambo district, Amathole district, the Chris Hani district, the Joe Gqabi district, the Alfred Ndzo district, the Western district and the East Griqualand Kei district. The largest part of the Alfred Ndzo district is rural (Massyn, 2015:104). Alfred Ndzo is one health district, with Maluti local service area being a sub-district. Matatiele community clinic forms part of Maluti local service area. Many of the areas around Matatiele are rural areas and clients travel long distances for health care services. Matatiele community is one of the clinics under Maluti local service area with a high number of antenatal and postnatal clients. Therefore, the Matatiele community clinic and the women who attended antenatal clinic at Matatiele community clinic were the focus of the study.

The target population is the definitive cases of which the researcher wants to make generalization (LoBiondo-Wood & Haber, 2010: 222). The target population for the study

was women who tested HIV positive for the first time during the antenatal period of pregnancy and attended antenatal clinic at the Matatiele community clinic. There were a total number of 109 women who tested HIV positive between January 2015 and July 2015 at the Matatiele community clinic (Matatiele community clinic, monthly statistics, 2015:1-4).

A sample is a group of the selected individuals, who through the process of sampling are to participate in the intended study (Grove et al., 2013: 351). Sampling is the process of selecting individuals to participate in the research study (Grove et al., 2013: 351).

The researcher used purposive sampling. Purposive sampling is a form of non-probability sampling. When non-probability sampling is used the researcher identifies and selects specific cases. This sampling method does not give every element in the population an opportunity to be included in the sample (Lobiondo-Wood et al., 2010:225). Purposive sampling is a process whereby the researcher intentionally selects individuals to participate in the research study because the researcher believes that the individual can provide abundant information (Grove et al., 2013: 365). Sample size refers to the number of individuals participating in the research study (Grove et al., 2013:371). Sample size in the study was dependent on when data saturation had been achieved. Data saturation occurs when additional information or individuals participating in the study provide repetitive data or information (Grove et al., 2013: 371). Speziale and Carpenter in LoBiondo-Wood et al. (2010: 237) state that the size of the sample in qualitative studies are usually small and cannot be predetermined because of the large amount of data gathered as well as the prolonged time the researcher spends on data collection. Therefore sample size is determined by data saturation.

The researcher anticipated doing eight to ten in-depth interviews, to gain in-depth information since HIV/AIDS is a sensitive topic in this particular community. Data saturation was achieved by the ninth interview. Interviews were conducted with women from various areas within the Maluti local service area who attend the Matatiele community clinic. The researcher selected women who had tested HIV positive for the first time during the antenatal period of pregnancy.

### **3.5.1 Inclusion criteria**

Inclusion criteria are the traits or qualities that the participant or sample must possess to be part of or qualify to be included in the target population (Grove et al., 2013:353).

Inclusion criteria used for the study were women who were:

- Eighteen years and older.

- Diagnosed with HIV for the first time during the antenatal period of pregnancy.
- Receiving antiretroviral treatment for at least two months.
- Attending the Matatiele community clinic for their antenatal- or postnatal care.

### **3.5.2 Exclusion criteria**

Exclusion criteria are the traits and qualities in a participant or element that make the participant unsuitable for selection as part of the target population (Grove et al., 2013:353).

The exclusion criteria used in the study were the following:

- Women diagnosed with other serious medical conditions during pregnancy such as pre-eclampsia as this may influence their overall experience and these women are treated at specialized clinics in a hospital setting for various periods of time.
- Women who were diagnosed in labour as the emotional trauma of being diagnosed during labour could have influenced their overall experience.

### **3.6 DATA COLLECTION TOOL**

The researcher used semi-structured, face to face, individual in-depth interviews for data collection. Interviews are described as interactions that occur between the researcher and the participant that provide data in the form of words. In an interview the researcher investigates or obtains information from different individuals (Grove et al., 2013:271). Semi-structured interviews are defined by Grove et al. (2013:271) as interactions or conversations between the researcher and the participants where there is a set of fixed, predetermined questions by the researcher. However, the responses from the participant are not fixed or predetermined to allow for the emic view to emanate from the conversation. The emic view is defined by Grove et al. (2013: 271) as the viewpoint of the insider or the participant. Hence the researcher developed four open-ended questions (Annexure 4) that were used in each interview with the participant for example, 'tell me about your thoughts and feelings when you tested HIV positive'. The participant was then allowed to respond to these open-ended questions. Probes were made by the researcher to obtain further information from the participants. Probes are gestures or prompts made by a researcher during an interview to ascertain further information from the interviewee (Burns & Grove, 2011:85). An example of a probe used was, 'what was positive or negative?' The researcher also used techniques such as reflection and summarizing during the interview to obtain additional data and verify what the participant was saying.

### **3.7 PILOT INTERVIEW**

A pilot study is a study conducted prior to the main study. It is a smaller study done to explore the practical aspects of a proposed main study. It is done with participants who meet the inclusion criteria for the main study and data obtained from a pilot study may or may not be included in the main study (Brink et al., 2012:174).

The researcher conducted one interview with a client who had tested HIV positive during the antenatal period and who had been enrolled on antiretroviral treatment during the antenatal period. The pilot interview was conducted to ensure that questions in the interview guide were clear and also to refine the interview skills of the researcher. The study supervisor assessed the interview skills of the researcher following the pilot interview and provided feedback. Since the pilot interview yielded very valuable data and no significant changes to the interview guide was made, data from the pilot interview was included in the data analysis.

### **3.8 DATA COLLECTION**

Data collection is an orderly and systematic process of obtaining information which is relevant to the aim and objectives of the research study (Grove et al., 2013:45). Brink et al. (2012:147) states that data collection is a process that focuses on the what, how, who, where, and when.

Prior to the interviewing the researcher met with the manager of Matatiele community clinic as well as the health sub-district Manager to discuss the research study and to obtain permission for the study.

Data collection occurred through individual interviews, using a semi-structured interview guide. Interviews are verbal and non-verbal interactions between the research participant and the researcher that produce data in the form of words. However semi-structured interviews are interactions that are conducted around a specific set of open-ended questions (Grove et al., 2013:271). Interviews were initiated by open-ended questions and followed by probing questions as discussed in section 3.6. Demographic data for each participant such as their age were also collected during the interview.

The researcher received training in qualitative interviewing skills. The researcher sought the assistance of professional nurses in the antenatal clinic to identify possible participants as the HIV status of an individual is confidential and not available to health workers who are not directly involved in the care of the client. The researcher, although employed at the Matatiele clinic, had no contact with the antenatal clients and did not have prior knowledge about the

HIV status of any of the antenatal women. Participants were referred to the researcher by the professional nurse rendering antenatal care, after the participant provided permission to the nurse to be referred.

The participants were met by the researcher after referral from the antenatal clinic at the Matatiele community clinic. The meeting between possible participants and the researcher took place in a private room as HIV is a sensitive topic. The research study was explained to the prospective participants, in private, prior to gaining consent from the participants and ascertaining that the participants met the inclusion criteria for the study. The researcher assured the participants that participation was completely voluntarily. The venue and time for the interview was based on the preference of the participants. Participants all opted or preferred to be interviewed at the Matatiele community clinic as it was convenient for the participants when they came for antenatal visits. Participants also opted for the clinic as the location as transportation to the clinic was easier and more readily available from different rural areas.

Interviews were conducted in a private, quiet room to avoid disruptions. Interviews were also conducted away from the antenatal department to ensure the privacy of the participants. A consulting room was used for the interviews. The researcher could arrange the room to create a relaxing atmosphere.

Interview skills such as summarizing and reflection were used to ensure that the responses were correctly understood. Interviews were audio-taped and written informed consent was obtained from the participant by the researcher prior to the interview. The main languages in the area are: English, Afrikaans, Xhosa and Sesotho. The researcher is fluent in English, but is able to understand the other languages. All participants were interviewed in English at the preference of the participants, although an interpreter was available for participants who preferred to use a language other than English, to ensure the information given by the participant was accurately captured and understood. However an interpreter was not used in the study as the participants all preferred English and were able to express themselves adequately.

The researcher conducted in-depth, individual interviews, with participants to ensure optimal data was collected. After introductory pleasantries, the researcher confirmed that the participant had met the inclusion criteria determined for the study. The participant was advised on the purpose of the study, the expected time required, the confidentiality of the information and the role that the participant would play in the interview. The participant was informed that the interview would be recorded using an electronic voice recorder and a cell



phone voice recorder would be used as a back-up for the interview. A pamphlet describing all the aforementioned information was given to the participant. The participant was then re-informed that she could withdraw from the interview at any time and that participation was voluntary. To create an easy atmosphere and to reduce anxiety that the participant may have felt, the interview was started by collecting demographic data first (Grove et al., 2013: 272). Participants were offered refreshments prior to the interview, such as fruit juice, as they were either pregnant or breastfeeding at the time of the interview.

Interviews were conducted in the antenatal period and early postnatal period. Interviews were between 30 minutes and 60 minutes in duration so as to ensure that the researcher obtained adequate data. The researcher conducted follow up interviews with three participants since the original interviews were less than 30 minutes in duration. Follow-up interviews were between 15 and 20 minutes and were also recorded. Data was collected from 1 May 2015 to 31 July 2015. None of the participants were emotionally upset and none of the participants required psychological support following the interviews. Participants expressed relief and had a positive experience of sharing their story.

### **3.9 TRUSTWORTHINESS**

Trustworthiness is a method of ensuring that quality data is being collected in qualitative research. Lincoln and Guba in Brink et al. (2012:172) propose a four step model for ensuring the trustworthiness of qualitative data in a research study. The four steps are credibility, dependability, confirmability and transferability.

#### **3.9.1 Credibility**

Credibility reflects the truthfulness and accuracy of the data collected (Brink et al., 2012:172). The researcher interacted with the participants for a prolonged time and consequently this allowed for rich data collection, for the researcher to gain adequate understanding of the experiences of the participant, and establishing a relationship of trust between the participant and the researcher. Data collection for the study took place over three months in which the researcher had time to interact with participants. The researcher made use of bracketing to ensure credibility of the research findings. Bracketing is a process whereby the researcher sets aside pre-existing knowledge, ideas and assumptions that he or she may have regarding the phenomenon under study, in order to allow the viewpoint of the participant to become evident (Grove et al., 2013:6). The researcher identified and set aside pre-existing ideas and information she possessed about the phenomenon to ensure the true, lived experience of the participants was reflected in the data collected, for example, general assumptions around pregnant women being non-adherent



and not caring about their babies, as well as pregnant women not being willing to test their infants because they did not accept their own HIV status. The researcher also made reflective notes after each interview and prior to the coding process. Bracketing further occurred through debriefing sessions of the researcher with the study supervisor. The researcher also used peer debriefing, by reviewing interviews with the study supervisor. One interview was co-coded with the research supervisor and then two more interviews were checked by the study supervisor and co-supervisor. Member checking was also used as a form of ensuring credibility in the study. Member checking is when the researcher intentionally takes the transcription of the interview back to the participant and allows the participant to confirm the accuracy of the information collected (Brink et al., 2012: 172). Member checking in qualitative research promotes the credibility of the study as the participant can verify that what is transcribed in the interview is what she intended to say (Shenton, 2004: 68). In the present study the researcher was able to perform member checking with four of the participants as the other participants were unable to meet with the researcher for personal reasons such as working hours and others had just delivered their infants and were not able to leave their homes. After the four participants read through their own transcripts, they agreed that the transcript was what they had said during the interviews.

