

The experiences of women diagnosed with HIV during pregnancy

by

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DECLARATION OF ORIGINALITY



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ABSTRACT

THE EXPERIENCES OF WOMEN DIAGNOSED WITH HIV DURING PREGNANCY

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Pregnancy is period in a woman's life when she has many fears, uncertainties and expectations. To receive an HIV positive diagnosis during this period, has devastating effects on women. The burden of HIV and AIDS does not fall evenly or equally. The overwhelming majority of those currently living with HIV/AIDS are young women in developing countries.

The impact of HIV on women's lives, including their roles as mothers, economic providers and caregivers within households, emphasises the importance of psychosocial counselling and other interventions. Most women only find out about their HIV status while pregnant. Being diagnosed with HIV infection during pregnancy has become one of the greatest complications of pregnancy in South Africa.

WHO (2012:2) predicted that the prevalence of HIV infection among pregnant women is likely to remain high for at least the next two decades, because of the number of people receiving life-long antiretroviral therapy (ART) in South Africa. It is still increasing and was predicted to plateau at around 3 million in 2016. South Africa has implemented a Prevention of Mother-To-Child Treatment programme in which all women who are pregnant are tested for HIV at the ante-natal clinics. If they are diagnosed with HIV, they are immediately enrolled in the PMTCT programme.

Despite the remarkably successful implementation of the PMTCT programme in South Africa, women diagnosed with HIV during pregnancy face many challenges. This research found that the HIV diagnosis has a complex mix of emotional, psychosocial, relationship, economic and even legal issues that arise directly from

the HIV diagnosis. HIV diagnosis provides concrete evidence that being HIV positive and pregnant at the same time is not a good experience; one is often filled with mixed emotions and uncertainties. The findings also indicate sadness and fear among HIV positive pregnant women, sadness in response to their HIV-positive status and the possibility of not seeing their babies grow up. The reality of an HIV diagnosis in pregnancy remains the same globally and continues to affect women who are diagnosed with HIV during pregnancy. A multidisciplinary approach is the most effective way to address the medical, psychological, social, and practical challenges. The biopsychosocial approach was also found applicable in underpinning this study.

The goal of the study was to explore and describe the experiences of pregnant women diagnosed with HIV while pregnant and how diagnosis influences their maternal needs. The guiding research question was: What are the experiences of women diagnosed with HIV during pregnancy?

A qualitative research approach was followed with a phenomenological research design. The population for this study was women who were diagnosed with HIV during their pregnancy in a state health centre, in Gauteng. Non probability purposive sampling was utilized to select a sample of 10 women who were diagnosed with HIV during pregnancy, who attended antenatal sessions in the health centre were selected. Their informed consent was obtained. Semi-structured individual interviews were conducted with participants. Interviews were voice recorded with the permission of the participants, and were transcribed by the researcher. Data gathered were analysed by the researcher and themes and sub-themes were identified. The research findings were presented by providing a biographic profile of the research participants, followed by a thematic analysis of the themes and sub-themes from the transcriptions. Literature control and verbatim quotes from the interviews were used to support the findings. The themes included the following: Theme One - Knowledge of HIV/AIDS; Theme Two - HIV diagnosis; Theme Three - Experiences of living with HIV Status; Theme Four – HIV Treatment; Theme Five - Knowledge of mother-to-child transmission; Theme Six - Relationship and disclosure and recommendations.

The conclusions of the study reflect that although women had general knowledge about HIV, education on HIV and treatment is of paramount importance. Finding out about the HIV diagnosis posed numerous traumatic reactions including: fear of death, deterioration of interpersonal relations, negative emotions, rejection of the results of the test, stress related to disclosure, anxiety, depression, guilt, loss of support, isolation, and difficulties with family dynamics. The study also found that the reality of an HIV diagnosis in pregnancy remains the same globally and continues to affect women who are diagnosed with HIV during pregnancy. The research also found the need for a multidisciplinary team, which includes social workers and psychologists to focus on pregnant women and their psychosocial needs.

The recommendations offered by this study can be used by professionals working in the field of antenatal care to understand the needs and experiences of pregnant women who were diagnosed with HIV during their pregnancy. Social workers can use the recommendations to find ways to make their services known to communities, and improve their intervention and support to these women.

List of key terms:

HIV /AIDS, experiences, women, pregnancy, diagnosis

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ABBREVIATIONS

AIDS	Human immune deficiency syndrome
ANC	Antenatal care
ARV	Antiretroviral
HIV	Human immune virus
MTC	Mother-to-child transmission of HIV
PMTCT	Prevention of mother-to-child transmission
TC	Testing and counselling
UNAIDS	United Nations programme on HIV/AIDS
VCT	Voluntary counselling and testing
WHO	World health organisation
ZDV	Zidovudine

1 CHAPTER ONE: GENERAL INTRODUCTION

1.1 Introduction

In many instances women are still only viewed in their role as a mother, mostly to the detriment of their own realities, needs and rights which include HIV-related issues (UNAIDS, 2011:1). Studies shows that women are more biologically and socio-culturally predisposed to the transmission of HIV through sexual intercourse (UNAIDS, 2008:2).

HIV/AIDS has claimed millions of lives, inflicting pain and grief, causing fear and uncertainty, and threatening the economy of severely affected nations (UNAIDS, 2003:10). Since the start of the global HIV epidemic, in many regions, women have remained at a much higher risk of HIV infection than men. Young women and adolescent girls in particular, account for a disproportionate number of new HIV infections among young people living with HIV.

In 2013, there were an estimated 380,000 new HIV infections among young women aged 15 to 35 every year, accounting for 60% of all new HIV infections among young people. Eighty percent of all young women living with HIV live in sub-Saharan Africa (UNAIDS, 2014:2). Women mostly find out of their HIV status when they are pregnant.

Pregnancy can have emotional, physical and economical complications for the mother and most find ways to adjust to these demands despite potentially negative influences. If pregnancy is accompanied by negative influences such as a diagnosis of HIV infection, it is likely that mothers may experience their pregnancy as a distressing event and struggle to come to terms with or manage the psychological impact (Dipietro, Ghera, Costigan & Hawkins, 2004:60).

WHO (2008:1) states that HIV infection in pregnancy has become the common complication of pregnancy in some developing countries. This has major implications for the management of pregnancy and birth.

The research will focus on exploring the experiences of women diagnosed with HIV during pregnancy – what it was like to be pregnant and being HIV infected. It will also look at the way in which HIV positive pregnant women deal with their daily challenges. It is hoped that the research will reveal what needs to be done if the emotional, social and material needs of HIV positive women are to be met.

1.2 Key concepts for this study

- **Pregnancy**

Ndala-Magoro (2010:10) states that pregnancy is the state where a woman has a child growing in her womb and the duration of pregnancy is approximately 40 weeks, divided into three trimesters, each lasting for approximately 12 weeks. For the purpose of the study pregnancy refers to a woman being pregnant and expecting a baby who is diagnosed with HIV when visiting the antenatal care clinic for the first time, a woman who is expecting a baby.

- **HIV/AIDS**

HIV is a disease that was identified in 1981. Whiteside (2008:1) states that HIV is transferred through bodily fluids such as the semen and blood of the infected person. The disease attacks immune system of the individual infected. Van Dyk (2008) further confirms that it is a virus that affects the immune system. An individual who has contacted HIV might live for a long time without any symptoms of being sickly; however, this varies from one person to person and is dependent on the nutritional, physical and social support offered to the individual. AIDS is the final advanced stage of HIV. For the purpose of this study the terms HIV and AIDS is used, as they are not synonymous.

- **Experiences**

Experience is defined by Collins Student Dictionary (2010:287) as a particular incident or feeling that a person has undergone. Experience “is seen as a product of social conditions or of systems of belief or practical contact with an observation or events.” It is commonly used in a variety of overlapping ways that involves appeals to lived realities and dead certainties (Williams, 1983 in Benett, Grossberg & Meaghan, 2005:123). For the purpose of the study experience will refer to biological, psychological and social aspects encountered by a women diagnosed with HIV when pregnant.

- **Woman**

Woman- According to Collins Student Dictionary (2010:670) a woman is defined as an adult human female. For the purpose of the study a woman is a female human being diagnosed with HIV during her pregnancy.

- **Diagnosis**

Diagnosis - is the identification of the nature of illness or other problems by examination of the symptoms (Squire, 1993:42). In this study diagnosis refers to a HIV diagnosis made during the pregnancy of a woman.

1.3 Theoretical framework

The research adopted the biopsychosocial approach. The model was formulated by George Angel. It was formulated as a dynamic, interactional, but dualistic view of human experience in which there is a mutual influence of the mind and body. Angel believed that to understand and respond adequately to patients' suffering, and to give them a sense of being understood, clinicians must attend simultaneously to the biological, psychological and social dimensions of illness. He offered a holistic alternative to the prevailing biomedical theory that had dominated industrialized societies since the mid-20th century. His new model came to be known as the biopsychosocial model. The model was formulated at a time when science was evolving from an exclusively analytic, reductionist and specialized endeavour to become more contextual and cross-disciplinary (Carrio, Schuman & Epstein, 2004:576).

Ross and Deverell (2004:12) state that biopsychosocial model is the psycho-socio-environment theory which focuses on the promotion and maintenance of health through socio-environmental and behaviour change. The model emphasizes the role of people's behaviour, what they live and their access to health services in determining their health status. For an example, life expectancy and the chances of contracting a disease such as cancer, tuberculosis or HIV and AIDS are influenced by socio-environmental factors. According to this framework, people are not passive victims of disease, but they can participate in their recovery as well as promote their good health.

Gehlert and Browne (2012:20) further indicated that biopsychosocial model addresses the biological, social-environmental, psychological and behavioural aspects of illness. This model expands the traditional medical model of health care that focuses primarily on the biological causes of disease. The theory is used to indicate an approach to health service delivery that addresses the psychological and social aspects of health and treatment that includes behavioural and environmental factors.

Eaton, Fisher and Aar (2003:149) mentioned that a growing body of evidence points to the complexity of sexual behaviour. HIV risk behaviour is influenced by factors at three levels which are: within the person, within the proximal context (interpersonal relationships and physical and organisational environmental) and within the distal context (culture and structural factors). The researcher is of the opinion that biopsychosocial theory will address HIV in pregnant women because HIV is a biological factor as it infects the human body and after the infection a person has to deal with emotions such as anger, denial, frustrations, guilt, sadness which are the psychosocial factors which will then determine a person's behaviour towards the disease.

1.4 Rationale and problem statement

The acquired immune deficiency syndrome (AIDS) is a profound tragedy and has been referred to as the "world's deadliest undeclared war," the Human Immune Virus (HIV) and AIDS continue their devastating spread, affecting the lives of people each day with women, babies, and young people being increasingly targeted (World Health Organization, 2000:4).

Looking at HIV around the Globe, UNAIDS (2014:1) states that worldwide, women constitute more than half of all people living with HIV and women in their reproductive years (ages 15–49), HIV/AIDS is the leading cause of death. Women are at least twice more likely to acquire HIV from men during sexual intercourse than vice versa.

A study in South Africa found that young women who experienced intimate partner violence were 50% more likely to have acquired HIV than women who had not experienced violence. In 2014, 73% of pregnant women living with HIV received

effective antiretroviral medicines to prevent the transmission of HIV to their children (UNAIDS, 2014:1).

UNAIDS (2012:1) states that at the end of 2011, it was estimated that out of 32 million adults worldwide living with HIV and AIDS, half of them were women. The epidemic has had a unique impact on women which has been exacerbated by their role within the society and the biological vulnerability to HIV infection. Globally, HIV and AIDS is the leading cause of death among reproductive age women. The profound effects of HIV and AIDS on individuals and populations pose great challenges to reproductive health care services. With the increased burden of reproductive health conditions associated with HIV/AIDS, reproductive health programmes, and primary care services more generally, have been overwhelmed with the spread and maturation of the epidemic. UNAIDS (2012:1) furthermore states that there were 35.3 million people living with HIV in 2012, up from 29.4 million in 2001, the results of continuing new infections, people living longer with HIV and general population growth and 1.6 million people died of AIDS in 2012, a 30% decrease in 2005. Women represent about half (52%) of all people living with HIV worldwide. HIV is the leading cause of death among women of reproductive age.

WHO (2008:2) states that HIV in pregnancy has become the most prevalent in some developing countries. The lives of HIV positive pregnant women are complex and unique. The disease forces women to incorporate their HIV diagnosis, treatment and psychosocial issues into their day-to-day life responsibilities as well as pregnancy experiences and as such women are often gate-keepers of care in the family.

Lack of social support combined with the burden of HIV and AIDS has turned the care burden for HIV-positive women into a crisis with far-reaching health, economic and social consequences (Edwards, Irving & Hawkins and 2011:1362).

The study is to be undertaken at the Protea Health Centre, which is situated in Soweto, South of Johannesburg. The clinic mainly deals with women and children and as mentioned, the study is to explore the experiences of pregnant women

diagnosed with HIV, thus women who have already given birth and are due for their 3 months follow-up for their infants.

Torku (2012:3) states that pregnant women with HIV/AIDS need psychosocial support to enable them to deal with all matters associated with their diagnosis and pregnancy, this Anti-Retroviral therapy (ART), uncertainty about the safety of their unborn babies, disclosure and identifying coping.

In many countries women and girls are at greater risk of HIV and AIDS due to gender inequality, discrimination and stigma. Women and girls are unable to talk with their sexual partners about abstinence, faithfulness and condom use. Many women face sexual or physical violence or the threats of violence. They are often blamed for causing AIDS and other sexual transmitted infections. Many women and girls lack access to prevention and health care services (National Department of Health, 2013:4).

Ingram and Hutchinson (2000:118) further stated that the cultural norms and values in most societies encourage reproduction and emphasize motherhood as a valued role for women. Different cultures place varying degrees of importance on reproduction. Pregnancy elevates a woman's status in some communities and is often an opportunity for women to feel good about themselves. Babies represent love, acceptance and a legacy for the future, even for a woman without a sense of future for herself.

Pregnancy brings joy and challenges with responsibilities and therefore the impact of being diagnosed with HIV may pose a challenge in pregnant women, having to focus on the HIV status and pregnancy can be stressful and exhausting.

The motivation for this study, therefore, lies in its contribution to increase an understanding of the experiences of pregnant women who were diagnosed with HIV during their antenatal visits and the impact the diagnosis makes in their lives and their experiences of pregnancy as well as health care services. The researcher will also strive to come up with possible recommendations on how social workers can use these experiences to address the problems women face when diagnosed with HIV during pregnancy. In addition, it addresses psychosocial issues which women

come across after the diagnosis, how social workers can address the problems pregnant women face when diagnosed with HIV, and how to cope effectively with whatever problems may arise.

Fouché and De Vos (2012:80) state that a research question is about what exactly we want to determine or achieve by undertaking the research which will flow from the general problem area or topic of interest. Against this background, the following research question was formulated to guide the undertaking: What are the experiences of women who are diagnosed with HIV during pregnancy.

1.5 Goals and objectives

• Goal of the study

The goal of this study is to explore and describe the experiences of women diagnosed with HIV during their pregnancy.

• Objectives of the study

A research objective is a clear, concise, declarative statement, which provides direction to investigate the variables (Babbie, 2007:22).

The objectives are formulated as follows:

- To contextualize HIV during pregnancy.
- To explore and describe the experiences of pregnant women diagnosed with HIV once hearing the diagnosis.
- To explore and describe how living with HIV during pregnancy influences the maternal needs of pregnant women.
- To make recommendations for practice with regards to the needs of pregnant HIV positive women at antenatal clinics.

1.6 Research methodology

The researcher adopted a qualitative research approach for this study, exploring the experiences of pregnant women who were diagnosed with HIV during their pregnancy. This applied study helped the researcher to make recommendations on how social workers can address these issues facing women who are diagnosed with HIV during their pregnancy.

Phenomenology was the research design, using semi-structured interviews and an interview schedule to guide the interview, which was voice recorded.

Smith and Bless (2004:84) define population as the set of objects or people which is the focus of research and about which the researcher wants to determine some common characteristics. The researcher identified Protea Glen Antenatal Clinic in Soweto, as a clinic where the population of women who tested positive during their antenatal visits. Participants were women who gave birth and were due for a 3-month check-up of their infants.

A sample is the subset of the whole population which is actually investigated by the researcher and whose characteristics will be generalized to the entire population (Smith & Bless, 2004:84).

For the purpose of the study non-probability sampling was used and specifically purposive or judgmental sampling, as the researcher wanted to gain a deeper understanding of the problem. Neuman (2006:202) describes purposive sampling as non-random sampling in which the researcher uses a wide range of methods to locate all possible cases of a highly specific and difficult to reach population. Purposive sampling is appropriate to select the unique cases that are especially informative (Newman, 2006:22).

Ten pregnant women were selected for the sample and interviewed until data saturation was reached. The criteria for selection was:

- Women who were diagnosed with HIV during visits to the antenatal clinic at the Protea Glen Antenatal Clinic in Soweto;
- Women aged 16-35 years;
- Women who gave birth 3 months prior to study;
- Women who are due for their 3-month antenatal follow-up visits; and
- Women who are conversant in English.

The researcher provided the nurse in charge or matron at the clinic with an information letter regarding the study. This was shared with patients at the clinic who meet the sampling criteria. Neuman (2006:23) states that voluntary sampling

is the type of non-probability sampling method which is made up of people who self-select into the survey, often those people have a strong interest of the topic. Those interested in partaking were asked to provide their contact details to the nurse. The researcher went to the clinic to get these contact details to contact potential participants. Participation was thus voluntarily. The researcher made an appointment with participants who met the criteria and had provided their contact details.

Lietz, Langer and Furman (2006:444) state that trustworthiness is established when findings as closely as possible reflect the meanings as described by the participants. They further explain that it is not something that just naturally occurs but instead is the result of rigorous scholarship that includes the use of procedures. In order to manage the threats to trustworthiness, the researcher engaged in a variety of strategies to describe research findings in a way that authentically represents the meaning as described by the participants (Glesne, 2006:37). This detail is found in chapter 3.

Strydom in De Vos et al. (2010:57), define ethics as a set of moral principles which is suggested by an individual or group, is subsequently widely accepted and which offers behavioural expectations about the most correct conduct towards experimental subjects and respondents, employers, sponsors, other researchers, assistants and students. The detail of the ethical considerations adhered to are discussed in chapter 3.

1.7 Limitations of study

Despite the fact that this research has yielded remarkable results, there existed some aspects that could have a negative effect on the findings:

Firstly, this research was restricted to women aged 25 to 35 of age, from one race, one province, one community and in one health centre. Therefore, these results are not representative of all South African women and cannot be generalised.

The women interviewed found out about their status when visiting the antenatal clinic after finding out that they are pregnant.

Also, HIV is a very sensitive topic and participants were somehow reluctant to fully engage, and as data were collected face-to-face, participants appeared not to be sincere, that is, all participants insisted they were fine throughout the process.

1.8 Contents of the research report

The study is divided into the following chapters:

- Chapter 1:* This focuses on the introduction of the research by discussing more on HIV and pregnancy. It will also give an overview of the study.
- Chapter 2:* This will focus on literature review, on HIV during pregnancy and all the aspects related to this phenomenon.
- Chapter 3:* The chapter will reflect the research methodology of the study, with phenomenological perspective as the research framework within which this study is conducted. The chapter will also discuss how results were obtained and analysed, sampling, data collection instruments, ethical procedures as well as data analysis.
- Chapter 4:* The chapter presents the findings based on the information gathered from the participants. The key research findings will be discussed in relation to the research question. This will also conclude by summarizing research finding and discussing these findings in relation to research question and literature gathered during the study.

The following chapter will discuss the literature study.

2 CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

The human immune virus has had a worldwide impact and there are virtually no areas that have not reported cases of infection; a number of factors are believed to have influenced the patterns of HIV epidemic globally. The pandemic is affecting the lives of many individuals, families and communities (Kennedy, 2003:15).

Mswela (2009:173) states that the burden of HIV/AIDS does not fall evenly or equally. The overwhelming majority of those currently living with HIV/AIDS are young women in the developing countries. Mswela (2009) further stated that the epidemic continues to have a disproportionate impact on women, with a number of premature deaths in South Africa. Many women find out their status when they are pregnant.

Schroder (2007:1) states that pregnancy can be viewed as a process of growth during which the relationship between the mother and her baby is prepared. For most women, acceptance of pregnancy is associated with the development of an attachment to the foetus. Schroda (2007) went on to say that the pregnancy experience is coloured by a complex of personal needs and expectations, health, status as well as emotional, psychosocial and physical circumstances. In this regard, an HIV positive status may influence an expectant woman's perception of health. There are many issues and considerations that HIV/AIDS presents to pregnant women, their partners, families and health care workers during pregnancy (O'Leary & Jemmott, 2010:173).

The literature will look at the HIV epidemic and women, psychological aspects of HIV in pregnancy, transmission of HIV from mother-to-child, HIV testing and the effects of HIV and AIDS on pregnancy.

2.2 Theoretical framework

2.2.1 Biopsychosocial perspective

In exploring the impact of HIV on women's functioning it is important to have a conceptual framework that serves as a foundation and guide for examining the

research question. For the purpose of this research the biopsychosocial approach will be adopted. The biopsychosocial perspective was formulated by George Engel. The model was formulated as a dynamic, interactional, but dualistic view of human experience in which there is a mutual influence of the mind and body. Engel believed that to understand and respond adequately to patients suffering, and to give them a sense of being understood, clinicians must attend simultaneously to the biological, psychological and social dimensions of illness. He offered a holistic alternative to the prevailing biomedical model that had dominated industrialized societies since the mid-20th century. His new perspective came to be known as the biopsychosocial perspective. The model was formulated at a time when science was evolving from an exclusively analytic, reductionist and specialized endeavour to become more contextual and cross-disciplinary (Carrio, Schuman & Epstein, 2004:576).

Ross and Deverell (2004:12) state that the biopsychosocial perspective is the psycho-socio-environment theory which focuses on the promotion and maintenance of health through socio-environmental and behaviour change. The perspective emphasizes the role of people's behaviour, what they live and their access to health services in determining their health status. For example, life expectancy and the chances of contracting a disease such as cancer, tuberculosis or HIV and AIDS are influenced by socio-environmental factors. According to this framework, people are not passive victims of disease, but they can participate in their recovery as well as promote their good health.

The biopsychosocial model expands the traditional medical model of health care that focuses primarily on the biological causes of disease. The perspective is used to indicate an approach to health service delivery that addresses the psychological and social aspects of health and treatment that include behavioural and environmental factors.

Eaton, Fisher and Aar (2003:149) mentioned that a growing body of evidence points to the complexity of sexual behaviour. HIV risk behaviour is influenced by factors at three levels which are: within the person, within the proximal context (interpersonal relationships and physical and organisational environments) and within the distal context (culture and structural factors). The researcher is of the opinion that the biopsychosocial model addresses HIV in pregnant women because HIV is a

biological factor, as it infects the human body, and after the infection the person has to deal with emotions such as anger, denial, frustrations, guilt, and sadness which are the psychosocial factors which will then determine a person's behaviour towards the disease. Gehlert and Browne (2012:20) further indicated that the biopsychosocial perspective addresses the biological, social-environmental, psychological and behavioural aspects of illness which will be discussed below.

2.2.1.1 Medical/biological factors associated with HIV

Although this study deals with only the experiences of women diagnosed with HIV during pregnancy (which is psychosocial), and not the biological factors, it is important for the reader to have an overview of the biological aspects of HIV. WHO (2008:2) states that The Human Immunodeficiency Virus (HIV) targets the immune system and weakens people's defence systems against infections and some types of cancer. As the virus destroys and impairs the function of immune cells, infected individuals gradually become immune-deficient. Immune function is typically measured by CD4 cell count. Immunodeficiency results in increased susceptibility to a wide range of infections and diseases that people with healthy immune systems can fight off.