### **3.9.2 Transferability**

Transferability means that the data collected in a study should be applicable in another context or with other participants in another study (Brink et al., 2012:173). However the transferability of a study is ultimately decided upon by the reader of the research report. Thus the researcher should ensure that the research report provides adequate detail of the context of the study to allow the reader to decide if the findings of a particular study will be applicable in another setting (Shenton, 2004: 70).

The researcher ensured that the context of the study was described richly and intensively in the research documentation. The researcher pursued data collection until data saturation was achieved to ensure all relevant information was obtained in the research study. In addition, the findings were discussed in the light of the literature to determine whether the findings resonate with other studies.

### **3.9.3 Dependability**

Dependability is established when the same study is performed in a similar context using similar participants and the results yielded are similar. It also relates to how stable the data can be over a period of time (Brink et al., 2012:171). However qualitative researchers recognize that individual experiences may vary and therefore a similar study may not yield the same results as another study in a similar context (Shenton, 2004:69). The researcher

ensured that all steps and activities undertaken throughout the study were well-documented to allow for dependability of the study. All the interviews conducted with participants followed the same interview guide and questions. Transcripts deducted from audiotapes were checked and verified by the study supervisor and the researcher. An audit trail of communication between the researcher and study supervisor was kept as proof, for example, electronic mail. In addition, the researcher made reflective notes of interviews and follow-up meetings with participants.

#### **3.9.4 Confirmability**

Confirmability is achieved when the data collected by the researcher is a true reflection of the information provided by the participants in the research study. There should be no evidence of any bias on the part of the researcher in the data, caused by perceptions that the researcher may have about the phenomenon under research (Brink et al., 2012:173). The researcher ensured confirmability of data by having all transcripts verified by the researcher and the study supervisor. The researcher also kept an audit trail of how themes and sub-themes were decided upon. Additionally participant verbatim quotes were used in the reporting of data collected, to substantiate themes identified. The researcher also had follow-up meetings with eight of the ten participants who confirmed the themes and sub-themes.

### **3.10 DATA ANALYSIS**

The procedure used for data analysis was Colaizzi's seven step method (Mackenzie 2009:26-28; Edward & Welch 2011: 163-171). This method is one of the most often used methods of data analysis in descriptive phenomenological enquiry and is in essence concerned with describing everyday human existence. The seven steps are:

1. Transcribing audiotaped interviews. This includes reading and listening to each interview in its entirety to obtain a sense of the whole.
2. Extraction of significant statements from each transcript.
3. Formulation of meanings from significant statements.
4. Organisation of meanings into clusters of themes. Themes are then validated by referring to original transcripts, ensuring that no data has been omitted or added to.
5. Integration of results into exhaustive descriptions (a comprehensive description of the phenomenon as articulated by the participants) of the topic under study.
6. Formulation of the essential or fundamental structure of the phenomenon.
7. Validation of descriptive results by returning back to participants to confirm if the analysis describes their experiences.

The application of these steps is discussed below.

### **3.10.1 Step 1: Transcribing of all interviews conducted with participants then reading and re-reading of transcriptions**

The researcher transcribed the interviews herself, manually, as soon as possible after the interview. Sandelowski (1994) in Mackenzie (2009:26) explains that verbatim quotes enhance the credibility of the study, as data that would be used for analysis are an accurate account of the participants' words. The researcher also read through the transcriptions and compared the transcriptions to the audio recordings. Transcriptions were read and re-read to gain a sense of the whole. Bracketing was done by the researcher to avoid possible bias and to ensure the subjective experience of the phenomenon by the participants is described and captured. The researcher identified previous experiences and opinions and beliefs such as the experiences with women refusing to test children post-delivery; and information obtained from facility support groups for women living with HIV and set them aside. Member checking (participant validation) was done with four of the participants, as the other six participants were not available at the time. In addition, transcriptions were checked and compared to audio recordings by the study supervisor to ensure their credibility. Thereafter the researcher thoroughly read the transcripts, and re-read the transcripts to become familiar with the data and as described, by Sanders (2003:294), to gain a sense of each participant's description of the experience.

### **3.10.2 Step 2: Extracting significant statements pertaining to the phenomenon under research**

Statements that were directly related to the lived experiences of women diagnosed with HIV in the antenatal period in a rural setting were identified by the researcher as significant statements that related to the phenomenon. The significant statements identified in the transcripts and verbatim phrases were manually highlighted in-text.

In Colaizzi's method, significant statements are extracted and numerically entered into a list to assemble all significant statements. A total of 450 significant statements were highlighted, but remained in-text to stay true and retain the integrity of each participant's story. Dierckx de Casterlé, Gatsman, Bryon and Denier (2011:362) state that the content from each interview is unique and different from other interviews. This process allowed further immersion in the data.

### **3.10.3 Step 3: Creating formulated meanings**

The researcher then formulated meanings for each significant statement. A total number of 85 meanings were formulated. The study supervisor and researcher discussed the

formulated meanings and cross checked the meanings to the significant statements. The researcher and study supervisor agreed upon the meanings as the meanings were cross checked to the significant statements in context, to ensure the rigor of the study.

#### **3.10.4 Step 4: Aggregating formulated meanings into sub-themes and themes**

The 85 meanings were placed in groups of similar meaning to develop theme clusters. Sixteen sub-themes were further grouped into four emergent themes. These themes, sub-themes and formulated meanings are illustrated in chapter 4 (Tables 4.1 and 4.2).

#### **3.10.5 Step 5: The development of an exhaustive description**

All the resulting ideas were then integrated into a comprehensive description of the phenomenon. The exhaustive description was presented by the researcher in a narrative form by integrating the themes, and sub-themes into a description that creates an overall structure that contains all the essential elements of the phenomenon. The narrative form was sent to my study supervisor for validation. A few alterations were suggested regarding the themes and sub-themes and adjustments were applied to the narrative.

#### **3.10.6 Step 6: Identifying the fundamental structure of the phenomenon**

In this step, a reduction of the findings is done in which redundant and misused descriptions are removed from the overall structure. Themes were described in context, using sub-themes and formulated meanings with attachment of significant statements to validate the description in context. The structure was reviewed by the study supervisor. The structure of the phenomenon was illustrated in chapter four as the findings of the study. The structure was examined for any repeated, misused or overestimation of findings and none were found. The essence of the phenomenon, as it relates to each of the study objectives, is also described in chapter 5.

#### **3.10.7 Step 7: Returning to the participants for validation**

The description of the essence of the phenomenon, including the themes and sub-themes, was taken back to six participants to provide the participants with the opportunity to examine the findings as described by the researcher and to validate whether the themes and sub-themes were a true reflection of their experiences. The researcher individually showed the participants the themes and sub-themes and discussed these with them. Participants accepted the framework and did not have any information to add. Four of the participants were not available for validation. The participants also stated that the description of the themes and codes comforted them in the sense that they realized that there were other women in the same situation who had experienced the same or similar realities.

### **3.11 SUMMARY**

In the preceding chapter the researcher discussed the research methodology that was applied in the research study as well as the research process that was used. The chapter that follows will focus on the presentation of the findings that resulted from the study.

### **3.12 CONCLUSION**

A phenomenological qualitative design was used to explore the real life experiences of women who test HIV positive during pregnancy. The design also guided the manner in which data was analysed and presented to provide a clear picture of the phenomenon. In chapter four the findings are presented and interpreted.

## **CHAPTER 4:**

# **FINDINGS**

### **4.1 INTRODUCTION**

In this chapter there will be the presentation and discussion of the findings of the study. All interviews were transcribed verbatim using Microsoft Word. Interviews were analysed in order to describe the lived experiences of women who are diagnosed with HIV in the antenatal period in a rural area. A partial transcription of an interview is attached as Appendix 5. Various quotations from interviews are included to verify the trustworthiness of the findings presented. Analysis of data was based on the approach by Colaizzi (Mackenzie, 2009: 26-28) as described previously in chapter 3. The researcher identified four major themes from the responses of the participants during interviews. Themes were related to their thoughts and feelings regarding an HIV diagnosis, their relationship with significant others, their feelings towards their unborn children as well as their experiences with healthcare facilities and healthcare workers. Data is represented in two sections. Section A describes biographical data gathered at the beginning of each interview. Section B follows with the themes that emerged during the data analysis of interviews.

### **4.2 SECTION A: BIOGRAPHICAL DATA**

The sample for the study consisted of ten participants. One of these participants was interviewed in the pilot study. All participants were clients attending the Matatiele community clinic and were diagnosed with HIV for the first time during the antenatal period of pregnancy. Six participants were postnatal clients and four were antenatal clients. Participants were from various rural communities except two participants who lived in the town, Matatiele. Eight participants were not married and two were married. From the eight single participants, three were in a stable relationship with their partners, while the five were not in a relationship. All participants had children prior to the present pregnancy and had tested HIV negative in previous pregnancies. Participants were between the ages of 24 and 46. Seven of the participants were black and three were coloured.

### **4.3 SECTION B: THEMES EMERGING FROM THE INTERVIEWS / SUBSECTIONS OF THE QUESTIONNAIRE**

The themes, sub- themes as formulated are depicted in Tables 4.1 and 4.2. Each of the emerging themes is discussed under a separate heading.

**Table 4.1: Themes and sub-themes**

<b>Themes</b>	<b>Sub- themes</b>
<b>Reality hits raw</b>	HIV positive results The effect on self, pregnancy, relationships and lifestyle Coping with the diagnosis Taking medication as a symbolic act
<b>A loneliness that hurts</b>	Blame and regret Fear of the unknown The cruelties of stigma, stereotyping and judging Avoiding closeness and relationships
<b>The hope for a fractured tomorrow</b>	Concern for safety of the unborn child The hope to live and see the future
<b>Support of a few</b>	Reactions hit raw Sources of support Healthcare facilities and health workers

**Table 4.2: Sub-themes and formulated meanings**

<b>Sub-themes</b>	<b>Formulated meanings</b>
<b>HIV positive results</b>	The effects of an HIV diagnosis on partner and family The feelings of the woman toward her unborn child Abortion becomes an option Reality of diagnosis dawn on the woman when she's alone There's a shattered illusion of being untouchable to HIV infection The woman is concerned for her children if she is hospitalized
<b>The effect on self, pregnancy, relationships and lifestyle</b>	Negative self-image The woman treasures the time she has to spend with children The lifestyle changes that have to be undertaken to accommodate treatment and diagnosis There's a shift in concern from self to child or others
<b>Coping with the diagnosis</b>	The decision to accept diagnosis and disease Acceptance of disease to protect the unborn child
<b>Taking medication as a symbolic act</b>	The effect of treatment on the woman Positive reactions to taking ARV's Negative reactions to taking ARV's Convenience of receiving ARV's through private suppliers
<b>Blame and regret</b>	The blaming of oneself Being blamed by partner Questioning where the virus or infection comes from Questioning of partner

Sub- themes	Formulated meanings
<b>Fear of the unknown</b>	The fear of families' reaction to diagnosis The fear of rejection The fear of partner dying The fear of disease progression and helplessness The fear of involuntary disclosure The fear of infecting her unborn child The concern for partners' health The anxiety of partner being unwilling to test for HIV
<b>The cruelties of stigma, stereotyping and judging</b>	Negative reaction of partner Reduced socializing The rejection by partner Hiding from disclosure Emotional abuse because of diagnosis
<b>Avoiding closeness and relationships</b>	Hatred felt towards partner Loss of hope Disillusionment Involuntary and inevitable disclosure of HIV if in a relationship Anger towards partner Partner's infidelity
<b>Concern for safety of the unborn child</b>	The unborn child motivates adherence to programme The concern for the child takes priority Physiological changes in pregnancy change feelings towards pregnancy
<b>The hope to live and see future</b>	The optimism after diagnosis The attending clinic as a way of improving life The determination to fight the disease The confidence in antiretroviral treatment A need to move forward A positive attitude towards the future Comparison of HIV to another chronic illness Minimizing the HIV diagnosis Understanding the diagnosis and care for the future
<b>Reactions hit raw</b>	Reaction by healthcare workers towards client after diagnosis Lack of empathy by healthcare workers Negative reaction by peers Reaction of family Partner's acceptance of diagnosis
<b>Sources of support</b>	Support of sister Support of healthcare worker Support of mother Support of the partner Support of colleagues Support from religion Support of friends Support from social media



### 4.3.1 Theme 1: Reality hits raw

The participants described that undergoing an HIV test and receiving the results as being HIV positive forced them to realise the reality of HIV and the fact that they are HIV infected. It is only after being diagnosed that the women realise that anyone can become infected with HIV. These participants only tested HIV positive with the second pregnancy and they therefore may have expected a negative result. It seemed as if the news came as a shock to them and they were not prepared.