The most advanced stage of HIV infection is Acquired Immunodeficiency Syndrome (AIDS), which can take from 2 to 15 years to develop, depending on the individual. UNAIDS (2002:3) states that a person with HIV may present with signs and symptoms of any of the stages of HIV infection. No physical findings are specific to HIV infection; the physical findings are those of the presenting infection or illness. Manifestations include the following:

- Acute seroconversion manifests as a flulike illness, consisting of fever, malaise, and a generalized rash;
- The asymptomatic phase is generally benign;
- Generalized lymphadenopathy is common and may be a presenting symptom;
- AIDS manifests as recurrent, severe, and occasionally life-threatening infections or opportunistic malignancies; and

- HIV infection can cause some sequelae, including AIDS-associated dementia/encephalopathy and HIV wasting syndrome (chronic diarrhoea and weight loss with no identifiable cause).

The history should address risk factors for possible exposure to HIV, including the following:

- Unprotected sexual intercourse, especially receptive anal intercourse;
- A large number of sexual partners;
- Previous or current sexually transmitted diseases (STDs);
- Sharing of intravenous (IV) drug paraphernalia;
- Mucosal contact with infected blood or needle-stick injuries; and
- Maternal HIV infection (for new-borns, infants, and children) UNAIDS (2002:3).

Currently, there is no cure for HIV/AIDS. People living with HIV will need lifelong treatment. The best treatments right now are combinations of prescription drugs. These medications include antiviral treatment, protease inhibitors and other drugs that help people who are living with HIV stay healthy.

2.2.1.2 Psychological factors associated with HIV

A considerable number of empirical findings unequivocally support the notion that psychological and behavioural factors have important implication for disease, illness and health. Chronic stress, depression and social isolation are all understood to impact the vulnerability or protection from certain diseases (Hatala, 2012:53).

According to Kaplan, Sadock and Grebb (2005:1) the psychological dimension of the biopsychosocial model emphasises the effects of psychodynamic factors in order to understand the patient's experiences of his/her condition and the extent to which he/she is motivated towards obtaining help.

A pregnant woman diagnosed with HIV during pregnancy faces many different practical stressors. HIV-positive pregnant women experience a dichotomy in that they are HIV positive, living with a chronic disease which will end in death, yet carry new life within them (Spencer, 2005:230). The psychological or internal challenges a person with HIV/AIDS faces vary from individual to individual, not everyone will

experience all of the emotional responses or stages of the emotional responses described. Mswela (2009:173) states that each HIV/AIDS situation is as unique as the people involved. There are individuals who might face catastrophic changes not only in their personal relationships, but in their physical bodies and in their self-image and self-esteem.

Mundell (2010:5) states HIV presents a multitude of different sources of depression, such as discrimination, stigma, violence, rejection, fear of infecting others, worrying about blood test results, concern about opportunistic infections, and the fear of death. HIV infected persons are normally in fear because they have to adjust to a new lifestyle. It is not easy to accept that one is infected and thus shock and disbelief, leading to denial, is a frequent initial response.

A researcher is of the view that it becomes easier for an HIV pregnant mother to deal with experiences of being infected while pregnant if the health care professionals and families join hands to give them emotional support.

2.2.1.3 Social factors

Körner and Henrike (2007:137) state that culture is one of many factors influencing human behaviour; it is a determinant of socially accepted behaviour, value systems, beliefs, and practical knowledge. Culture is deeply rooted in all aspects of a society, including local perceptions of health and illness and health seeking behaviours. However, culture in the broader sense, includes also traditions and local practices, religious affiliations, gender roles, marriage and kinship patterns, and so forth.

According to UNAIDS (2005:10) the degree which women and men are able to control the various aspects of their sexual lives (their ability to negotiate the timing of sex, conditions under which it takes place, and the use of condoms), plays a critical role in determining their vulnerability to HIV infection. Women determine and reinforce themselves through traditional practices such as wife sharing, widowhood related rituals, and early marriage, female genital mutilation and the condoning of gender based violence.

WHO (2008:3) states that vulnerability to HIV arises from a coming together of biological, structural (social cultural, economic and political) and infrastructural

(programmes and services) factors. Vulnerability refers to the likelihood of being exposed to HIV infection because of a number of factors or determinants in the external environment, some of which are beyond the control of the person or particular social group.

Hatala (2012:58) states that culture impacts not only the social embeddedness of individuals (family relationships, social support, political structures and law) but the psychological and the biological.

The researcher concludes that pregnant women diagnosed with HIV need all the structures to give emotional support and to join hands in fighting the disease. Culture plays an important role in human behaviour.

2.3 HIV/AIDS pandemic amongst the antenatal women in South Africa

UNAIDS (2014:1) states that the number of people who are newly infected with HIV is continuing to decline in most parts of the world. There were 2.1 million (1.9 million – 2.4 million) new infections in 2013, a decline of 38 percent from 2001, when there were 3.4 million (3.3 million - 3.6 million) new infections. Progress in preventing new infections among children has been dramatic. In 2013, 240 000 (210 000-280 000) children were newly infected with HIV, this is 58% lower than in 2002, the year with the highest number, where 580 000 children became newly infected with HIV. Providing access to antiretroviral medicines for pregnant women living with HIV has averted more than 900 000 new HIV infections among children since 2009.

Fatti, Shaik, Eley, Jackson and Grimwood (2014:874) state that globally, South Africa has the highest burden of childhood HIV infection and the greatest number of pregnant women living with HIV, with approximately 280 000 annually needing antiretroviral to prevent mother-to-child transmission of HIV. Maternal and perinatal outcomes in South Africa are poor and HIV-infected women have poorer pregnancy outcomes than HIV-uninfected women.

UNAIDS (2012:4) states that in 2011, provincial HIV prevalence in South Africa was extremely heterogeneous, ranging from 3.8% in the Western Cape province to 15.8% in KwaZulu-Natal province. Mpumalanga and KwaZulu-Natal had the highest number of HIV prevalence. It was estimated that more than 15% of the population

were living with HIV, while in the Province of Gauteng, North West and Free State, more than 10% were estimated to be HIV positive. In the Provinces of Eastern Cape, Limpopo, Northern Cape and Western Cape, less than 10% were living with HIV. Women, especially young women continue to be the worst affected by the HIV epidemic in South Africa.

Statistics SA (2014:2) further asserted that the overall HIV prevalence rate is approximately 10.2% of the total of South African population. The total number of people living with HIV is estimated at approximately 5.51 million in 2014 and for adults aged 15-49, an estimated 16.8% of the population is HIV positive.

National Department of Health (2012:5) states that nationally the HIV prevalence among women at the age of 25-35 years who are pregnant remains the highest with the slight increase from 42.2% in 2011 to 42.8% in 2012. The HIV prevalence trends continue to show that women in the 24-39-year-old group are the most at risk of acquiring HIV infection. In 2012, an estimated 280.000 women were receiving PMTCT.

2.4 HIV and women

Since the start of the global HIV epidemic, in many regions, women have remained at a much higher risk of HIV infection than men. Page, et al. (2006:19), states that during the first few weeks after the body first becomes infected with HIV there is a period of acute infection. The immune system is unprepared for the virus and so it takes some time for the body to recognize the virus as foreign and start preparing to fight the virus. HIV is able to invade host cells without interference by the immune system, and the host cells produce many new viruses. During this period the body has an extremely high viral load and the person is very infectious. The person may show flu-like symptoms that include fever, night-sweats, aching joints and swollen lymph nodes. Lymph nodes are an important part of the immune system because they contain cells that fight infections. It takes a while for the body to start producing antibodies against the H1 virus. But eventually the antibodies are produced and there are enough to bring the viral load down. The period of time between infection and when there are sufficient antibodies against HIV for these to show in an HIV antibody test, is known as the window period. The window period is followed by an

asymptomatic period, which can last from six months to 10 years. During this time, a person feels and looks well, but the virus is being produced in the body on an ongoing basis and is progressively damaging the immune system.

Gradually the immune system becomes weaker and the viral load increases and the person enters the symptomatic stage. During this stage a person may show symptoms such as swollen lymph nodes, weight loss, fever, chronic diarrhoea and yeast infection. The illness finally enters the stage known as AIDS. The symptoms shown are many and they vary from person to person, but they include fatigue, memory and concentration problems (Page et al., 2006:20).

O'Leary and Jemmott (2010:14) state that HIV infection in women may be detected in any of several circumstances. Women may perceive themselves to be at risk and seek testing. Research shows that asymptomatic HIV infection among women is poorly detected in perinatal care clinics.

Evian (2000:195) states that some women learn of their infection by voluntarily requesting an HIV test. However, most HIV positive women find out through routine antenatal screening, while being treated for STIs and after their sexual partner or new-born baby is found to be HIV positive. In these situations, a woman is often without any symptoms of HIV disease. During pregnancy is thus often the first time a woman finds out that she is HIV positive. This means that she now has to cope with the new crisis of an HIV diagnosis and all the potential problems associated with this, as well as her pregnancy or a new-born baby.

2.5 Testing for HIV during pregnancy

Van Dyk and Van Dyk (2003:118) state that testing programmes are regarded as an important strategy in the management of the HIV and AIDS pandemic worldwide. Chersic and Rees (2008:34) state that HIV testing is a cornerstone of HIV prevention and prerequisite for the provision of more nuanced sero-status-specific intervention for HIV prevention.

Kennedy (2004:62) states that the issue of testing pregnant women has been regularly, and often heatedly, debated ever since the disease was discovered. The advantages and disadvantages of testing pregnant women have evoked strong

opinions and feelings on both sides. However, as more information emerged about medical management of the disease and ways to reduce vertical transmission, so policy has altered.

Van Dyk (2008:84) has indicated that HIV testing was previously used mainly to confirm or diagnose suspected HIV infection in patients who experienced certain symptoms or diseases. People are now encouraged to make use of voluntary counselling and testing as it is lately focused on in SA.

The WHO (2008:26) states that wherever possible, voluntary counselling and testing should be available to any pregnant woman who requests it and offered to all in areas of moderate or high prevalence. Routine testing of pregnant women without consent or without access to counselling is, however, an unacceptable practice and the disadvantages may negate any benefit obtained from knowing the HIV status of the women. These include a reluctance to utilise maternity services through fear of discrimination, denial of a positive diagnosis and stigmatisation.

There are, however, a number of potential benefits to women of voluntary HIV testing prior to or during pregnancy. These benefits include:

- Where a woman is found to be HIV infected, this knowledge can facilitate early counselling and treatment.
- A diagnosis in the mother allows appropriate treatment and follow-up of her child.
- Knowledge of her HIV status enables the woman to take decisions on continuation of the pregnancy and on future fertility.
- Testing allows an opportunity to implement strategies to attempt prevention of transmission to the child.
- Knowledge of HIV status enables the woman to take precautions to help prevent transmission to sexual partners.
- Women diagnosed as HIV positive can tell their sexual partners and enable partners to be counselled and tested.
- If the test result is negative, women can be guided in appropriate HIV prevention measures and risk reduction behaviour (WHO, 2008:26). From the given literature it is clear that pregnant women diagnosed with HIV, and the unborn baby, could live healthy lives if ARVs are accessed timeously. South Africa has

a good prevention of mother-to-child transmission programme (PMTCT) because it allows each and every pregnant woman to be tested and initiated on ARVs, which helps to deal with the high mortality rate.

2.6 Effects of HIV on pregnancy and childbirth

Forsyth, Davis, Freudigman, Katz and Zelterman (2002:471) state that previous studies examining the effect of HIV infection on pregnancy and birth rates among HIV-infected women have provided conflicting results. In general, studies performed in the earlier years of the epidemic suggested that HIV infection did not alter the likelihood of women becoming pregnant, nor did it affect the rate of either spontaneous abortions or therapeutic terminations of pregnancy.

Pregnancy is a very important and emotional period for a woman. There are many challenges that HIV and AIDS present to mothers, their partners, their families and to the health care workers during the pregnancy. HIV infection does not usually appear to seriously affect the pregnancy; however, reports from parts of Africa do suggest that HIV infection may cause an increased likelihood of inter-uterine growth retardation, prematurity, stillbirths and congenital infection (Evian, 2000:196).

Bury, Morrison and Mc Lachlan (1992:45) disagree with Evian (2000) by stating that HIV infection does not increase the risk of having a miscarriage, a stillbirth, premature baby or a baby of low birth weight. He further stated that it is not yet known if symptomatic HIV infection is more likely to affect pregnancy. UNAIDS (2008:8) states HIV infection has been reported to have little effect on pregnancy outcome or complications in the developed world. It is often difficult to determine the inadequate antenatal care to adverse outcomes in women. Higher rates of ectopic pregnancy have been reported in HIV-positive women than in uninfected women, which may be related to the effects of other concurrent sexually transmitted disease. Genital tract infections such as Neisseria Gonorrhoea, Chlamydia Trachomatis, Candida Albicans and Trichomonas Vaginalis infection have been reported to be associated with pneumonia. Urinary tract infections and other infections are more common during pregnancy in HIV seropositive women.

2.7 Management of HIV in pregnant woman

The management of HIV infection during pregnancy is complex. Perinatal transmission of HIV can occur in utero, during labour and delivery or postnatal through breastfeeding. Transmission will vary from less than 2% in the developed world (with its access to antiretroviral therapy, caesarean section and formula milk) to more than 30% in the developing world where access to therapy is limited and breastfeeding is prolonged (McIntyre & Gray, 2007:334).

The British HIV Association (2012:97) states that one of the major successes in the management of HIV-positive patients has been the prevention of mother-to-child-transmission of HIV, with the widespread implementation of routine antenatal screening for HIV. The management of HIV in pregnant woman needs a multidisciplinary team which includes an HIV specialist, obstetrician, specialist midwife and paediatrician with the recommendation of peer and voluntary sector support. It may be necessary to involve some of the following: psychologists, social workers, patients, advocates, counsellors, health advisors, and legal advocacy.

Sexual health screening is recommended for pregnant women newly diagnosed with HIV. The diagnosis and treatment of genital infection in any individual has clear benefits in terms of both individual morbidity and infectivity to any sexual partner. In pregnancy, the welfare of the baby is an additional issue. In HIV pregnant women, additional considerations are the potential effects of the presence of a genital infection (British HIV Association, 2012:97).

McIntyre and Gray (2007:951) further stated that antenatal care provides an opportunity to counsel pregnant women about HIV risk and offer HIV testing. The management of a pregnant woman with HIV infection will depend on the resources available and individual needs of a woman. Laboratory investigations should be done in any pregnant HIV infected woman, and these should include liver function tests, complete blood count, plasma HIV viral load, and screening for sexual transmitted infection. Antiretrovirals can be used in pregnancy when indicated as an ongoing treatment for maternal health and can be provided for prevention of mother to child transmission. Management of HIV in pregnant women and

preventing HIV infection in children has become possible in the past decade, with intervention for minimizing mother-to-child transmission of HIV.

2.8 Mother-to-Child transmission of HIV

For many years, little was known about preventing transmission of HIV infection from mother-to-child. Many advances have been made in developing effective and affordable interventions that reduce the likelihood that a woman will pass HIV on to her baby. The two most important interventions are the provision of antiretroviral drugs and the avoidance of breastfeeding which only applies to HIV-positive women. Both therefore require that a woman know whether she is infected by HIV (UNAIDS, 2008:4).

The South African National PMTCT programme adopts an approach to infant feeding that maximizes child survival, not only the avoidance of HIV transmission. All mothers who are known to be HIV infected either on lifelong ART or not, who exclusively breastfed their infant should do so for six months, introduce appropriate complementary food thereafter and continue for the first 12 months of life. Infants born to HIV-positive women should receive skin-to-skin contact with their mothers, regardless of the mother's infant feeding choice. All infants should start feeding and if the mother has not made a decision about breastfeeding yet, she should be counselled on infant feeding (National Department of Health, 2010:30). Furthermore, in 2012 the South African government introduced a new regulation to promote and support breastfeeding as the best infant feeding option, even in HIV positive women, and protect parents and health professionals from aggressive or inappropriate marketing of breast milk substitutes such as formula milk, milk-like drinks and teas specifically marketed as a suitable product for infants and young children. Pregnant women are initiated on ART if not yet on it, the baby receives ART at birth and the mother breastfeeds exclusively for six months. In 2013 the PMTCT guidelines which were last reviewed in 2010, were updated in accordance with international good practice. The updated guidelines advocate for a standardised triple-drug regimen including a fixed-dose combination (FDC), to be administered to women, regardless of CD4 count or clinical stage, during pregnancy and breastfeeding. There is continuation of ART after breastfeeding for women with CD4 counts less than 350 (Manyani & McIntyre, 2013:64).

Routine reporting estimated that at the end of March 2013 (the conclusion of the 2012/3 financial year), there were 2 309 411 patients on ART in the public sector in South Africa, of whom 148 331 (6.4%) were children. It is estimated that 250 000 patients were on ART in the private sector at this time (the last robust estimate was for 2011 when 190 000 patients were estimated to be on ART in the private sector), putting the number of patients in care at the end of March 2013 at between 2.5 and 2.6 million. As a model-based estimate was not available for 2013, it was estimated that the combined (public and private) patients in care nine months previously was 2 322 000, which is consistent with this estimate (SANAC, 2014:8).

UNAIDS (2005:3) states that HIV can be passed on from mother-to-child in the womb, during childbirth or through breastfeeding. McIntyre and Gray (2007:950) further confirm that perinatal transmission of HIV can occur in utero, during labour and delivery, or postnatal through breastfeeding.

PMTCT forms part of a four-pronged strategy to prevent new HIV infections in children and keep mothers alive and families healthy. The four prongs are: halving HIV incidence in women; reducing the unmet need for family planning; providing antiretroviral prophylaxis to prevent HIV transmission during pregnancy, labour and delivery, and breastfeeding; and providing care, treatment and support for mothers and their families. Some countries prefer to use the term 'vertical transmission' to acknowledge the role of the father/male sexual partner in transmitting HIV to the woman and to encourage male involvement in HIV prevention (SANAC, 2014-1).

The WHO (2013:26) came up with the consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection and include important recommendations for simplifying and further scaling up HIV interventions among pregnant and breastfeeding women living with HIV, their HIV-exposed infants and children living with HIV, including the following:

- ART should be offered to all pregnant and breastfeeding women living with HIV, regardless of CD4 count; and
- ART for pregnant and breastfeeding women should be simplified by using a standardized one-pill-daily, fixed-dose combination of three ARV drugs (TDF + 3TC (or FTC) + EFV), which is the same as for first-line general adult treatment.

ARV drug regimens for adults living with HIV and for pregnant and breastfeeding women living with HIV should be harmonized. Previous WHO ARV guidelines recommended different adult ARV regimens for PMTCT of HIV and for treatment. The 2013 consolidated guidelines recommend the same, fixed-dose, single-pill, triple-drug regimen for all adults and adolescents, including for pregnant women, as first-line therapy. This will simplify the forecasting, supply and delivery of ART and enable pregnant women living with HIV to continue on the same drug regimen for their own health.

- ART delivery should be expanded in antenatal, maternal and child health settings. The 2013 consolidated guidelines recommend that, in many settings, including generalized epidemics, lifelong ART (option B+) be initiated and maintained for all pregnant and postpartum women and infants and for all children younger than five years in maternal, new-born and child health care settings, with linkage and referral to ongoing HIV care and ART clinics where appropriate. In some settings, ART is to be provided to all pregnant women living with HIV throughout the duration of the mother-to-child transmission risk period (until the end of breastfeeding) and then should be continued lifelong in women who meet other treatment eligibility criteria (for example, CD4 cell counts <500 cells/mm³, option B). Expansion of nurse-initiated ART, decentralization and integration will facilitate access to effective ARV interventions in maternal, new-born and child health services.
- Existing systems need to be strengthened and new technologies should be incorporated to expand infant testing. In addition to further scale-up of dried blood spot polymerase chain reaction testing in central laboratories, point-of-care virological tests, which are expected to become available in late 2014, should help the early identification of HIV-infected infants and promote more rapid linkage to treatment and care. Final diagnosis of infants in settings for PMTCT of HIV, and broader provision of provider-initiated testing and counselling outside settings for PMTCT of HIV to identify HIV-exposed or -infected infants who are not being followed up for PMTCT of HIV, should also continue to be emphasized.

- Immediate, lifelong ART is recommended for all children living with HIV younger than five years of age, regardless of CD4 count. This should facilitate more rapid access to treatment for children diagnosed with HIV infection.

WHO (2008:17) recommends the ideal intervention for the reduction of mother-to-child transmission would be one that is widely applicable in resource-poor settings. Vaginal disinfection and vitamin A administration would not require identification of HIV positive women, but would be applicable to all pregnant women. The minimum requirements for the implementation of other interventions would include:

- Access to and use of appropriate antenatal, intra-partum and postpartum care with adequately trained health workers;
- Adequate pre- and post-test counselling services;
- Ability to afford the cost of reliable HIV testing;
- Appropriate laboratory facilities to monitor blood parameters during therapy;
- Delivery units with access to disinfectants, gloves and clean needles;
- Acceptance and uptake of the intervention by HIV-infected women;
- A regimen that is logistically possible to implement: in terms of dosing times and routes, drug storage and distribution; and
- A regimen which is affordable for the health service.

WHO (2008:18) further states South Africa has a good HIV monitoring system. HIV pregnant women are giving birth to HIV negative children and as a result, HIV testing in all pregnant women visiting clinics for ante-natal monitoring is essential. Counsellors have been trained by the South African Government so that they are able to counsel pregnant women when they start attending the antenatal classes. Free ARVs also plays a major role in strengthening life of both the mother and the child.

Manyani and McIntyre (2013:65) state that in the past few years, South Africa (SA) has made significant progress in the provision of prevention of mother-to-child transmission (PMTCT) of HIV services, both in the delivery of more efficacious PMTCT interventions and also an increase in the proportion of women receiving the interventions. The health care system and patient factors are important in the scale-up and success of HIV programmes (including PMTCT).

2.9 Receiving an HIV diagnosis

Sanders (2008:47) states that when a woman seeks health care for the confirmation of pregnancy, she is faced with a multitude of decisions, including those related to testing. The Centre for Disease Control in the United Kingdom (2006:6) recommends routine HIV screening of all women during pregnancy. Health care providers are expected to routinely encourage all women to be tested because of the risk of HIV transmission to a foetus is significantly reduced in HIV-infected women if they begin ART during pregnancy.

Beacon-Smith (2006:1) states that HIV/AIDS is a complex and unpredictable disease, impacting people's lives in a variety of ways. Some individuals living with the disease experience an immediate deterioration of their physical and mental health, while others do not experience the negative consequences of the disease for many years. Beacon-Smith further stated that being diagnosed with HIV illness is considered by many to be a psychologically traumatizing experience. Being diagnosed with HIV is irreversible and requires a lifelong struggle both physically and emotionally.

Valdiserri, Holtgarve and West (1999:2317) state that from the primary care perspective, the early diagnosis of HIV infection has the potential to facilitate entry into a stable care system, optimize clinical outcomes and health care system planning capabilities. Encouraging the diagnosis and treatment of persons infected with HIV has the substantial possibility of reducing further the spread of the virus.

Sanders (2008:47) states that receiving HIV diagnosis for pregnant women can be stressful but knowledge regarding HIV status benefits both the pregnant woman and her developing foetus. Women who received HIV diagnosis face many challenges as they adjust to life with this chronic illness. Problems such as substance abuse, stigma and depression are common (Bova, Burwick & Quinonnes, 2008:58).

Van Dyk (2005) further confirms that most individuals experience a deep sense of loss ranging from perceived loss of control and independence, to awareness of the possibility of an early demise and the loss of life itself. These feelings coupled with a chronic sense of uncertainty can precipitate suicidal ideation, anxiety and other somatic and psychological symptoms of distress.