#### 4.3.1.1 HIV positive results

Participants were sent to HIV lay counsellors for HIV counselling and testing. Results were given in a private room by the HIV counsellor, prior to returning to the professional nurse for further antenatal care. The participants were alone in a room with the HIV counsellor throughout counselling, testing and receiving their results. HIV counselling and testing was seen as a routine activity by healthcare workers, for all women who were pregnant and was done at the first antenatal visit. Pregnant women that tested HIV negative initially would routinely repeat HIV counselling and testing every three months throughout pregnancy. However all participants in the study tested HIV positive at their first antenatal visit.

Participants experienced the news of being HIV positive as a shock. Some participants could not believe that they were HIV positive: *"I was shocked because I didn't know where I got HIV from."* (participant 2) Participants were disillusioned since they felt that they would never be HIV positive, that they were safe from HIV and that they would be able to avoid HIV infection: *"I thought this could never happen to me. That's what I honestly thought. It will never happen to me. I'm too wise for this to happen to me."* (participant 8) They described going home after the news as an unbearable time and did not want to be alone as it was too much to think about. They went to friends in an attempt to avoid thinking about what had happened at the clinic: *"I got home. I didn't even eat. I just went for a walk the whole afternoon. I went visiting people just to be with anyone. I didn't want to talk. I didn't want to think about it. Just different companies, people talking their own things."* (participant 8).

Receiving the news changed the feelings some participants had towards the pregnancy and the unborn child they were carrying: *"Do I honestly want this child?"* (participant 8) Consequently they considered abortion as an option as they could not face the pregnancy and they thought that terminating the pregnancy would improve their situation: *"I am pregnant, and I am positive [Silence] and there was this burden, I was considering doing an abortion."* (participant 5)

For many of the participants the news of an HIV diagnosis haunted them when they were alone or at night when they had to sleep. They were kept awake at night pondering on the reality that they have HIV: *“In the night, when I’m lying down it honestly bugs me.”* (participant 8); *“I can’t sleep, it comes to me, I’m HIV positive. Yoh, how’s life going to be you know?”* (participant 7) For others the reality of the news caused them to anxiously consider what would happen if they were hospitalized due the illness and how their other children would be affected: *“What if I am the way I am and I become weak and this child is also sick now. Who’s going to take care of this child? Who’s going to want this child?”* (participant 7)

#### **4.3.1.2 The effect of the diagnosis on self, pregnancy, relationships and lifestyle**

Some felt that an HIV diagnosis changed how they saw themselves and described themselves as being different from the person they were prior to the diagnosis. This was manifest in a negative self-image: *“I feel dirty.”* (participant 7) Others still saw themselves as the same person: *“I still see myself as normal, because nothing severe has happened.”* (participant 8)

Some participants felt that they could only experience their pregnancy once they were certain and reassured that the unborn child was safe and protected from an HIV infection: *“So there’s lots of things that can be done for the child, to prevent the child from being positive. I’ve learnt to accept the pregnancy and enjoy it”.* (participant 1) One participant felt that caring for the unborn child after an HIV diagnosis would be a life changing experience. The participant was concerned with how she would bond with the infant after delivery, as she decided against breastfeeding: *“I think I’ve bonded more with the child I was breastfeeding. So this one it’s going to be a totally different setting. I think it will be as if it’s for the first time having a baby”* (participant 1)

The reality of the HIV diagnosis caused some participants to value the time spent with loved ones as they felt they had a limited time to live. Therefore, participants felt that the time they had would be more valuable if spent with their children: *“I can’t even be away from these children. I’m thinking if I die tomorrow. I can’t miss a second with them, Genny. I’ve never been apart from Adam (pseudonym). He’s four; he’s turning four next month. I’ve never, not once gone out. For the same reason. I don’t want to lose out on his life.”* (participant 8) . Many expressed drastic changes in their socializing patterns and that they spent more time alone. They did not socialize with friends the way they used to before they tested HIV positive: *“You can’t do the things you used to. Like I used to like going out, having a good time with people.”* (participant 8)

Some participants changed their behaviour and routines in the home to accommodate taking treatment at a specific time: *“Honestly, it put my life on hold. I can’t even go visit people. After a certain time, six or half past six, I make sure I’m at home because I have to take medication.”* (participant 8) Others expressed changing unhealthy habits to ensure the safety of the pregnancy and their own well-being: *“I even stopped drinking.”* (participant 6)

Participants expressed that they became anxious about their appearance and constantly examined any physical changes that would indicate that they are HIV positive: *“Every day I get up and when I see a small little pimple, I’m already assuming. What is this now?”* (participant 8) Others stated that they blamed every illness they had on HIV: *“You find that you are sick, you know sometimes in the morning you feel, today that I’m not ok. Maybe it’s my CD4 count or maybe HIV is doing this to me, because the only thing you think is that HIV is doing this thing to me today?”* (participant 5)

An HIV diagnosis for some participants meant a change in the dreams they had for their lives. Many saw no reason to have any other kids and did not dare to imagine having families and marriages: *“My whole life is finished . I might not get married.”* (participant 7)

#### **4.3.1.3 Coping with the diagnosis**

Since many participants had no symptoms at the time of diagnosis, there was a constant reflection on whether they could really be HIV positive: *“Even when she was giving me my results... is this my CD4 count, really? And then she said ‘Yes it is’. But I was so healthy, healthy and healthy and I couldn’t believe how. Is this true?”* (participant 5)

There was an oscillation in emotions between being positive about their HIV diagnosis and the feeling of doom or negativity: *“It was so hard to accept, and I told myself ‘I will be ok. I will be ok’. The thing is I was scared my CD4 count [laughing] was very, very low and I know that at least to be pregnant with more than three-hundred CD4 count. What is going to happen to me?”* (participant 5)

Participants stated that their diagnosis was constantly on their minds and described the only way of coping with the disease was to accept the reality that they have HIV and then live with the reality: *“So at first it is a shock but at the end you have to accept it and you have to live with that.”* (participant 5) Others were able to cope as they relied on their spiritual beliefs: *“My faith really came into play. I honestly prayed. I honestly told God that I ask you for a lot of things. You must honestly keep my child healthy and safe.”* (participant 7)

#### **4.3.1.4 Taking medication as a symbolic act**

Participants stated that every time they would take the antiretroviral treatment, they were reminded that they were HIV positive: *“But every time I take that pill that medication. It comes to mind that this is a reality. That me I’ve got this condition.”* (participant 7) Some used the antiretroviral treatment as proof of being HIV positive to partners who did not believe the news when it was disclosed to them: *“And then he looked at me and said ‘you’re lying’, and I decided to give him ARVs. I’m taking this and unfortunately it was with other medication that he knows.”* (participant 5)

For some the initiation onto antiretroviral treatment gave them hope as they had confidence that the treatment would improve their health, extend their life and protect their unborn children: *“Because the doctors tell me that if I’m using the ARV’s it’s going to protect my child. That’s when I feel safe when I know that my child is safe when I’m using the treatment in the right way.”* (participant 4) However for others the initiation onto antiretroviral treatment was a sign of doom that death was near and that they were very ill: *“When I was told that now you going to start medication and take ARV’s for life. That’s when I really got scared. That night I cried myself to sleep. I thought now I am really sick and I just thought my life is over.”* (participant 7) Many had side-effects of the medication but the side effects were mild and did not cause major discomfort.

Participants took medication as a means of protecting their unborn child: *“I didn’t have a problem taking the treatment, because I knew I’m even protecting the child.”* (participant 3) For others the antiretroviral treatment dictated their decisions regarding employment: *“I will never be able to work at Spar. Even if I wanted to. I can’t work there. What is going to be my excuse every morning I start at seven? Before I go start work I must go and take my medication.”* (participant 8) Although the standard antiretroviral treatment regimen consists of a fixed-dose combination tablet taken at night, pregnant women who have high creatinine levels or other contraindications to the fixed-dose combination tablet had to take other antiretrovirals which is usually taken 12 hourly.

Participants who received antiretroviral treatment from private suppliers found it more convenient and less disruptive to their lifestyle. These women opted to use their medical aid for the procurement of antiretroviral treatment after the initial diagnosis at the antenatal clinic. They had their antiretroviral treatment couriered to a central dispatch area and were notified when to collect treatment, while others paid for their antiretroviral treatment from the pharmacies around Matatiele: *“You got from day 1 to day 14 to collect your medication. So it doesn’t disturb me in anyway. I can even go after work. Go to work as usual then after work go and collect the medication.”* (participant 1) However, they would bring their doctors

prescriptions and antiretroviral treatment with them at each antenatal visit to verify to the compliance and adherence. One participant saw antiretroviral treatment as a sign of a cure to the disease and was optimistic that antiretroviral treatment would cure her: *“I was happy because I told myself, I’m going to. This thing is going to be cured in my body.”* (participant 2)

#### **4.3.2 Theme 2: A loneliness that hurts**

Participants described their lives after an HIV diagnosis as filled with loneliness. A loneliness that hurts as nobody else could comprehend the thoughts in their mind that constantly haunted them, the feelings of isolation and fear from loved ones. The women, throughout their pregnancy, and for many after the delivery of their babies, experienced blame, fear, cruelties of stigma, stereotyping and judging and ultimately avoided any closeness or romantic relationships.