Kwalombota (2002:431) states that the diagnosis of HIV in pregnant women may leave a woman particularly vulnerable to suicidal thoughts and feelings of depression, denial and condemnation. Many women only discover their HIV-positive status once they are pregnant and making the use of antenatal services. Receiving an HIV-positive diagnosis during pregnancy is particularly traumatic, as HIV-positive diagnosis is further complicated by the foetus and health of the pregnant mother. Being diagnosed with HIV during pregnancy is distressing for the newly diagnosed woman, as she is concerned about her own and her child's wellbeing. In particular, she may fear transmitting the virus to her infant. To this end, pregnant women living with HIV may experience a range of distressing emotions such as guilt, anxiety and remorse at the thought of transmitting the virus into their children (Kotze, 2011:18).

2.10 Coping with an HIV diagnosis

Lazarus and Falkman (1984:141) state that the term 'coping' refers to constantly changing cognitive and behavioural efforts to manage specific and external or internal demands that are appraised as taxing or exceeding the resources of the person. Numerous studies in the social sciences have explored HIV coping.

Pittiglo and Hough (2009:184) state that HIV was once thought to be a disease that was inevitably fatal, however with early treatment and effective anti-retroviral therapy, individuals are living longer with the disease. This means that HIV-infected individuals have to deal with the associated stressors of living with a chronic illness, including the uncertainty of disease progression and social stigma associated with the disease.

Sandelowski, Lambe and Barroso (2008:122) state that the infected women must learn to live with the unique challenges and stressors of HIV including disclosure, stigma, HIV testing, caretaker issues, poverty and gender roles while raising the children. When experiencing a chronic and stressful illness such as HIV, coping behaviour becomes an important aspect of illness management.

Lazarus and Folkman (1984:181) identified two coping strategies as problem-focused (active, confronting) and emotional (passive-avoidant).

Kotzé, Visser, Makin, Sikkema and Forsyth (2014:188) state that active coping refers to behavioural and cognitive attempts that are aimed at actively engaging with a stressful situation to change it. It includes strategies such as problem-solving, cognitive restructuring and seeking information. Previous research has found that active coping is associated with positive psychosocial and health outcomes in people living with HIV, including less HIV- and AIDS-related symptoms, enhanced quality of life, high positive affect, high self-esteem, less symptoms of psychological distress, lower frequency of substance use and adherence to antiretroviral treatment (ART).

Lazarus and Folkman (1984:183) state that most studies in coping with illness argue that problem-focused coping strategies like assertiveness, adopting a fighting spirit, and planning a course of action result in a more beneficial or adaptive outcome than emotional coping strategies aimed at reducing distress.

Avoidant or Passive coping refers to behavioural and cognitive attempts to avoid directly addressing a stressful situation, including disengagement, denial and distraction. Avoidant coping has been associated with negative psychosocial and health outcomes, including increase in HIV- and AIDS-related symptoms, decreased physical functioning, poor quality of life, low self-esteem, more symptoms of psychological distress, more frequent substance use and non-adherence to ART (Kotze et al., 2014:188).

Passive coping strategies like denial, avoidance, self-blame, fatalism, withdrawal, mental disengagement, and helplessness have been associated with increased psychological distress and poor adaptation (Fleishman & Fogel, 1994:161).

Emotional support plays a role in coping with HIV diagnosis. Phillips (2007:668) states that having people in one's life during a stressful episode from whom one receives emotional, informational, and/or tangible support is a major factor mediating such outcomes. It is postulated that individuals who have access to resources such as social support, are more likely to find it effective in managing stressful situations and less likely to experience poor outcomes. Extensive evidence suggests that social support contributes to positive adaptation outcomes, even in

the most difficult of situations, and its absence contributes to poor outcomes (Hudson, Lee & Miramontes, 2001:68).

Cohen and Willis (1985:55) discussed four different kinds of support resources, although not independent of each other.

- *Esteem or Emotional Support:* The support shows the individual they are valued and accepted unconditionally, despite any faults. It may counterbalance any threats to the individual's self-esteem, which may have occurred as a response to the stressor.
- *Informational Support:* This kind of support assists the individual in gaining a better understanding and insight into a specific problem, and can also assist the individual in their coping process. This would counter the individual's perception of a lack of control.
- *Social Companionship:* The physical act of spending time with others, thereby reducing stress through either distraction or through the facilitation of positive affective moods.
- *Instrumental Support:* This kind of support involves the provision of financial aid, material resources or other services. This type of support is also often termed material support.

2.11 The pattern of HIV and Women in South Africa

Mswela (2009:174) states that the HIV/AIDS epidemic in South Africa is mainly regarded as a heterosexual type of epidemic. An additional distinctive feature is the onset of the infection of the women. Mswela (2009) further explains that there are a number of pre-disposing factors that put women at risk of becoming infected with HIV. These include a range of biological, psychosocial and cultural factors, which shows how complex the women's increased exposure to HIV is.

2.11.1 Biological factors

Ndala-Magoro (2010:14) states that the leading cause of death in women between the ages of 15-44 worldwide is HIV and AIDS. Women are biologically more vulnerable than men to all sexually transmitted diseases. Consequently, they are twice as likely to acquire HIV from an infected partner during unprotected

heterosexual sex. Ramjee and Daniels (2013:2) confirm that women are at a greater physiological risk of contracting HIV than men. This is in part because women have a greater mucosal surface area exposed to pathogens and infectious fluid for longer periods during sexual intercourse and are likely to face increased tissue injury.

UNAIDS (2008:16) states that women's high vulnerability is due to the following physiological reasons:

- The larger surface area of mucus membrane exposed during sexual contact with a man;
- The lining of the vagina which is a larger area, hence there is exposure to larger quantity of infected semen;
- Semen contains higher levels of HIV than vaginal fluid does;
- More semen is exchanged during sexual contacts than vaginal fluid;
- Having untreated sexual infections makes it more likely for women to contract HIV; and
- High levels of vaginal fluid increases the presence of vaginal yeast infection and sexual transmitted infection.

2.11.2 Psychosocial Factors

HIV diagnosis during pregnancy may be a profoundly shocking and life-changing experience for the newly diagnosed HIV-positive women. There may be a complex mix of emotional, psychosocial, relationship, economic and even legal issues that arise directly out of the HIV diagnosis. The newly diagnosed woman also has a relatively brief time in which she needs to develop trust in her medical carers and attain sufficient medical knowledge of her situation to be able to make informed decisions that will affect the long-term health of herself, her foetus and her male partner (British HIV Association, 2012:134).

Hackl, Somlai, Kelly and Kalichman (2007:53) state that most women find out about their HIV status when they are pregnant and most of these women will die at an early age, leaving their children motherless. During their HIV illness, women confront the challenge of being a patient and a family caregiver. According to Faithfull (1997:144), mothers infected with HIV face many challenges as they

struggle to raise children in the face of a life-threatening disease. Since the diagnosis of HIV or clinical AIDS carries both the stigma of being contagious, women face many issues as will be discussed subsequently.

2.11.3 Emotional distress

Siegel and Lekas (2002:70) states that from the onset of the AIDS epidemic, there has been considerable documentation of the adverse psychological consequences of knowing one is infected. Infected individuals become particularly emotionally vulnerable shortly after the diagnosis when HIV-related symptoms first appeared, in the last stage of the disease, and after suffering multiple AIDS-related losses in the social network.

2.11.4 Anxiety and depression

Blaney, Fernandez, Ethier, Wilson, Walter and Koenig (2004:405) state that perinatal depression is a major risk for adverse pregnancy outcome, including impaired neuro-behavioural functioning, low birth weight and post-partum depression that may lead to long-term maladjustment as well as disruption of the mother-child relationship.

The anxiety and depression felt by many women living with HIV and AIDS can be severe and long-lasting and will have implications on the way they behave. They have a number of fears related to their illness including dying a slow, painful death isolated from the people they know and care about. Anxiety and depression are exacerbated by poor self-image, lack of fiscal resources and lack of opportunities to make choices. Sadock and Sadock (2003:67) further confirm that anxiety and stress for those with HIV and AIDS is unavoidable. The stresses facing anyone in a life threatening situation are numerous and often very complex. They may not arise simply from the way persons feel about their health – but other people will sometimes contribute to or generate stress by the nature of their own reaction.

2.11.5 Discrimination and stigma

UNAIDS (2005:2) states that women have suffered disproportionately from discrimination against people living with HIV/AIDS. The pandemic has led to increased gender-based violence as HIV positive women are assaulted, prevented

from having children, dismissed from employment, disowned, shunned by their families and communities and sometimes even killed. Women are more likely than men to be held responsible for spreading the disease and to be labelled as promiscuous. Fearing violence, stigma and ostracism, many women avoid taking a HIV test, thereby denying themselves crucial information about their health and excluding themselves from programmes to prevent HIV transmission to their newborns.

WHO (2004:16) further indicated that women suffer greater stigma than men, with women often being blamed for bringing AIDS into the family. As a result, women are reluctant to inform their partners and families about their positive HIV status because they fear abandonment. The expression of discrimination includes:

- HIV testing of people without their knowledge or consent.
- Gossip and negative remarks being made about people with HIV and AIDS, including the idea that they became HIV-positive because of immoral behaviour.
- Dismissal from jobs and stigmatization of children at schools.
- Avoidance and isolation by family, friends and health care workers. HIV still carries a stigma in South Africa, where people still do not understand that being infected is not the end of the world; they take this disease as if it is for those who are unfaithful to their partners and as a killer disease. Many people in our country are still lacking knowledge on the disease. Stigma causes people to continue spreading the disease because people do not disclose their HIV status with the fear of being stigmatized. As a result, they engage in unprotected sex and infect others. People with HIV are also dying because of fear of disclosing their status; they prefer to die with a secret.

2.11.6 Profound Grief

Sadock and Sadock (2003:67) state that feelings of profound grief are experienced by everyone affected by HIV infection. This is brought about by loss of health, body image, sexuality and reproductive potential. Most people with HIV infection are concerned about the question of procreation, an issue which often concerns those who face terminal illness. Many of the women affected by HIV will already be in a vulnerable position. Women are still subordinate to their male partners in many

countries, and hold many and complex roles. Women are the main care-providers in the community, as mothers, daughters, partners and siblings. They are affected as well as infected.

Kennedy (2004:94) further indicated that care for an HIV infected woman and her family, whether before or after conception, is diverse and multifaceted. Areas it needs to address must include:

- Her physical care, both generally and in relation to her HIV infection.
- Her pregnancy care from conception throughout the pregnancy and birth to postnatal period.
- Her emotional and psychological wellbeing, including her response to diagnosis, and support to develop coping strategies for dealing with the implications of pregnancy and infection.
- The social and cultural aspects of her life and how HIV and pregnancy may impact on them.
- The clear and informed channels of communication between the woman and those directly involved in her care. Women who are diagnosed with HIV during pregnancy must continue to get emotional support from the counsellors so that they may find courage to be able to disclose their status to their loved ones. Women hold many complex roles within the family as said by Sadock and Sadock (2003:7) but they still need to be cared for and emotionally supported. Continuous education for both partners and children is needed so that they may know how to support women. The importance of self-care should be emphasized more as they tend to spend more of their time taking care of families than themselves.

2.12 Cultural factors

Mswela (2009:176) states that traditional practices fulfil a purpose for those who practice them. Although traditional practices may have a positive impact on reproductive health, they may also be harmful.

Ndala-Magoro (2010:23) further stated that men and women are affected by gender norms that define gender roles. Gender roles describe what it means to be a man or a woman in a specific culture. In traditional African societies which are mostly

paternalist, men are in a powerful position. Women often feel disempowered when it comes to owning their sexuality, they are often not able to insist on condom use or on when and how they want sex. In addition, the mere fact that a condom, especially the one for males, is still the only physical barrier used for prevention of HIV which leaves women without choice but to depend on men for their own protection (Department of Health, 2013:2).