##### **4.3.2.1 Blame and regret**

For many participants blame and regret went together. Many blamed themselves for the trust that they felt for their partners. They felt the trust they had allowed them to forego an HIV test prior to initiating a sexual relationship with their current or ex-partners: *“I blamed myself because the first boyfriend I had, we came together to the clinic and we tested. We both were negative and then we decided to have a child. I had a miscarriage and the second one, I don’t know, because I was supposed to tell him, ‘no.’”* (participant 7) Accompanied with the blame, participants felt regret towards the current pregnancy: *“I’m not happy at all. To be honest, being pregnant now. I think it is a mistake.”* (participant 6) Regret was followed by thoughts of aborting the pregnancy: *“I even felt I should do an abortion (participant 3).*

Participants also blamed their partners for infecting them: *“You know what I told my boyfriend? I said ‘you know what, I’m HIV positive because of you.”* (participant 5) The blame manifested in feelings of anger toward their partners: *“At first I was angry because I knew myself, so I was angry with my partner.”* (participant 1) Some felt that their partners had consciously intended to infect them with the virus, knowing that they were living with HIV when entering into a relationship with the participant: *“He infected me purposely.”* (participant 3) For some the reality of an HIV positive diagnosis led them to hate their partners: *“I started hating my child’s father.”* (participant 3) However, in other instances the pregnant women received blame from the partner for bringing HIV into the relationship: *“He blames me, but I don’t say anything.”* (participant 8) This was especially relevant in cases where the participant’s partner tested HIV negative and the woman tested HIV positive: *“In a way he says that I am the one. How would I say now. If his results had come back positive now. I’m the one that came with it to him.”* (participant 8) One of the participant’s partner

made it known to her that he did not want to be seen as the one who brought the HIV infection to the relationship: *"I don't want your mother to blame me and say that I'm the one who gave it to you."* (participant 8)

#### **4.3.2.2 Fear**

An HIV diagnosis initially invoked fear in the pregnant women and as they began to work through the realities of being HIV positive, different types of fear became evident to them.

Throughout the pregnancy and breastfeeding many participants were haunted by the fear of dying: *"Definitely death. That I'm going to die. We all know we are going to die, but, eyh, when you are told that you are positive. You think. You, think, Kuthi, eyh, I might die. Maybe I may not even live up to three years."* (participant 7) Others lived with the fear of becoming ill and helpless and being hospitalized. They feared that the disease would progress and eventually lead to people knowing that they were HIV positive without them voluntarily disclosing: *"I know I am going to bleed and I am going to be weak when I am giving birth or it is going to be like someone is going to see that Pat (pseudonym) is HIV positive."* (participant 5)

For others concern was felt for the partner, they feared that their partner would die: *"Then I used to say 'I don't want to be a single parent. So please go to the clinic.'" (participant 2);* or feared for the well-being of the partner: *"We have to stick to the using the condom because I don't want to re-infect him."* (participant 5) In some instances the health of the partner took priority over their own health: *"But then I learnt that I have to be positive for him also because he was in denial...I'm scared to start the treatment whilst you are not on treatment because it obvious we are both infected."* (participant 1)

The fear of how families would react to the news that they were HIV positive also created anxiety for the participants: *"Uhm how is my mother and them going take it? My mother and them obviously know. My twin sister doesn't know. I never told her. How is my sister going take it, especially my twin sister going to take it?"* (participant 8)

The main fear that seemed to be felt consistently by all the participants was the fear of possibly infecting their unborn children. Some because of the stage of their illness: *"What if I infected the child already. Or what if you don't know"* (participant 7); others just because they were HIV positive: *"I'm asking myself 'what is going to happen to my baby. I'm asking myself, eish my God, this baby is going to be HIV positive."* (participant 2)



#### 4.3.2.3 *The cruelties of stigma, stereotyping and judging*

The participants described the worst form of cruelty as being a negative reaction from the partner after disclosing their HIV status: *“He just went and he never spoke to me for quite some time, when I was pregnant, for that matter.”* (participant 8) Some participants experienced rejection from their partners due to their disclosure: *“He didn’t stand by me while I was pregnant.”* (participant 3) While for others there was no obvious rejection but disclosure of the diagnosis altered their relationship in a negative manner: *“After that when I got that results, I told him that I am positive. So he treated me some kind of treatment that eh different like eh, like he didn’t eat the house, didn’t want to talk to me... then I told him that I’m coming to the clinic and he didn’t talk to me. When its end of the month he doesn’t give me the money. So like I told myself that it’s because I went to get tested and I’m positive. That is why he treats me different.”* (participant 9) For others partners resorted to infidelity which the participants were aware of and feared that their partner would infect the women that they were having sexual relationships with, but due to the fear of judgement, they silently pondered on the fact: *“He was seeing someone else, so I thought now it’s the end of part one. Cause I’ve got two things to look at. I’m HIV positive and I’m worried about his girlfriend.”* (participant 3)

Emotional abuse was also experienced by some participants after disclosure, as well as involuntary disclosure by partners of the woman’s HIV status: *“I never planned on telling my mother. He was drunk and he phoned my mother and he told her over the phone when he was drunk [crying]. And I could hear cause he had it on loud speaker”* (participant 8)

Many lived in isolation, preferring to be alone than in crowds: *“So now most of the time I go to work, come back. I keep to myself.”* (participant 7); for fear of accidentally disclosing their HIV status in a crowd: *“Because I’m afraid that I might say it out loud...but I’m trying to avoid bursting out and saying people I’m like this.”* (participant 7). There was an acknowledgement that their peers would not see them as the same after disclosure: *“There’s the fear that they may not see me the way they used to see me. They going to look at me in a different way.”* (participant 7). Others felt that the crowds they used to socialise with before were not ready for an HIV positive disclosure due to remarks they would make of people in similar situations: *“Even at work. Aids, aids she’s sick. She was this big. Look at her now. Aah she must be sick. You know, those kinds of things.”* (participant 7) For others their peers would not even accept HIV as a reality: *“Then some of them tells us, no, man, there’s no such thing. It’s just for whites to scare us and we didn’t get so much pregnancies.”* (participant 3)

Many sought private health care as a means of avoiding stigma: *“I used to go to the private doctor, because I was scared to come to the clinic because there are a lot of peoples who*

*knows me.*" (participant 6) Others were isolated from certain family members because their family members feared that they would possibly infect them: *"They didn't even like us to come close to the children. To come play with the children."* (participant 6)

#### **4.3.2.4 Avoiding closeness or relationships**

The thought of having a romantic relationship with anyone was inconceivable to participants who were not married or in a stable relationship. Many felt that they did not need a man and could survive on their own: *"It's fine you can live with this, even if you don't want a man. It's fine you can let him go."* (participant 5) While others felt that initiating a new relationship was too stressful and that it would require disclosure of their HIV status at some point and thereafter the companion would inevitably abandon the relationship: *"Because when you meet someone and they try and talk to you and you scared because you know at the end of the day you will have to tell them. You will have to tell them."* (participant 7) Some of the participants had the desire to exit their current relationship as it had become unbearable: *"In a way I want to walk away from him and go with my children. Cause I am tired of hearing it."* (participant 8)

### **4.3.3 Theme 3: A hope for a fractured future**

Although participants lived in constant fear of dying, many had a hope for a partial future in that they wanted to give birth to healthy children and had a hope to see some part of their future. Participants did not envision a long life after the diagnosis of HIV. Many were concerned for the well-being and safety of their children and their own health.

#### **4.3.3.1 A concern for the safety of the unborn child**

Many of the participants emphasized that the most important thought or hope they had for the future was that their unborn child would be protected. Many prayed to God that their child would be safe from HIV: *"My faith honestly came into play. I honestly prayed. I honestly told God that I ask you for a lot of things. You must honestly keep my child safe. He can do anything to me. Hurt me in anyway. But my baby didn't do anything wrong. He must honestly keep the baby healthy."* (participant 8) For many the safety of the child was the motivation for taking treatment and for adhering to prevention of mother to child transmission programmes: *"I didn't have a problem taking the treatment, because I knew I'm even protecting the child. They made me take the treatment right for my baby."* (participant 3) Participants described how they researched about breastfeeding as they wanted to ensure their babies would be safe: *"As I was doing research saying that a positive woman can breastfeed."* (participant 5)

Although many women thought about having an abortion after the diagnosis, many changed their feelings toward the pregnancy as they experienced the physiological changes of



pregnancy and then inevitably yearned for a healthy baby: *“I wasn’t happy at first, but now as she starting kicking I feel its relieving my stress. I’m feeling better. I’m starting to accept that he’s there. Yes.”* (participant 6) Other participants endured the burden of HIV, accepted the condition and the fears, and avoided stress and confrontation in an attempt to protect the pregnancy from any danger and threat: *“But then I told myself it will be of no use to play blaming games because even if I tell him that it is because of you, he won’t agree. So it’s better I accept and for the sake of the pregnancy... because at some stage when I came to the clinic my blood pressure was high because we had an argument at home.”* (participant 1)

#### **4.3.3.2 The hope to live and see the future**

Participants described the taking of antiretroviral treatment as giving them hope for a future: *“Firstly I have to accept and knowing that yes HIV positive is not the end of the world. The thing that’s going to help me. I have to take the medicine in the right way.”* (participant 4); *“it means a lot because what I can see, these ARV’s are going to help me. Yes are going to help me a lot.”* (participant 2) There were also participants who felt accepting the disease is a means of moving forward and anticipating a future: *“I told myself, no, this is not the end of the world. I have to live with this. I’m not the first one.”* (participant 5) While others felt that HIV could be compared to other illnesses and then it was easier to hope for a future: *“Like it’s nothing, mmm, its nothing. It’s the same like a headache... I think now I can control it. To be positive I take it as someone who has diabetes or you know those diseases. Yes I’m taking it just like that. Really.”* (participant 2)

Clinic visits became a beacon of hope as they described clinic visits as a way of improving their health and life: *“When it’s a day it’s my date to come to the clinic, I wake up early in the morning about four o’clock. I’m awake. I’m hurry to get my treatment so that I can drink it.”* (participant 2) One participant embraced the HIV disease and believed that since she had overcome cancer, she would overcome HIV as well: *“So then I told myself that HIV and Aids cannot be more than cancer. I survived cancer from 2000, so this is nothing for me because at the end of the day there will, there is medication.”* (participant 1)

#### **4.3.4 Theme 4: The support of a few**

For some participants support was found without difficulty and unconditionally, while others struggled with very little support.

##### **4.3.4.1 Reactions hit raw**

For many of the participants the reactions of the significant people in their lives were painful and unexpected, especially reactions from partners such as refusal to test. Participants felt that they had done something wrong and that they were at fault: *“It was like so hard. I’m the*

*one who was not honest. It was me who was HIV positive. For him it's not like... he doesn't understand how?"* (participant 5) The reaction of family members also left the participants distressed, like the HIV diagnosis should not be discussed, and that they were alone: *"I could hear in her tone that she's depressed. And he just said, 'oh can you hear'. Maybe, maybe he thought she's not taking it serious. 'Can you hear she's taking it serious?' I could hear [crying]... but she never ever asked me"* (participant 8)

Continued negative reactions of partners led to the participant reliving the diagnosis and the trauma thereof: *"Then he says to me... 'and your results? You have Aids you.' He'll say to me. He keeps throwing it in my face."* (participant 8) For others the disbelief of the partner was saddening and the lack of insight into disease left the participant alone: *"I told him. He didn't care much. He just took it as a sickness that somebody can go and apply for a grant and money. In the meantime I was sick. I saw it as a sickness."* (participant 3) Participants described situations where their partners distrusted them bringing home the myth that HIV positive women are promiscuous: *"When he's talking to me, he is talking like as he, as he don't care about me. When I am told him I am going to the clinic to take my pills, he said to me 'you are not going to the clinic, you are going to the jolling'."* (participant 9)

#### **4.3.4.2 Sources of support**

Participants described support from mothers as positive and encouraging: *"And I told my mother, and my mother is encourage me. I am becoming right"* (participant 9); *"No my child it's not a problem, if you like that it doesn't mean that your life is over'. She was very supportive since."* (participant 7) Others found it more supportive to disclose to their sisters and received the needed support. For one participant her sister assisted her in disclosing to her partner: *"I told my sister who is working at Doctor Bob (pseudonym) I told him that sissie I'm coming from clinic it's oh. I'm tested, I'm becoming positive. So I'm scared to tell my husband. He said hay, I'm going to tell him. She called him. Sit down and tell him that your wife come to the clinic and tested and become positive. So I wanted you to treat him as a normal person"* (participant 9) Others found support from their partners: *"He did support me every time. He asking me how I'm feeling."* (participant 5) For few participants support was found in colleagues: *"After having being diagnosed, I then phoned my then manager and tried to talk to him. He then tried to put things to perspective. Then I took things one step at a time."* (participant 1)

Religion was a consistent form of support for the participants when they were alone with their thoughts: *"I was always praying. I wouldn't sleep, but I said 'God you are going to show me the way.'"* (participant 5) Participants also described the support that they found in their

friends: *“Even my friends that I was with was supporting me a lot. Even though I didn’t talk to my family but my friends was supporting me a lot.”* (participant 6)

#### **4.3.4.3 Health care facilities and health care workers**

Participants described health facilities in a contradictory manner. Some felt that health facilities inevitably disclosed their HIV status to the public because of queues and designated areas for collecting antiretroviral treatment: *“Everyone sees it. They know exactly how the clinic works. There’s for critical conditions and there’s for children and whatever. So if I’m going in there what am I going to do there? That is why I avoid going in there”* (participant 8); *“Even when you are queueing there it’s so difficult. Someone might see you and start talking about you kind of stuff... it’s hard because when you sitting there they know kuthi that row they are sick.”* (participant 7)

Participants described health workers as not understanding the pressures of work and their lives outside the clinic: *“They don’t understand that kuthi we work for difficult people”* (participant 7) Others felt that the constant rotation of staff placed them at a disadvantage as they would develop a relationship with one health worker then have to start anew at the next visit when health workers have changed: *“The fact that they keep changing the nurses. You already confided in someone in one person. The next time you come it’s changed again. You have to. Somebody else knows your news again. That was the one thing that used to irritate me.”* (participant 8) They also described the mistrust in the ability of health workers to maintain the desired confidentiality: *“I don’t believe in that confidentiality. I honestly don’t. I would lie.”* (participant 8)

However participants also described positive relationships with health workers. Others valued the reassurance given by healthcare workers. They described talking to health workers as a form of relieving their burden: *“And then I think it’s much nicer by the clinic because I know I’m going to reveal myself and I’m going to tell everything. And then that helps, so much because I know that I’ve off loaded my stuff.”* (participant 5)

Many preferred the specific clinic they were attending in contrast to the clinic that were situated closer to their homes. While others felt that the lay health workers needed more training on counselling skills as they were not happy with the counselling they received: *“Then the pricking time came. She couldn’t look me in the eye to give me the results, because I don’t know what was going through her mind.”* (participant 1) Participants also described greater comfort in the professional nurses in the antenatal facility than the HIV lay counsellors: *“I think I tried to hide my feelings, by, up until I got to the room number nine the ANC room. Then after that, that’s where I was able to talk to the sister, that side. Because I*

*couldn't get what I was expecting from the previous one.*" (participant 1) One participant also described a desire for nurses to address the public in the rural areas, in their homes to improve the adherence and stigma of HIV: *"I think that the clinic the thing that they can do, for those people who are affected, mmm, I think to visit them. I think it can help them a lot. Not to be scared to face anything."* (participant 6)

#### **4.4 SUMMARY**

In this chapter the findings of the research project were presented. Four themes emerged and were discussed. In the chapter that follows the discussion of the findings are presented.

# **CHAPTER 5:**

## **DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS**

### **5.1 INTRODUCTION**

The chapters that preceded the present chapter provided a foundation for the study and a literature review that explored the lived experiences of women who were diagnosed with HIV during the antenatal period of pregnancy. Thereafter the research methodology that was applied in the study was described as well as the findings. Four themes emerged from the research data, which were as follows: Reality hits raw; a hope for a partial tomorrow; a loneliness that hurts; and the support of a few. The chapter that follows provides a discussion of the findings, the conclusions that were drawn from the findings and the recommendations.

### **5.2 DISCUSSION**

In the discussion the results from the study are linked to the research problem and the research objectives of the study. The discussion makes sense of the research results. The researcher states the research objectives again and discusses the results as the objectives were developed initially. It is also in the discussion that the researcher indicates whether what was expected was found or how the results of the present study compare to the existing research presented in the literature review. The limitations of the study are also presented and recommendations are indicated (Brink et al., 2012: 201- 202).

The aim of the study was to explore the lived experiences of women who are diagnosed with HIV during the antenatal period in a rural area. The descriptive phenomenological approach used in the study values the subjective experiences described by the participants. The researcher describes the contextual realities of the participants as they are subjectively experienced by each participant. Therefore, Finlay (2009:12-13) suggests that the researcher has to actively remove her personal beliefs, emotions, experiences and prior knowledge about the phenomenon from her consciousness to ensure the true description of the realities as experienced by the participants. It is assumed that there are commonalities in any lived experience of a phenomenon. In the description of a lived experience, when applying descriptive phenomenology, common features need to be identified by the researcher for the description to be scientific and to allow for generalization of the description (Finlay, 2009:12-13).

## **5.2.1 Objective 1: Understand pregnant women's lived experiences of being diagnosed with HIV during the antenatal period**

### **5.2.1.1 Reality hits raw**

Similar to a study conducted in Malawi by Kasenga et al. (2008:31), women experienced disbelief and shock after being diagnosed as being HIV positive. One participant stated that she believed she could never become HIV positive. Participants in present study did not experience death of a partner to illness or possible HIV infection. All ten participants were in stable, long-term and monogamous relationships. Therefore, an HIV positive result was unexpected. Participants in the study felt that their lifestyle activities, such as having one sexual partner would protect them from becoming HIV positive. Unlike a study in Malawi, where women perceived themselves to be at a high risk for contracting HIV because their partners had sexual relationships with multiple women Kasenga et al. (2008:31). Unlike previous studies conducted on HIV positive pregnant women, participants in the study emphasized that the reality of the HIV positive status was re-lived when the participants were alone. One of the participants reported feeling depressed after being diagnosed with HIV. Similar to the findings of Simpson et al. (2007:40), in a study conducted on women who were mandated by law to undergo HIV counselling and testing in Connecticut. In the Connecticut study, participants had experienced depression and suicidal tendency after being diagnosed as HIV positive.

### **5.2.1.2 A loneliness that hurts**

Following the HIV diagnosis, some stated that all they thought of during the post-test counselling period was death and how a HIV diagnosis was a death sentence. These findings were similar to a study conducted on pregnant women in Eastern Uganda by Rujumba et al. (2012:6-7). The study was also conducted in a rural setting and found that women equated an HIV diagnosis to death, regardless of the initiation of antiretroviral treatment.

Disclosure of their HIV status to a partner, however stressful, was done by the participants in the study, soon after the HIV diagnosis. This is contrary to findings reported by Rujumba et al. (2012:4-6), examining the experiences of women following an antenatal HIV test in Uganda. The study found that disclosing an HIV diagnosis by a pregnant woman to a partner was too difficult to do. Participants of the present study, unlike participants in the study by Rujumba et al. (2012:7) were not financially dependent on their partners and did not fear the loss of economic support, after disclosing their HIV positive status. The participants in the present study did not fear rejection from their partners as much as they feared rejection from family members. In the study there were no differences between married participants and

single participants who were in a stable relationship with their partners. Participants disclosed to their partners regardless of their marital status. Unlike studies in Abidjan, where research found that the women who lived with partners in a house away from extended family members, were more likely to disclose their HIV status to their partners. Whereas, women who shared a home with their partners and extended family members, were less likely to disclose HIV status to partner (Brou et al., 2007:1915-1916). After disclosure of their HIV status, the participants had an expectation that the partner would undergo an HIV test as well. As soon as the partner was diagnosed as HIV positive, concern was transferred to the well-being of the partner, instead of the well-being of the participant. Similarly the study performed by Rujumba et al. (2012:4-6), found that women avoided disclosure because they did not want to stress their partners. In the present study, HIV disclosure was voluntarily conducted during pregnancy, prior to delivery, with the exception of one, single participant that never disclosed to her partner. This is contrary to findings of Brou, et al. (2007:1915-1916), where women disclosed their HIV status to their partners, close to the time of delivering their babies or when they were about to resume sexual relations with their partners. Abuse after the disclosure of HIV positive status was still experienced by participants in the present study. Two participants experienced emotional abuse from their partners, but none of the participants experienced physical abuse, as found by Kalembo et al. (2013:5-6).

### **5.2.1.3 *The hope for a fractured tomorrow***

Abortion was considered by some of the participants in the study, soon after the HIV diagnosis. This is similar to a study conducted in Thailand where women opted for abortions. The Thai women felt that abortion was a means of protecting unborn babies from being infected with HIV virus (Liamputtong et al., 2014:3-5). Additionally, the women felt that they would not live long enough to see their children grow older, as they were HIV positive. The HIV positive women felt they would die soon. Similarly, in the present study participants were concerned that they would not live to see their children grow older. Participants felt they would become ill and then their children would be left alone or orphaned. However, the participants only contemplated fears of death and having to abandon their children. Unlike a study conducted by D'Auria et al. (2006:14), where the participants who had tested HIV positive, began seeking guardians for their children. Study participants believed that death, for them, was imminent. The women in the present study were not advised on abortion as an option. In another study conducted by Messersmith, Semrau, Anh, Trang, Nhu, Hoa, Eifler and Sabin (2012:3) HIV positive pregnant women were encouraged to undergo abortions, by the health workers. Concern for the well-being of the unborn child was proclaimed by the majority of the participants, which is similar to another study by Lamputtong et al. (2014:3-5).



However, in the present study some of the participants felt that they were responsible for putting their children at risk of contracting HIV.

Stigma after an HIV diagnosis was still experienced and feared by participants in the study and still remains the greatest source of anxiety after an HIV diagnosis, as was found in a study conducted in Zimbabwe by Chivonivoni et al. (2008:1621).

Participants in the study felt that they should rather accept the HIV diagnosis as speedily as possible. The acceptance of their HIV diagnosis was done to avoid complications in the pregnancy and as a way of moving forward and embracing the future they had left. This reaction to an HIV diagnosis was not mentioned in previous literature. Participants compared HIV to other chronic illnesses in an attempt to diminish their fear and anxiety after diagnosis and to have a hope for the future; a form of coping not reported in previous literature.

#### **5.2.1.4 Support of a few**

The present study also found that some participants were dissatisfied with the quality of counselling they received by health workers in the facility. As found in a study conducted in Indonesia, by Hardon et al. (2009:840), women also received poor post-test counselling, especially on ways of improving health and antiretroviral treatment. Although in the present study, participants, were provided information on antiretroviral treatment.