2.13 Summary

In this chapter, the theoretical background and literature pertaining experiences of HIV and pregnant women were discussed. It gave a clear background that women who were diagnosed with HIV during pregnancy face many challenges. Previous researches pointed out that a pregnant woman diagnosed with HIV is not only worried about her wellbeing but also the wellbeing of her unborn child.

From the literature one would conclude that HIV diagnosis is not only a medical disease, it also affects a person as a whole and other spheres of the society. This has motivated the researcher to see the need for qualitative study to explore the experiences of women diagnosed with HIV during pregnancy in order to gain a deeper understanding and to recommend the best practices with regards to the needs of HIV positive women.

The next chapter will focus on the research methodology and findings.

3 CHAPTER 3: RESEARCH METHODOLOGY AND EMPIRICAL FINDINGS OF STUDY

3.1 Introduction

This chapter outlines the research methodology of the study and includes a detailed description of the data collection methods. In this specific study, qualitative research was used. In order to provide a clear idea of how research results were obtained, sampling methods and data analysis will also be discussed. The chapter will also look into the ethical considerations taken into consideration when collecting data. The goal of the study is to explore and describe the experiences of women diagnosed with HIV during their pregnancy.

The objectives are formulated as follows:

- To contextualize HIV during pregnancy.
- To explore and describe the experiences of pregnant women diagnosed with HIV once hearing the diagnosis.
- To explore and describe how living with HIV during pregnancy influences the maternal needs of pregnant women.
- To make recommendations for practice with regards to the needs of pregnant HIV positive women at antenatal clinics.

The research findings are later presented and discussed. The empirical study was guided by the following question: **What are the experiences of women who are diagnosed with HIV during pregnancy?**

The research methodology is organised under the following headings, research approach and design, type of research, data collection and analysis methods, pilot study and ethical considerations.

3.2 Research Approach

The study is qualitative in nature as it seeks to understand and explore the experiences of pregnant women who were diagnosed with HIV during their antenatal visits, the impact the HIV diagnosis made on their lives and come up with possible recommendations on how social workers can use these experiences to

address the problems women face when diagnosed. This process involves emerging questions and procedures, data typically collected in participants setting; data analysis will be inductively built from general themes (Creswell, 2009:4).

Claive and Wigson (2004:41) further confirm that the purpose of qualitative exploratory research is to gain a broad understanding of a situation, phenomena, community or person. The qualitative approach will answer questions about the complex nature of the phenomena, with the purpose of describing and understanding the phenomena from participants' points of view. Qualitative work is exploratory in nature and they may use observation to build theory from the ground (Fouché & Delport, 2011:64). Babbie (2007:321) adds that qualitative research uses detailed descriptions of the research participants themselves as a means of examining specific issues and problems under the study.

Creswell (1994) proposed five underlying assumptions of qualitative research:

- The focus is on process and not on product or outcome.
- The interest is placed on the meaning, i.e. how people make sense of their life's experiences and how they structure their worlds.
- The mode of inquiry may involve fieldwork, depending on the nature of the study, whereby the researcher physically goes to people's settings, sites or institutions to observe and record the behaviour.
- The process, meaning and understanding are gained through words and pictures.

A researcher builds abstracts, concepts, hypothesis and theories from details, thus making the inquiry inductive.

3.3 Type of research

Sharon (2006:03) states that applied research is conducted to improve the quality of practice of a particular discipline. The study adopted applied research as it was designed to offer practical solutions to a concrete problem or address the immediate and specific needs, with the view in mind that the government and other policy makers will take into consideration the experiences of pregnant women who were diagnosed with HIV (Neuman, 2006:25). This is in line with what Higson and Smith

(2000:38) has said, i.e. in applied research, the researcher's primary motivation is to assist in solving a particular problem facing a particular community. It may assist the community to overcome the problem and the recommendations of interventions which will help solve it.

3.4 Research design

Fouché, Delpont and De Vos (2011:142) cited De Jong who defines the research design as a plan outlining how observations will be made and how the researcher will carry out the study. For the purpose of the study the researcher adopted the phenomenological design as she wanted to explore the experiences of women diagnosed with HIV during their pregnancy. The research described a participants' conscious experience of everyday life and social action.

Cresswell (2009:13) states that phenomenological research is a strategy of inquiry in which the researcher identifies the essence of human experience about a phenomenon as described by participants, understanding the lived experiences marks phenomenology as a philosophy as well as a method. Procedures involve studying a small number of subjects through extensive and prolonged engagement to develop patterns and relationships of meaning. Phenomenology aims to explain how the life world of a subject is developed and experienced by them.

3.5 Research Methods

The research methods section will discuss methods used to select population and sample. It also discusses data collection methods and analysis as well as data verification processes

3.5.1 Population, sample and sampling method

Smith and Bless (2004:84) define population as the set of objects or people which is the focus of research and about which the researcher wants to determine some common characteristics. This study is based on data collected from Protea Glen Antenatal Clinic in Soweto, as a clinic where the population of women were tested positive during their antenatal visits. Participants were women who gave birth and were due for a 3-month check-up of their infants.

A sample is the subset of the whole population which is actually investigated by the researcher and whose characteristics will be generalized to the entire population (Smith & Bless, 2004:84). Non-probability sampling was used and specifically purposive or judgmental sampling, as the aim was to gain a deeper understanding of the problem. Neuman (2006:202) describes purposive sampling as non-random sampling in which the researcher uses a wide range of methods to locate all possible cases of a highly specific and difficult to reach population. Purposive sampling is appropriate to select the unique cases that are especially informative (Neuman, 2006:22).

Ten pregnant women were selected for the sample and interviewed. The criteria for selection was:

- Women who were diagnosed with HIV during visits to the antenatal clinic at the Protea Glen Antenatal Clinic in Soweto,
- Women aged 25-35 years;
- Women who gave birth 3 months prior to the study;
- Women who are due for their 3-month antenatal follow-up visits; and
- Women who are conversant in English.

The researcher provided the nurse in charge or matron at the clinic with an information letter regarding the study. This was shared with patients at the clinic who meet the sampling criteria. Neuman (2006:23) states that voluntary sampling is the type of non-probability sampling method which is made up of people who self-select into the survey; often those people have a strong interest in the topic. Those interested in partaking were asked to provide their contact details to the nurse. The researcher went to the clinic to get the contact details of these potential participants. Participation was voluntarily. The researcher contacted participants who had provided their contact details and met with them. The first 10 who met the criteria were selected.

3.5.2 Data collection methods

An interview is the process whereby the investigator or an assistant reads the questions directly to the respondents and records their answers (Dejong, Sullian & Monnette, 1998:182).

Greeff (2010:295) outlines some of the characteristics of qualitative data collection methods as follows:

- They tend to be open-ended and have less structured protocols.
- They rely more heavily on interactive interviews.
- Generally, their findings are not generalised to any specific population; rather each case study produces a single piece of evidence that can be used to seek general patterns among different studies of the same issue.

A semi-structured interview was adopted as it involves direct personal contact with the participant who is requested to answer questions relating to the research problem (Smith & Bless, 2000:104). A semi-structured interview allows for the discovery of new aspects of the problem by exploring in detail the explanation supplied by participants. The interviews were conducted at the Protea Glen Antenatal Clinic, Soweto where each interview was voice recorded, with the consent of the participants. An interview schedule was used to guide the interviews. According to Babbie (2007:345) this is a set of prepared questions designed to be asked exactly as worded. A private office was used to conduct the interviews to ensure confidentiality.

Greeff (2002:302) asserts that semi-structured interviews can be used to gain a detailed picture of a participant's beliefs, or perceptions, or accounts of, a particular topic while giving the researcher and the participant much flexibility.

3.5.3 Data Analysis

Schurink et al. (2011:397), state that data analysis is the process of bringing order, structure and meaning to the mass collected data. Qualitative data analysis is a search for general statements about relationships among categories of data. Creswell (2009:182) stated that the process of data analysis involves making sense out of text and image data. It involves preparing the data for analysis, conducting different analyses, moving deeper into understanding the data, representing the data and making an interpretation of the larger meaning of the data. For the purpose of the study, data was analysed using different steps described by Schurink et al. (2011:405), which are:

- **Organising and preparing data for analysis**

Once all of the participants had completed the study measures and all of the data had been collected, the researcher prepared the data to be analysed. The researcher planned for the recording of data in a systematic manner that was appropriate to the setting, research participant or both, and that facilitated analysis before data collection commenced (Schurink et al., 2011:405). Researcher checked all the collected data in order to make sure that the data from all participants was saved and stored under a number for each participant. Researcher checked whether all questions were answered and that she had all the signed letters of informed consent. The field notes were typed and stored.

- **Data collection and preliminary analysis**

This was the first step in data analysis away from the site. Data analysis in qualitative inquiry necessitates a two-fold approach; the first one involves data analysis in the field during data collection while the second involves data analysis away from the field following a period of data collection. The second part, known as the office approach may be conducted between the visits to the field, prior to, as well as after, completion of data collection (Schurink et al., 2011:406).

The researcher performed preliminary data analysis in order to process the data and prepare it for further analysis, describe the key features of the data, and summarize the result. The researcher explored the data in order to become familiar with the interview information. This entailed listening to the recordings and transcribing each interview verbatim and reading the transcripts multiple times. From this initial review of the transcript, the researcher will be able to identify themes emerging from the data.

- **Managing data**

The researcher organised data into the file folders, and then converted the files into appropriate text units, for example a word or a sentence for analysis. The researcher properly labelled all data with a notation system, namely a number for each participant, that made retrieval manageable; saving the transcribed interviews of each participant, optimally scanning material, typing field notes, and sorting and arranging the data into different types depending on the source of information. The

researcher read through the data and obtained a general sense of the information and reflected on its overall meaning, the impression of overall depth, credibility and the use of information (Schurink et al., 2011:408).

- **Reading and writing memos**

Schurink et al. (2011:409), state that after the organisation and conversion of the data, researchers continue the analysis by getting a feel for the entire database. The researcher read and reread the transcripts in their entirety to become immersed in the details. Writing memos in the margins from field notes helped in this initial process of exploring the data base.

- **Generating and coding the data**

The researcher coded labels and their meaning. Different coding is discussed below:

- Open coding

Schurink et al. (2011:412), state that open coding is the part of analysis that pertains specifically to the naming and categorizing of phenomena through close examination of data which are broken down into discrete parts, closely examined, compared for similarities and differences, and questions are asked about the phenomena as reflected in the data. The researcher collected the raw data in the form of interviews and from the collection; and then broke data into segments in order to interpret it. The researcher read the transcripts closely and coded the data line by line. The researcher used colour highlighter pens and pencil and paper when doing coding.

- Axial coding

Schurink et al. (2011:413), state that data will be put back together in new ways after open coding by making connection between categories. The researcher identified the relationship among the codes. Categories were related into sub-categories then worked to understand the categories in relationship to other categories and their sub-categories.

- Selective coding

Selective coding is the process of selecting the core category systematically relating it to other categories, validating those relationships and filling in categories that need further refinement and development.

The aim of selective coding would be to give a short descriptive overview of the case and would therefore comprise only a few sentences (Flick in Schurink et al., 2011:414).

The research results are presented in the qualitative narrative. This is followed by a final step which involves making an interpretation or meaning of the data; asking, 'what were the lessons learned'?

- **Testing emergent understandings and searching for alternatives**

Schurink et al. (2011:415), states that as categories and themes are developed and coding is well underway, part of this phase is evaluating the data for their usefulness and centralities. One should determine how useful the data are in illuminating the questions being explored and how central they are to the story that is unfolding about the social phenomenon being studied. The researcher critically challenged every pattern that seemed apparent and made a comparison between the extremes of dimension with different contexts which are ways to challenge the contents of category and explore alternative explanations.

- **Interpreting and developing typologies**

Interpretation involves making sense of the data. Several forms exist, such as interpretation based on hunches and intuition and insights, interpretation within a social science construct or idea, or a combination of personal views and a social science construct or idea.

Developing typologies or systems for categorizing things or concepts is a very useful aid when making sense of qualitative material. By developing typologies, one begins to make conceptual linkages between seemingly different phenomena. The criteria for good typologies are exhaustiveness and mutual exclusiveness (Schurink et al., 2011:416).