Disclosure in the present study, for the majority of the participants led to an improved relationship with their partners. Similar to findings, reported by Kasenga et al. (2008:33), mothers in the present study were also found to be the safest individuals for disclosure and provided the women with needed support after an HIV diagnosis. A minority of the participants avoided disclosing to their mothers, initially, for fear of the mother's reactions and the mother's health. Participants in the present study also found support from colleagues at work, sisters and partners. Similar to a study conducted by Treisman et al. (2014:148-149) some participants found comfort and support in religious practices such as prayer; however they did not interpret an HIV diagnosis as a form of punishment from God. Participants embraced the diagnosis and relied on their spiritual beliefs to provide them with strength to endure.

Having to attend antenatal clinic was not experienced as different due to the HIV diagnosis, by the participants. However, the structure and outlay of the health facility concerned participants, as they feared their HIV status would be disclosed inevitably; for example, a certain section of the clinic provides antiretroviral treatment and when an individual is seen to be sitting in the waiting area of the ART services, the assumption that the individual is HIV positive follows. Although the disclosure was a concern by the participants, none of the



participants actually experienced the inevitable disclosure of the HIV positive status as discussed in the study by the Sanders (2008:50). Two participants stated that they had no confidence in the ability of health workers to maintain confidentiality, although none reported an incident in which confidentiality was breached by the health workers, as described in a study in Northern Ireland by Kelly et al. (2011:135).

## **5.2.2 Objective 2: Describe the thoughts and feelings of pregnant women about having to take antiretroviral treatment**

### **5.2.2.1 Reality hits raw**

In South Africa all women are initiated on option B plus as of November 2014. HIV positive pregnant women are initiated on triple-drug treatment immediately after diagnosis regardless of their health or CD4 result (Department of Health South Africa, 2014:7). None of participants declined antiretroviral treatment, although participants had conflicting emotions regarding antiretroviral treatment. The participants stated that the taking of antiretroviral treatment everyday brought home the reality of being HIV positive, which was not explicitly stated in the literature reviewed.

### **5.2.2.2 A loneliness that hurts**

The present study found that woman structured activities of daily living, such as cooking and serving dinner to family members, to adapt to taking the treatment at the same time daily. Also evident in the study is the impact of antiretroviral treatment on the selection of employment for the pregnant woman. Some participants stated that having to take their treatment at work at a specific time, every day, would raise suspicion by fellow employees. Therefore, the type of employment and the hours of work have to be considered when seeking and accepting employment. None of the reviewed studies highlighted the impact of HIV diagnosis on employment.

### **5.2.2.3 The hope for a fractured tomorrow**

Some saw antiretroviral treatment as a beacon of hope for a prolonged life which is similar to a study done by Ngarina, et al. (2014:5-6). Others saw the initiation of antiretroviral treatment as a sign of doom.

Taking of antiretroviral treatment for some was a means of protecting the unborn child as found by Simpson & Forsyth (2007:39-40). Participants did not state any concern about the effects of ART on the unborn child, as found by Sanders (2008:51); instead the well-being of the child became the motivation for adhering to antiretroviral treatment. Women in the present study described side effects such as dizziness, only. None of the participants described having problems with the taking of antiretroviral treatment for the rest of their lives.

Additionally, participants described the taking of treatment, as a means of improving their health and to protect the baby.

### **5.2.3 Objective 3: Describe the influence of an HIV diagnosis on their experience of being pregnant, their self-care and relationships with significant others**

#### **5.2.3.1 Reality hits raw**

As described in a previous study conducted in Thailand, by Liamputtong and Harivatorn (2014:4-5), an HIV diagnosis influenced the experience of pregnancy in a negative manner, in that the initial focus of the women was on the prevention of HIV transmission throughout pregnancy. Additionally, the present study found that the experience of pregnancy was only felt when women were reassured that babies could be protected from infection through antiretroviral treatment. Sanders (2008:50) found, similarly, that women who were HIV positive, found nothing more reassuring than the assurance that their baby was not infected with HIV.

#### **5.2.3.2 A loneliness that hurts**

For some the pregnancy and period of nine months gestation was too long and they were anxious.

For some participants an HIV diagnosis changed the perception they had about themselves. For others, an HIV diagnosis did not impact on their self-image. Research shows that self-care of HIV pregnant women was motivated by the mothers concern for her unborn child (D'Auria et al., 2006:14-15). However, self-care for some participants became a way of assessing how obvious their HIV status was to others. Some participants were obsessed with their body image, as the state of their body image would imply their HIV status to society and this finding is similar to the findings of Treisman and Shaw (2014:149).

Interacting with peers was reduced by some participants because they feared disclosure. Others preferred spending time with their children as they felt that they had a limited amount of time left after an HIV diagnosis. D'Auria et al. (2006:14-15) had similar findings, accompanied by appreciation for life after an HIV diagnosis.

#### **5.2.3.3 The hope for a fractured tomorrow**

The pregnancy was filled with anticipation of the birth of the child; however the emphasis was on the HIV test result of the baby. For women in the study the meaning of a healthy baby was different as it meant an HIV negative baby only. One participant felt that caring for the unborn child after an HIV diagnosis would be a life changing experience.

The present study found that some participants were concerned with how they would bond with the infant, after delivery, as they decided against breastfeeding. These findings were not found in previous reviewed studies.

#### **5.2.3.4 Support of a few**

Some participants feared the reaction of the significant people in their lives. However, they were faced with acceptance and support from loved ones. For others their HIV diagnosis led to their partner testing HIV positive and the focus shifted to the partners' well-being and supporting of the partner. This contrasts with findings from a study conducted by Simpson & Forsyth (2007:40) which found that spousal support was good initially after disclosure but decreased after a period of time and that abuse and abandonment from partners became evident. Although some of the participants claimed to have developed positive relationships after disclosure of their HIV status, some women still felt anger towards their partners for their HIV-positive diagnosis. Some married participants claimed to accept HIV infection and build on their relationships, whereas one of the participants was abandoned by her husband.

For some participants who were living with partners and not married, relationships were positive and participants anticipated marriages. Yet some were abandoned by partners, while others remained with partners although they wanted to leave the relationship because of the emotional abuse that followed disclosure, which was also described by Simpson and Forsyth (2012:40). Some questioned the origin of the HIV diagnosis as they were only sexually active with one partner; others professed hatred towards their partner as they felt the partner had intentionally infected them. Some did not anticipate future romantic relationships with men as they felt they would inevitably have to disclose their HIV status to new sexual partners and disclosure would lead to rejection.

### **5.3 LIMITATIONS OF THE STUDY**

The study was performed at one clinic in the Alfred Ndzo health district of the Eastern Cape province. Clients from other clinics may have had different experiences. Due to the sensitivity of an HIV diagnosis and the need to protect her current pregnancy and unborn child from any undue stress of the participant about her pregnancy, some participants may have withheld emotional experiences to avoid distressing the unborn child. Additionally, only women who attended antenatal and postnatal visits were recruited and women who may have defaulted were excluded.

### **5.4 CONCLUSIONS**

Descriptive phenomenology is guided by the philosophy that what the participant experiences is perceived to be a reality and the perceived reality influences the actions

taken by the person (Finlay, 2009:9-12) The researcher therefore had to use bracketing as a means of identifying pre-existing opinions and attitudes regarding the phenomena and put them aside to ensure that the true lived experiences of the HIV positive pregnant women were highlighted in the study. In listing her preconceived ideas of reduced discrimination against HIV positive women, knowledge from nurse training and experiences from consulting HIV positive clients, the researcher could describe the true lived experiences of the HIV positive women from their interviews, such as the loneliness and fears that plague HIV positive pregnant women. For the researcher a pre-existing opinion was that HIV in pregnancy was an accepted occurrence and that stigma related to pregnancy had been reduced. However, the researcher's opinions were altered at the initiation of the data collection where women referred by antenatal services still were not always willing to speak out about their HIV diagnosis and experiences. Many of the women still would not utter the word, HIV, and refused to participate in anything related to HIV. The pain and suffering disclosed by the participants also diminished the preconceived ideas the researcher may have had regarding societal awareness of HIV.

The research question that guided the study was: What are the experiences of women who are diagnosed with HIV during the antenatal period and residing in the rural Eastern Cape? From the findings, one can conclude that an HIV diagnosis is an unexpected outcome for any pregnant woman. The HIV diagnosis is followed by emotional turmoil for the woman ranging from shock, disbelief, anger and hatred towards her partner. There is a lingering question about the partner's fidelity after the diagnosis. An HIV diagnosis is still seen by many as a death sentence regardless of the advances in HIV management.

Women diagnosed during pregnancy ultimately were concerned with the well-being of their unborn children and this concern motivated the adherence to antiretroviral treatment. Some experienced a negative self-image such as dislike of who they are, while others saw themselves as the same person they were before a HIV diagnosis.

Disclosure was easier to mothers and sisters, but all married participants as well as the participants that were living with partners disclosed to their partners soon after diagnosis. However one single participant had never disclosed to the partner and the other single participants had disclosed to partners prior to the termination of the relationship. Participants found support from a few close people such as: partners, family and friends. Many of the participants did not disclose to anyone except their partners or spouses, as they feared that people would find out about their status and that they would be subjected to the cruelties of stigma and judgement.

Feelings towards the pregnancy were influenced by the HIV diagnosis and some considered terminating the pregnancy. However, all participants reconsidered and decided to continue with the pregnancy. Many found support and encouragement in religious beliefs.

In chapter 1, the researcher observed that many women do not return for care, following the delivery of their baby or do not return for the HIV results of the baby after testing. The study findings, offer a possible explanation for this in that women may not return for follow-up care due to fear of having infected their unborn children. Women still blame themselves for not protecting themselves and their children from HIV. Participants also described inadequacies in the counselling provided during routine HIV screening. Many of the participants described how health facilities and clinic routines assist in stigmatising HIV. An HIV diagnosis indirectly impacts on the interactions with peers, family and society. Women felt isolated and wanted to keep their HIV diagnosis to themselves for fear of societal reactions towards them and their children. The company of their children was preferred to optimize on the time they had left, while social gatherings were avoided out of fear that they would disclose their HIV status and be rejected by peers. Many found solace and acceptance in the privacy of their own homes and avoided society due to the cruelties of stigma.

## **5.5 RECOMMENDATIONS**

Recommendations that follow are based on the scientific data generated by the study and the literature review conducted during the study. The findings indicate that women experience an increased amount of emotional distress after an HIV diagnosis. An HIV pregnant woman's greatest concern is the well-being of her baby and the reaction and support of significant people in the woman's life impacts on decisions made by the pregnant mother.

### **5.5.1 Skills development of staff on counselling and testing**

In South Africa HIV counselling and testing can be provided by a midwife, a trained HIV counsellor or a nurse (Department of health South Africa, 2013: 15). Participants reported a lack of empathy from the HIV counsellors throughout the HIV counselling and testing process. Some participants felt more at ease after speaking to a professional nurse than an HIV lay counsellor. As HIV counselling and testing is done by lay counsellors, in the facility where the study was conducted, the researcher recommends that the lay counsellors be monitored by professional nurses, to ensure that counselling skills are applied effectively when counselling, to identify gaps and opportunities of skill development. For example, professional nurses should join group sessions at least once a week, to observe how the lay counsellor interacts and educates the pregnant women. Additionally, with the consent of the

clients, the nurse should observe a session of pre-test, testing and post-test counselling of HIV, randomly at least once a week, as these activities occur daily. Lay counsellors should be updated on new guidelines and policies regarding HIV counselling and testing as well as updates that relate to the application of counselling skills. Counsellors are seen as resources of information to the clients and a participant in the present study felt that the counsellors did not display adequate levels of empathy.