- **Presenting the data**

This is the final phase of data analysis. The researcher presented the data, a packaging of what is found in text and tabular or figure form. Schurink et al. (2011:419), states that writing about qualitative data cannot be separated from the analytic process. It is central to that process as the researcher engages in the interpretive act when shaping the raw data. The process of writing is an integral part of understanding. The written report remains the primary mode for reporting the results of the research.

3.5.4 Qualitative data verification

3.5.4.1 Trustworthiness

Lietz, Langer and Furman (2006:444) state that trustworthiness is established when findings as closely as possible reflect the meanings as described by the participants. They further explain that it is not something that just naturally occurs but instead is the result of rigorous scholarship that includes the use of procedures. In order to manage the threats to trustworthiness, the researcher engaged in a variety of strategies to describe research findings in a way that authentically represents the meaning as described by the participants (Glesne, 2006:37).

3.5.4.2 Credibility

Brink et al. (2012:172), states that credibility reflects the truthfulness and accuracy of the data collected. The researcher interacted with the participants for a prolonged time. Consequently, this allowed for rich data collection and for the researcher to gain adequate understanding of the experiences of the participant, and to establish a relationship of trust between the participant and the researcher.

Data collection for the study took place over three months. 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). In this study, credibility was ensured through multiple reviews of the field notes and audiotapes; the neutrality of the researcher during the interviews,

member checking, careful handling of emotional expressions, and the examination of findings by the supervisor as peer debriefer.

3.5.4.3 Dependability

Dependability is concerned with whether similar results would be obtained with similar participants in a similar context (Kumar, 2011:350). According to Shenton, (2004:69), the meeting of the dependability criterion in a qualitative work is difficult. However, in this study, the researcher observed the principle of dependability by providing detailed descriptions of the data management and analysis procedures in the report. The research methodology was fully explained, the field notes and the audio recordings were kept safe on the computer and on a separate removable storage system in a locked cupboard.

3.5.4.4 Transferability

Shenton (2004:70) states that 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), further state that 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.

The researcher interacted with the participants until data saturation, because of the sensitive nature of the topic the transferability was ensured through the provision of thick description.

3.5.4.5 Confirmability

Confirmability refers to the degree of the objectivity of the results, recommendations, and conclusion as well as the neutrality of the researcher in the research process (Kumar, 2011). Confirmability in this study was achieved through the ethical clearance process of the Research Ethics Committee of the Faculty of Humanities of the University of Pretoria and the researcher's adherence to the approved research protocol. The researcher also kept an audit trail of the whole research process and how themes and sub-themes were generated.

- **Reflexivity**

Horsburgh (2003:308) defines reflexivity as an active acknowledgement by the researcher that her/his own actions and decisions will inevitably impact upon the meaning and context of the experience under investigation. Reflexivity involves deconstructing who we are and the ways in which our beliefs, experiences and identity intersect with that of the participant. This reflection occurs both in individual thought and through dialogue with others that acknowledges the researcher's own experience and perspective. The researcher kept her journal to reflect her own thoughts after the interviews and used supervision sessions to monitor her feelings.

- **Member Checking**

Member checking, also known as participant validation was done to a certain extent during the debriefing after the interview. Furthermore, it allows participants to review findings from the data analysis in order to confirm or challenge the accuracy of the work. The researcher went back to the participants after the data had been interpreted, to verify whether this reflects what the participants were conveying in the interviews. The participants were able to identify areas that may have been missed or misinterpreted (Lietz, Langer & Furman, 2005:454).

- **Peer Debriefing**

The researcher engaged with other researchers to learn from them and also to share experiences and challenges around the study; however, this was done out of the research premises (Lietz et al., 2006). Through discussions about the generated themes, the vision of the researcher was widened as others brought to bear their experiences and perceptions. This increased the trustworthiness of the findings (Lietz et al., 2006).

3.6 Pilot Study

A pilot study can be defined as a trial run of the study, using questions and participants, similar to those in the final study (Landman, 1998).

The researcher did the pilot study to address the logistical issues such as testing the interview schedule to check if she will obtain sufficient data. This was also done

in order to obtain trustworthiness, to check how long the interview duration will be, whether the voice recorder works and the privacy of the venue.

Two women who were diagnosed with HIV during their antenatal visits, who already gave birth at Protea Glen Health Centre, and complied with the selection criteria were selected for the pilot study. The researcher interviewed them before conducting the main research. Participants in the pilot test did not form part of actual research and the data obtained from the pilot test was not incorporated into the main study. It was used to test the interview schedule and other practicalities such as the venue, duration of interview and voice recorder.

3.7 Ethical considerations

Strydom (2011:114) define ethics as a set of moral principles which is suggested by an individual or group, is subsequently widely accepted and which offers behavioural expectations about the most correct conduct towards experimental subjects and respondents, employers, sponsors, other researchers, assistants and students. For the purpose of the study the following ethical considerations were applied.

3.7.1 Avoidance of harm

De Vaus (2002:86) mentioned that where there is any danger of harm to participants, the principle of informed consent requires that participants be told of the possible dangers before participating in the study. The researcher informed the participants of any possible emotional harm, bearing in mind that HIV is a sensitive issue, therefore potential harm was monitored, and participants were promised to be referred to a social worker who works at the clinic if needed.

3.7.2 Informed consent

Strydom (2011:117) state that informed consent implies that all possible or adequate information on the goal of investigation, the procedure to be followed during the investigation, the possible advantages and disadvantages and dangers to which respondents may be exposed, as well as the credibility of the researcher be rendered to potential subjects or their legal representatives. The participants were given all information about the research, purpose of the study, the voice

recording of the interview, identity which will be kept anonymous and participation which will be voluntary, as well as that the data will be stored for 15 years at the University of Pretoria (UP). Participants signed the informed consent letter before the interview commenced.

3.7.3 Assurance of honesty

For the purpose of the study, the participants were provided with the description of the study in the letter of informed consent. The researcher did not make any empty promises to the participants. The researcher provided assurances of confidentiality as it is important for research. Information is kept confidential to ensure the privacy of the subjects (De Vaus, 2001:84).

3.7.4 Debriefing

Strydom (2011:122) state that debriefing sessions are sessions during which subjects are given the opportunity, after the study, to work through their experience and its aftermath, and where their questions are answered and misconceptions removed. The researcher will provide debriefing to each participant after the interview and if any need exists, participants will be referred to a social worker at the clinic. After the completion of the research, the researcher rectified any misconceptions that had arisen in the minds of the participants.

3.7.5 Confidentiality/violation of privacy/anonymity

Strydom (2011:119) state that every individual has the right to privacy and it is his or her right to decide when, where, to whom and to what extent his or her attitudes, beliefs and behaviour will be revealed. This principle can be violated in a variety of ways, and it is imperative that researchers be reminded of the importance of safeguarding the privacy and identity of the participants and to act with the necessary sensitivity where the privacy of subjects is relevant. The researcher addressed the issue of confidentiality with the participants. Confidentiality was kept at all times to avoid stigma, and the researcher did not use participants' names, instead pseudonyms were assigned to protect their identity. Participants were ensured of confidentiality between the researcher and them.

3.7.6 Compensation

Strydom (2011:121) state that it can be indeed asked whether compensating clients in one other way is unethical. It seems reasonable to reimburse participants for cost incurred such as time away from work, free time spent on the project or transportation. The researcher did not reimburse the participants and this was addressed with them in the letter of informed consent. Participation was voluntary and the researcher collected data at a time which suited the participants. The venue where the researcher conducted the interviews was accessible to the clients.

3.7.7 Publication of findings

The information must be formulated and conveyed clearly and unambiguously to avoid or minimize misappropriation by subjects, the general public and even colleagues. Care should be taken that no biased language is used regarding gender, sexual orientation, racial or ethnic group, disability or age (Strydom, 2011:126). The researcher informed the participants about the publication of the findings. The findings were revealed to participants as a form of recognition and to maintain future good relationships with the clinic staff. The research report will be available in the UP library and a possible journal article with supervisor as co-author. The findings were conveyed to the participants in simple language in the form of a seminar. The researcher did not manipulate results in order to confirm a point of view. The report was compiled as accurately and objectively as possible because the researcher was aware and appreciated the fact that fabrication or falsification of data is a very serious issue in research (Strydom, 2011:126).

3.8 Empirical findings

In this section findings will be presented and discussed. This chapter presents the findings of the study about the experiences of women who were diagnosed with HIV during pregnancy. Research findings will be substantiated with literature where applicable. This research was based on the qualitative paradigm as the topic dealt with the subjective nature of the women's experiences.

A sample of 10 women who were diagnosed with HIV during pregnancy were used. The selection criteria included: Women who were aged 25 – 35 years, who had already given birth and who were due for the 6 weeks baby check-up at the clinic.

The results derived from qualitative thematic analysis are subsequently presented.

3.8.1 Biographical data

Mbedzi (2011:53) states that in order to give clarity to the data collected, it is essential that the profile of the participants should be clearly described as the participant's background and personal experiences will affect how the participants respond to the research from their contextual reference.

Biographical data included the following variables as presented in the following table:

Table 3.1: Profile of participants

Participants	Age	Marital status	No. of children	Religion	Language	Qualification
Participant 1	35	M	2	Christian	Zulu	IT specialist
Participant 2	30	S	3	Christian	Zulu	Nurse
Participant 3	26	M	2	Christian	Pedi	Grd 12
Participant 4	30	M	2	Christian	Tsonga	Grd 12
Participant 5	34	M	2	Christian	Pedi	Grd 12
Participant 6	35	M	3	Christian	Tsonga	Diploma
Participant 7	26	S	4	Christian	Sotho	Grd 11
Participant 8	32	M	2	Christian	Pedi	Diploma
Participant 9	30	M	3	Christian	Pedi	Grd 12
Participant 10	31	S	1	Christian	Zulu	Grd 12

From the table it is clear that the majority of participants are above the age of 30, whereas 20% of participants are below the age of 30. All participants are Christians and 50% have grade 12, whereas 40% have a diploma and 10% have grade 11.

A discussion of the thematic analysis follows:

3.8.2 Thematic analysis

This section describes the various themes and sub-themes, as they emerged from the analysis of data collected.

Table 3.2: Themes and sub-themes

Themes	Sub-themes
Theme 1: Knowledge of HIV	Understanding of HIV
Theme 2: HIV diagnosis	Reaction to the HIV diagnosis Coping with HIV
Theme 3: Experiences of living with HIV	
Theme 4: Treatment	Experience regarding ARV treatment Experience regarding Health Care services
Theme 5: Knowledge of mother-to-child transmission	PMTCT Infant feeding options
Theme 6: Disclosure and support	Disclosure of HIV status Support system
Theme 7: Recommendations	

3.8.2.1 Theme 1: Knowledge of HIV

This theme discusses participants' knowledge on HIV, their understanding of HIV and the modes of transmission.

3.8.2.1.1 Sub-theme 1.1: Understanding of HIV

The participants responded as follows to their understanding of HIV:

“What I understand by HIV is that most people says it comes through transmission, like if have sex with someone who is HIV positive and you didn't protect yourself by using a condom that's where you are going to get HIV.”

“HIV is a virus that affect the immune system and it lives within your body and it does not have medicine.”

“When it comes to HIV, HIV is a pandemic disease that is destroying you this days, that you get it through sexual transmitted, you also get it through cut and all the wounds if you are not protected more especially when you are helping someone who is HIV positive, you find yourself in the situation that you are helping that person and you have a wound that is open you get infected.”

All ten participants demonstrated knowledge of the HIV virus, they mostly only indicated that it is a virus which is incurable that passes through sexual intercourse. Very few indicated all three means of transmission, namely, through sexual intercourse, blood contamination and breastfeeding.

The responses of the participants is in line with how the Centre for Disease Control (2001:1) defines HIV, namely as a virus which is spread through certain body fluid that attacks the body’s immune system. Unlike certain other viruses, the human body cannot get rid of HIV which means that once you have HIV, you have it for life.