### **5.5.2 Implementation of a follow-up counselling schedule**

In the study women did not return to counselling after diagnosis. The women interacted with professional nurses they had felt comfortable with it. Development of a structured schedule or guideline that would stipulate follow-up counselling at specific intervals with specific topics for each session could create an awareness of the need for follow-up counselling. Counsellors may gain additional experience from counselling. Follow-up sessions could address gaps and misunderstandings that could have occurred in initial counselling and testing sessions. Interaction between counsellors and clients will be established and could enhance follow-up counselling and testing of infants, postnatally. Just as routine HIV testing is conducted in antenatal care for women diagnosed as HIV negative and has become a norm, as identified in the present study, follow-up counselling could also become an accepted practice.

HIV testing and counselling should be a continuous process. In a study conducted by Rujumba et al. (2012:7) Women felt that they needed more counselling after HIV testing to address fears relating to living with HIV and coping with an HIV diagnosis. In the present study, participants also experienced ongoing fear and anxiety from an HIV diagnosis. Counselling should therefore not end after the diagnosis of HIV. In the present study, participants described ongoing fears and concerns. Concerns could be addressed in follow-up counselling sessions. Issues such as, negotiating safer sexual practices, breastfeeding infants, disclosing an HIV diagnosis, coping with antiretroviral treatment, should be addressed in follow-up counselling sessions, as these issues were found to cause distress in participants in the study. Although topics are discussed during pre- and post-test counselling, follow-up counselling sessions allow for emphasis on positive living strategies such as: safe sex, nutrition and exercise. Women could be able to draw up an individual plan for: adherence, taking medication, motivation and reminder to take treatment as described in Cleynen and Saar (2013:9-36). Difficulties in maintaining individual plans could be addressed and resolved in sessions, empowering women to manage and control their disease.

### **5.5.3 Training of all midwives on initiation and management of patients on antiretroviral treatment**

Competent midwives trained in management of women on antiretroviral treatment, would ensure that pregnant women or post- delivery women are not referred to ART services as they would receive integrated care at the antenatal clinic. Stinson, Jennings and Myer (2013: 2-3) found that facilities where ART and antenatal service were integrated there was a higher level of ART uptake than in facilities where ART services and antenatal care were separated.

### **5.5.4 Training of midwives on mental health**

Participants in the study described feelings of blame, anger and hopelessness. Training midwives on mental health through non-governmental projects such as Perinatal Mental Health Project (PMHP) could address mental health issues experienced by the HIV positive woman during pregnancy to avoid escalation of psychological problems and eventual depression. It is estimated that 10-15% of women in developing countries suffer from mental health problems, especially those who are ill. It is estimated that one out of every three women in South Africa develops depression or anxiety either during pregnancy or after pregnancy (Flisher, 2015:1).

### **5.5.5 Implementation of integrated chronic disease management system at health facility**

Integrated chronic disease management (ICDM) system is an initiative that allows for all chronic illnesses to be combined and managed together (Sunpath, 2014:13-15). The integration of all chronic conditions into one section of the health facility may improve the adherence of HIV positive women to treatment and PMTCT services after completion of PMTCT services as they have to take antiretroviral treatment for the rest of their lives. . There would also be less concern for disclosure of their HIV status as ART services would not be isolated and would be seen as any other chronic illness. Some of the participants in the study had concerns about the inevitable disclosure of their status by health workers and also the constant rotation of health workers in health facilities. The clinic where the study was performed separated the ART unit from the other clinic services and this could lead to community members' associating the building with HIV treatment and care. Implementation of ICDM would allow HIV clients to be consulted with other chronic illnesses such as diabetes, hypertension and asthma. This would reduce the stigma of an isolated ART service.



### **5.5.6 Implementation of peer support groups**

There should be implementation of peer support groups to enhance the adherence of women to prevention of mother to child transmission. Shroufi et al. (2013:4) found that peer support groups motivated mothers and improved their self-confidence. Peer support mentors in the support groups aided in changing societal norms and behaviours in a means to improve the health of mothers and babies on PMTCT programmes. The use of mobile applications, such as WhatsApp, to connect women who are HIV positive could provide a platform for the women to voice their fears and uncertainties. The women can remain anonymous, which would protect their status and interaction with others will reduce social isolation that was reported by some of the participants in the study. Participants will not need to leave the comfort of their homes or spend less time with their children as the interaction with peers can occur in the privacy of their homes, as the majority of the clients attending the clinic provide cell phone numbers as a means of contact. A study conducted in Thailand, on HIV positive women during pregnancy, found that women who had telephonic support found it helpful and convenient in comparison to traditional support groups (Ross, Sawatphanit, Sawunsujarid, Stidham, Drew & Creswell, 2013:e21-e22).

### **5.5.7 Implementation of peer mentors**

For women who are diagnosed with HIV for the first time in pregnancy, peer mentors could assist in preventing depression and suicidal tendencies. Although there were no suicidal tendencies found in the participants of the study. An HIV diagnosis still raised anxiety and fear of death. Peer mentors were found to reduce levels of depression in women living with HIV in South Africa (Rotheram-Borus, Richter, Van Heerden, Van Rooyen, Tomlinson, Harwood, Comulada & Stein, 2013:4-5). One participant requested the intervention such as support and home visits to people infected with HIV.

### **5.5.8 Future research**

The following research areas could be explored further:

- The emotional wellbeing of women diagnosed with HIV during pregnancy.
- How taking antiretroviral treatment on a daily basis, revives the reality of the individual being HIV positive.
- The lived experience of women who deliver HIV infected infants.
- The lived experiences of the partners of women who were diagnosed as HIV infected during pregnancy.



## **5.6 DISSEMINATION**

The researcher will share findings with the clinic management of the clinic where the research was conducted. Findings will also be presented at institutional Peri-natal meetings at the sub-district level. The researcher further plans to present the findings of the study at a national midwifery conference in April 2016 and submit an article to a peer reviewed journal.

## **5.7 CONCLUSION**

In the chapter the findings of the study were discussed in relation to the study objectives. The research question was answered by the findings. The prevention of vertical transmission of HIV has been implemented, assessed and changes have been recommended since the year 2000. However, the reality of an HIV diagnosis in pregnancy remains the same globally and continues to affect women who are diagnosed with HIV during pregnancy. Women initiate antenatal care, in an attempt to ensure the safety of their lives and the lives of their unborn children. Regardless of HIV, antiretroviral treatment, stigma or their support system, the goal of every woman throughout the process of preventing mother to child transmission is a healthy HIV free baby, as identified by participants in the study. The focus should be on how we cultivate and sustain this goal in every woman who is diagnosed with HIV in pregnancy.

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# APPENDICES

## Appendix 1: Ethical approval from Stellenbosch University



UNIVERSITEIT-STELLENBOSCH-UNIVERSITY  
Jou Sake van die mens • your love for the people

### Approval Notice Response to Modifications- (New Application)

22-Jan-2015  
Fords, Genevieve GM

**Ethics Reference #:** S14/10/245

**Title:** The lived experience of women diagnosed with HIV during the antenatal period in a rural area.

Dear Mrs Genevieve Fords,

The **Response to Modifications - (New Application)** received on **16-Jan-2015**, was reviewed by members of **Health Research Ethics Committee 1** via Expedited review procedures on **16-Jan-2015** and was approved.

Please note the following information about your approved research protocol:

Protocol Approval Period: **22-Jan-2015 -22-Jan-2016**

Please remember to use your **protocol number** (S14/10/245) on any documents or correspondence with the HREC concerning your research protocol.

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

#### **After Ethical Review:**

Please note a template of the progress report is obtainable on [www.sun.ac.za/rds](http://www.sun.ac.za/rds) 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 to the language applicable to the study participants should be submitted.

Federal Wide Assurance Number: 00001372  
Institutional Review Board (IRB) Number: IRB0005239

The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

#### **Provincial and City of Cape Town Approval**

Please note that for research at a primary or secondary healthcare facility permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health ([healthres@pgwc.gov.za](mailto:healthres@pgwc.gov.za) Tel: +27 21 483 9907) and Dr Helene Visser at City Health ([Helene.Visser@capetown.gov.za](mailto:Helene.Visser@capetown.gov.za) Tel: +27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.  
For standard HREC forms and documents please visit: [www.sun.ac.za/rds](http://www.sun.ac.za/rds)

If you have any questions or need further assistance, please contact the HREC office at 219389156.

#### **Included Documents:**

Declaration\_Fords  
MOD\_Cover letter  
Provincial permission  
CV\_Crowley

Application form  
CV\_Van der Merwe  
Synopsis  
Declaration\_Crowley  
MOD\_Consent form  
Protocol  
CV\_Fords  
MOD\_Protocol  
Signatures  
Consent form  
Declaration\_Van der Merwe

Sincerely,

Franklin Weber  
HREC Coordinator  
Health Research Ethics Committee 1

## Investigator Responsibilities

### Protection of Human Research Participants

Some of the responsibilities investigators have when conducting research involving human participants are listed below:

1. Conducting the Research. You are responsible for making sure that the research is conducted according to the HREC approved research protocol. You are also responsible for the actions of all your co-investigators and research staff involved with this research.
2. Participant Enrolment. You may not recruit or enrol participants prior to the HREC approval date or after the expiration date of HREC approval. All recruitment materials for any form of media must be approved by the HREC prior to their use. If you need to recruit more participants than was noted in your HREC approval letter, you must submit an amendment requesting an increase in the number of participants.
3. Informed Consent. You are responsible for obtaining and documenting effective informed consent using **only** the HREC-approved consent documents, and for ensuring that no human participants are involved in research prior to obtaining their informed consent. Please give all participants copies of the signed informed consent documents. Keep the originals in your secured research files for at least fifteen (15) years.
4. Continuing Review. The HREC must review and approve all HREC-approved research protocols at intervals appropriate to the degree of risk but not less than once per year. There is **no grace period**. Prior to the date on which the HREC approval of the research expires, **it is your responsibility to submit the continuing review report in a timely fashion to ensure a lapse in HREC approval does not occur**. If HREC approval of your research lapses, you must stop new participant enrolment, and contact the HREC office immediately.
5. Amendments and Changes. If you wish to amend or change any aspect of your research (such as research design, interventions or procedures, number of participants, participant population, informed consent document, instruments, surveys or recruiting material), you must submit the amendment to the HREC for review using the current Amendment Form. You **may not initiate** any amendments or changes to your research without first obtaining written HREC review and approval. The **only exception** is when it is necessary to eliminate apparent immediate hazards to participants and the HREC should be immediately informed of this necessity.
6. Adverse or Unanticipated Events. Any serious adverse events, participant complaints, and all unanticipated problems that involve risks to participants or others, as well as any research-related injuries, occurring at this institution or at other performance sites must be reported to the HREC within **five (5) days** of discovery of the incident. You must also report any instances of serious or continuing problems, or non-compliance with the HRECs requirements for protecting human research participants. The only exception to this policy is that the death of a research participant must be reported in accordance with the Stellenbosch University Health Research Ethics Committee Standard Operating Procedures [www.sun025.sun.ac.za/portal/page/portal/Health\\_Sciences/English/Centres%20and%20Institutions/Research\\_Development\\_Support/Ethics/Application\\_package](http://www.sun025.sun.ac.za/portal/page/portal/Health_Sciences/English/Centres%20and%20Institutions/Research_Development_Support/Ethics/Application_package) All reportable events should be submitted to the HREC using the Serious Adverse Event Report Form.
7. Research Record Keeping. You must keep the following research-related records, at a minimum, in a secure location for a minimum of fifteen years: the HREC approved research protocol and all amendments; all informed consent documents; recruiting materials; continuing review reports; adverse or unanticipated events; and all correspondence from the HREC
8. Reports to the MCC and Sponsor. When you submit the required annual report to the MCC or you submit required reports to your sponsor, you must provide a copy of that report to the HREC. You may submit the report at the time of continuing HREC review.
9. Provision of Emergency Medical Care. When a physician provides emergency medical care to a participant without prior HREC review and approval, to the extent permitted by law, such activities will not be recognised as research nor will the data obtained by any such activities should it be used in support of research.
10. Final reports. When you have completed (no further participant enrolment, interactions, interventions or data analysis) or stopped work on your research, you must submit a Final Report to the HREC.
11. On-Site Evaluations, MCC Inspections, or Audits. If you are notified that your research will be reviewed or audited by the MCC, the sponsor, any other external agency or any internal group, you must inform the HREC immediately of the impending audit/evaluation.

## Appendix 2: Permission obtained from institutions / department of health

From:

To:0862312317

26/03/2015 11:51

#405 P.001/001



### Eastern Cape Department of Health

Enquiries: Zonwabele Merile

Tel No: 040 608 0830

Date: 25<sup>th</sup> March 2015

Fax No: 043 642 1409

e-mail address: [zonwabele.merile@echealth.gov.za](mailto:zonwabele.merile@echealth.gov.za)

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Dear Mrs G. Fords

**Re: The lived experiences of women diagnosed with HIV in the Antenatal period in a rural area  
(EC 2015RP55 289)**

The Department of Health would like to inform you that your application for conducting a research on the abovementioned topic has been approved based on the following conditions:

1. During your study, you will follow the submitted protocol with ethical approval and can only deviate from it after having a written approval from the Department of Health in writing.
2. You are advised to ensure, observe and respect the rights and culture of your research participants and maintain confidentiality of their identities and shall remove or not collect any information which can be used to link the participants.
3. The Department of Health expects you to provide a progress on your study every 3 months (from date you received this letter) in writing.
4. At the end of your study, you will be expected to send a full written report with your findings and implementable recommendations to the Epidemiological Research & Surveillance Management. You may be invited to the department to come and present your research findings with your implementable recommendations.
5. Your results on the Eastern Cape will not be presented anywhere unless you have shared them with the Department of Health as indicated above.

Your compliance in this regard will be highly appreciated.

SECRETARIAT: EASTERN CAPE HEALTH RESEARCH COMMITTEE



*Ikamva elisaqambileyo!*

**PROVINCE OF THE EASTERN CAPE**



**ISEBE LEZEMPILO**

**DEPARTMENT OF HEALTH  
MATATIELE COMMUNITY CLINIC  
JAGGER STREET  
MATATIELE  
4730**

**Ref No :**

**Tel : 039 373 3513**

**Fax : 039 737 3698**

**Enquiries: L. M. Mosala**

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Dear Mrs G. Fords

Re: The lived experiences of women diagnosed with HIV in Antenatal period in a rural area

Matatiele Community Clinic Management takes pleasure in informing you that your request to conduct a research on the above mentioned topic in the Clinic has been approved subject to you adhering to the conditions set out by the Eastern Cape Department of Health. I refer to their letter to you dated 25<sup>th</sup> March 2015. (EC 215R55 289)

We wish you all the best in you pursuing studies that are evidently essential in improving the lives of women in our rural communities.

Regards

Leonard M. Mosala

Operational Manager

## Appendix 3: Participant information leaflet and declaration of consent by participant and investigator

### PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

**TITLE OF THE RESEARCH PROJECT:** The lived experiences of women diagnosed with HIV in the antenatal period in a rural area.

**REFERENCE NUMBER:**

**PRINCIPAL INVESTIGATOR:** G.M. Fords

**ADDRESS:** 50 Station Road Matatiele 4730

**CONTACT NUMBER:** 0834435283 or 0833411226

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff or doctor any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

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

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

The research study aims to explore the lived experiences of women who are diagnosed with HIV during antenatal period in a rural area. The study will take place at the Matatiele Community Clinic. The study aims to recruit ten to fifteen pregnant women. Participants will be selected from antenatal clinic at Matatiele Community clinic. Participants will be subjected to an in-depth interview by the researcher for 40- 60 minutes. Participants will not be exposed to any medication in the study.

#### **Why have you been invited to participate?**

Participants are selected because they are HIV -positive, pregnant and also living in a rural area. Participants are able to provide real life experiences about the research topic.

#### **What will your responsibilities be?**

Participants are expected to respond honestly to the questions posed in the interview. Participants are required to provide personal details for record keeping and will be audiotaped during the interview session.



**Will you benefit from taking part in this research?**

Participants will be given an opportunity to verbalise experiences of being diagnosed with HIV and being pregnant. There will be no financial benefit to participating in the study. The study will provide the researcher with in- depth knowledge about the experiences of HIV – positive pregnant women and this will assist nurses and other healthcare providers to provide care that will meet the needs of pregnant women in the future.

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

The possible risk to participation in the study is emotional trauma. You will be referred to a counsellor after the interview if you become distressed during the interview if you so wish.

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

Participation is voluntary. Refusal to participate in the research study will have no impact or effect on the care provided at the Matatiele Community clinic.

**Who will have access to your medical records?**

We will not access your medical records. Research records (audio recordings and consent forms) will be accessed by researcher, study supervisor, interpreter and transcriber. All parties will maintain confidentiality by signing confidentiality clauses.

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

No you will not be paid to take part in the study.

**Is there any thing else that you should know or do?**

- You can contact Mrs. G.M. Fords at tel. 0834435283 or 0833411226 if you have any further queries or encounter any problems.
- You can contact the study supervisor, Mrs T Crowley or the Head of the Division of Nursing at 021 9389036.
- You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by your study doctor.
- You will receive a copy of this information and consent form for your own records.

**Declaration by interpreter**

I (*name*) ..... declare that:

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

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

.....  
**Signature of interpreter**

.....  
**Signature of witness**



**Declaration by participant**

By signing below, I ..... agree to take part in a research study entitled (*insert title of study*).

I declare that:

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

Signed at (*place*) ..... on (*date*) ..... 2015.

.....  
**Signature of participant**

.....  
**Signature of witness**

**Declaration by investigator**

I (*name*) ..... declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use a interpreter. (*If a interpreter is used then the interpreter must sign the declaration below.*)

Signed at (*place*) ..... on (*date*) ..... 2015.

.....  
**Signature of investigator**

.....  
**Signature of witness**

## Appendix 4: Interview guide

### Appendix A (Interview Guide)

#### Section A

##### Demographic information

Age .....

Race .....

Gravity, Parity .....

Single/ Married/Partner .....

Residing in the town or the rural areas .....

#### Section B

1. Tell me about your thoughts and feelings when you tested HIV positive.
2. How did you feel about taking the treatment (ARVs)?  
*(probing words: what was positive / negative)*
3. Describe how being diagnosed with HIV and taking ARV's impacted on your life.  
*(probing words: feelings toward unborn child, and motherhood relationships with significant others, caring for yourself, work, travelling expenses, extended family)*
4. What do you think would make the experience easier for women undergoing the same experience ?  
*(probing words: counselling, support, disclosure)*
5. What do you think the clinic can do to make the experience better for women and their children?  
*( probing words: clinic routine, attitudes of staff, support from counsellors, return dates, referral system)*

## Appendix 5: Extract of transcribed interview

### Interview with participant 8

Researcher : Hi, how you doing?

Participant : I'm ok.

Researcher : Just relax. Feel free to answer as it comes. Ok tell me when you tested HIV positive. What went through your mind?

Participant : Funny enough, Jenny, thinking back. When I came the first time. Something at the back of my mind said to me, because I knew the person I was with, and I knew ok, the previous girlfriends. So I kept on insisting to aunty Anne (pseudoname) at the time. So she said to me: "you must come back when you two or three months, so we can sort out your pregnancy, one time". And I said to her: "no man, just do it". And she said to me: "ok ". I went to the room and to find out if I was positive. So I did the test and everything, and I was sitting there, and I was anxious now for the result to come. I couldn't wait for this thing. And when the result came back, I could see the nurse, the way she was looking at me. I already knew in the back of my mind, ok, it is what it is. She said to me: "are you ok? ". I said: "no it's fine, can I have my card? Can I go now to aunty Anne (pseudoname). She said to me: "wait relax". I said to her : "no I'm fine". And I went to aunty Anne. Only when I got to aunty Anne, it hit me, someone that I knew now. Ok you pregnant. One of the days you may die. With who will you leave your children? What can I do with this pregnancy? Do I honestly want this child? A lot of things were honestly going through my mind , Genny. Even when I went home. I was quite depressed. I didn't tell anyone at home. I got home, I didn't even go eat, I just went for a walk the whole afternoon. I went visiting people just to be with anyone. I didn't want to talk. I didn't want to think about it. Just different

companies, people talking their own things. In the night when I'm lying down it used to honestly bug me. It still does at times. Then I honestly think now. Who do I leave my children with? It's quite depressing at, eh, and sad at the same time.

Researcher: You say a lot of things went through your mind, like what?

Participant: If I had to die? Who do I leave my children with? Firstly. My health. Will I end up lying in hospital, being honestly sick? Which I don't want for myself. I want if I die one die I must just die, I musn't be in hospital. Uhm how's my mother and them gonna take it? My mother and them obviously know, Tasha(pseudo name) knows. My twin sister doesn't know. I never told her. How is my sister gonna take it especially my twin sister, going to take it. And my children one day. If somebody has to tell them, my cause of dying or whatever. Peter (pseudo name) is there for me at times. U know when people throw it into your face and he blames me but I don't say anything [crying], because I already came for my test and I know my results. So I can't blame him, so I just keep quiet. So it's basically me alone, I don't talk to anyone about it.

Researcher : So you say it's your problem. You keep it to yourself. It's not easy to talk about.

Participant: Uhm.

Researcher : But you say there's people that know. How did you tell them?

Participant: The first person I honestly told was our pastor's wife. Aunty Pat (pseudo name). I knew I had to tell someone. After I spoke to aunty Anne, she said she would give me a referral letter to the hospital to take the treatment at the hospital. She wanted to transfer me to Santa, but I didn't want to go there because of reasons. I didn't want to go there. So she said: " ok go to the hospital, because there's more


## Appendix 6: Declarations by language and technical editors

Ms Alison Hulley  
91 Van Zyl Street  
Cedarville  
4720  
Cell: 084 587 1570

### TO WHOM IT MAY CONCERN

I am an English Educator at St Monica's Diocesan School in Matatiele. I hereby confirm that I conducted the Language editing for Sister G. M. Fords on her thesis.

Should you have any queries please do not hesitate to contact me.

  
Ms A. Hulley

Lize  
Vorster  
Communication

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To whom it may concern

This letter serves as confirmation that I, Lize Vorster, performed the Technical Formatting of Genevieve Fords' thesis. Technical formatting entails complying with the Stellenbosch University's technical requirements for theses.

Yours sincerely



Lize Vorster  
Language Practitioner

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