Ndala-Magoro (2010:2) states that HIV is transmitted through bodily fluids such as semen, blood and breastmilk of an infected person. It is a fragile virus that cannot pass through intact skin. Infection can only occur if infected body fluids, particularly semen, vaginal fluids or blood, enter the body. HIV attacks the CD4 cells (known as T-helper cells) of the human body which are defensive cells that form part of the human immune system. CD4 cells defend the human body against harmful elements such as bacteria, viruses and certain cancer cells and produce aid in the development of substance that further protect the body (Van Dyk, 2008).

The theme indicates that participants showed that they understood and had knowledge about HIV and AIDS as indicated above. Participants gave a general overview of understanding and knowledge about HIV. However, 2 of them understand it to be a sexually transmitted disease only, they did not have knowledge on other forms of transmission which thus shows the need for continuous education on HIV. This concludes that participants have a general understanding and knowledge of HIV. This therefore supports the biopsychosocial model because having knowledge of HIV as an illness gives a person an opportunity to deal with psychosocial issues associated with the diagnosis. The individual becomes emotionally ready to face all the challenges associated with diagnosis, these are

challenges such as fear of stigma within the society, disclosure to family members and also fear of the unknown.

3.8.2.2 Theme 2: HIV diagnosis

In this theme the reaction to the HIV diagnosis was a sub-theme that emerged.

3.8.2.2.1 Sub-theme 2.1: Reaction to the HIV diagnosis

All of the participants reported that they were scared when told that they were HIV positive, the majority related that they felt the counsellor was joking when she gave them a positive result. The following are their statements:

“I was so nervous; I was so scared.”

“I honestly didn’t believe it was me, I felt like is the end of the word, I couldn’t understand what to do, I was shocked and I was not expecting myself to have HIV. I thought I am healthy enough that I could not have HIV and I thought I was having a faithful partner in a such an extent that I won’t have it.”

“It was not simple but I accept myself that I am HIV positive.”

It is important to note that the fear associated with HIV has a general pattern. This fear and anxiety is caused by the stigma and discrimination people experience when they test positive for HIV. It was observed in the study that nine participants had a negative response when they were told about the HIV positive results. One participant indicated that her mother is HIV positive also and she did not take her disclosure hard.

“My mother is also HIV”

Taylor, Clayden, Dhar, Gandhi, Gilleece, Harding, Hay, Kennedy and Low-Ber (2012:135) state that diagnosis during pregnancy may be a profoundly shocking and life-changing experience for the newly diagnosed HIV-positive woman. There may be a complex mix of emotional, psychosocial, relationship, economic and even legal issues that arise directly out of the HIV diagnosis. The newly diagnosed woman also has a relatively brief time in which she needs to develop trust in her medical carers and attain sufficient medical knowledge of her situation, to be

equipped to make informed decisions that will affect her own long-term health, her foetus and her male partner.

All participants reported that they 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 health care workers for all women who were pregnant, and testing 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.

The following quotes reflect their reactions:

“I got to know about my HIV status by the time I was pregnant, they had to test me and I realize I was HIV.”

“I get to know when I go to the clinic they always test us so first time they test me they say you are HIV positive; I think I was 2 or 3 months.”

“I found out about being HIV positive during the time I’m going to clinic to book, they started testing me and I found that I’m HIV positive.”

“I thought I was gonna die and leave my child.”

From all participant’s responses it shows that many women found out about their status when they went to their antenatal clinic. This may show that many women do not take HIV tests regularly. The disclosure of HIV-positive results to a patient sometimes also led to negative reactions such as shock, loss of hope and thoughts of the end of life for the person.

Finding out about the HIV diagnosis can propose numerous traumatic reactions including: fear of death, deterioration of interpersonal relations, negative emotions, rejection of the HIV antibody test, stress related to the hiding of the condition, anxiety, depression, guilt, loss of support, isolation, difficulties with family dynamics,

emotional or physical violence, as well as deterioration of relations with health care providers. After a person tests HIV positive, he or she faces many difficult issues, including whether to disclose their HIV positive status to partners, friends, family, and health care providers, as well as how to enter and adhere to care (Herek, 1999).

Holt, Court, Vedhara, Nott, Holmes and Snow (2008:49) state that the psychosocial impact of receiving an HIV-positive diagnosis has been well documented. Major stressors identified include the uncertainties of living with HIV, related to the unpredictability of disease progression and therefore anxiety over future health, concerns about health and dying and other more general lifestyle losses such as changing interpersonal relationships and financial status.

Anderson, Elam, Solarin, Gerver, Fenton and Easterbook (2009:1060) state that receiving an HIV/AIDS diagnosis is often a life changing and traumatic event. Coming to terms with HIV-positive status is crucial for the mental and physical health and quality of life of people living with HIV/AIDS (PLWHA). There has been a great deal of research on how HIV positive people cope with their illness.

Receiving an HIV-positive diagnosis “is the beginning of a long road of challenging life events and extraordinary personal changes, which can overwhelm even the most psychologically well-adjusted individual” (Joseph & Bhatti, 2004:30). HIV/AIDS has been described as the ultimate biopsychosocial phenomenon, as its impact is not limited to the immune system, but also effect the social network, psychological functioning, culture and religion of individuals. The diagnosis affects the psychological functioning of a human being.

3.8.2.2.2 Sub-theme 1.2: Coping with HIV

All the participants reported that it is not easy to cope with being a mother and also having a virus at the same time. The majority of participants have accepted their HIV status. Nine of the participants indicated that it was hard but they had no choice but to accept it. One of the participant indicated that she accepted her status on the day of disclosure as the mother is also HIV.

Below are some quotes confirming this sub-theme:

“I was stressed but I have to manage to accept my status of HIV because I was carrying a baby.”

“I think mostly is the support I am getting from my family and my husband, they make things easy for me to see that only different between me and them is HIV disease and is manageable, I am able to manage it as I am coping with it.”

Coping with emotional, social and physical stressors shows to be an important part of surviving and living positively with the virus. All participants indicated that they relied on family support to cope with their present predicament. It emerged from the theme that all participants found it easy to cope with the disease as there was family support, however they did not mention other coping mechanisms which they applied to be able to cope better with the diagnosis.

These statements are a reflection of Pearlin and Schooler (1978:211), who defined coping as a behaviour that protects people from being psychologically harmed by a problematic social experience, a behaviour that importantly mediates the impact that societies have on their members.

Kotze (2011:18) states that previous research indicates that testing for HIV, and especially receiving HIV-positive diagnosis can be an extremely stressful and life-changing experience. In particular, people experience various short- and long-term emotional and behavioural reactions immediately after being diagnosed with HIV. With regard to emotional reactions previous research has identified the following reactions: shock, surprise and disbelief, anger, denial, deep sadness, guilt, and bereavement (Minaar & Bodkin, 2009:4).

A number of behavioural reactions have been identified, these are behaviours such as dizziness, needing to leave the testing room, sweating, numbness, crying uncontrollably, inability to hear anything the counsellor said after hearing the result (Sanders, 2008:36).

Kotze (2011:24) states that coping is a vast concept that includes numerous behavioural, cognitive and effective responses. Habib and Rahman (2010:80) further added that the individual's physical survival is abruptly challenged by the

diagnosis of HIV/AIDS, and his life is disrupted as the disease penetrates into the immune system, blood and the semen. This creates psychosocial distress and withdrawal from the society.

Receiving the news of the HIV diagnosis changed the feelings some participants had towards the pregnancy and the unborn child they were carrying. The theme indicates participants' diagnosis was constantly on their minds and described the only way of coping with the disease as to accept the reality that they have HIV and then live with the reality. In summary, spousal support is one very important support participants dearly needed as pregnant women. Some were given the necessary support by their families. This confirms the relevance of the biopsychosocial approach that the person diagnosed with HIV will not only have to worry about health complications and the fear of inevitability dying, there may be disruptions in relationships with family, friends and neighbours or people at work.

3.8.2.3 Theme 3: Experiences of living with HIV during pregnancy

Ramkinssoon, Coovadia, Hlau, Catsoudis, Mthembu and Smit (2007:325) state that HIV infected mothers are faced with coping both with physical demands of their illness and child care, and with the emotional burden of decision-making about disclosure of HIV status, use of health care services and use of ART.

Participants confirmed this as follows:

“Honestly it was hectic, I dint know what to do and then I was facing a lot of challenges like I have to tell my man about the situation and I didn't know how to tell him. I was always tired sometimes stressed, it was so depressing with this HIV, I didn't accept it at all, it took me for a while to accept it, so I don't know what to do by the times I was depressed, I was going through hell at that moment, I was in a bad space.”

“At the beginning it was stressing, I thought that my child was going to be affected and I go to the clinic they explained that my child will not be affected and that made my pregnancy to be normal.”

From what the participants said it is therefore concluded that they face many challenges including fear of disclosure, stigma attached to HIV, stress and

confusion. Ingram and Hutchinson (2000:117) relate that societal values and expectations influence reproductive experience and mothering, the presence of HIV complicates the experiences of HIV-positive women. Pregnancy elevates a woman's status in some communities and is often an opportunity for women to feel good about themselves. Babies present love, acceptance and a legacy for the future, even to a woman without a sense of future for herself.

Mohammadpour, Yekta, Nasrabadi and Mohraz (2009:250) state that discovering that one has any serious illness can be very traumatic, but coming to terms with an HIV diagnosis is made more difficult by social constructs and negative reaction to the infection. HIV can damage all physical, social, spiritual, psychological and financial aspects of human function.

All participants highlighted the importance of having support from the family as the most important aspect. These are some of the views they gave on their experiences of being pregnant and HIV at the same time:

“It was difficult for me and that time I experienced lot of things because when I woke up every morning, if it's not pain its dizziness, sometimes I felt weak and couldn't do anything, it was not me at all. Sometimes I was deciding that it is better for me to abort this child because I was not feeling to have a baby on that time because I am HIV and pregnant, so I had lot of things in my mind and I was thinking that this child maybe she was HIV positive because I was not thinking well, my experience was very bad because I experienced lot of things every day when I woke up.”

“I don't know what to say; actually it was bit better because I often go to the clinic check-ups and taking some treatments.”

The participant's response provides concrete evidence that being HIV positive and pregnant simultaneously is not a good experience; one is often filled with mixed emotions and uncertainties. The findings also indicate sadness and fear among HIV positive pregnant women, sadness in response to their HIV-positive status and at the possibility of not seeing their babies grow up.

Spencer (2005:230) states that HIV-positive pregnant women experience a dichotomy in that they are HIV positive, living with a chronic disease which will end in death, yet carry new life within them. Special care and support is needed to ensure a relatively healthy mother and baby.

Pittiglio and Hough (2009:184) state that HIV was once thought to be a disease that was inevitably fatal, however with early treatment and effective antiretroviral therapy, individuals are living longer with the disease. This means that HIV infected individuals have to deal with the associated stressors of living with a chronic illness, including uncertainties of disease progression and social stigma associated with HIV.

The general awareness that HIV infection can have impact on a person's future proved to be true. Participants experienced different emotions ranging from frustration, fear of disclosing, uncertainties, closure, shock and wanting to abort the baby. Research has consistently found psychological distress among individuals living with chronic and life threatening illnesses (psycho), which can be linked to the biopsychosocial approach, as participants' experiences of HIV and pregnancy may lead to their immune system weakening (bio) and they start becoming sick. When one gets sick they withdraw from society because of fear of stigmatization (external stigma – social). This becomes one of the challenges for those who did not disclose their status. One of the problems in dealing with HIV related stigma is that many PLWHA reinforce the belief that HIV is something to be ashamed of, by remaining silent and denying their status to the society, thus enforcing internal stigma (psycho).

3.8.2.4 Theme 4: Treatment

Theme four has four associated sub-themes that have emerged, including knowledge regarding treatment of HIV, experiences regarding health services, knowledge of PMTCT of HIV infection, and disclosure.

3.8.2.4.1 Sub-theme 4.1: Knowledge and experience regarding ARV treatment

This theme focuses on the participants' knowledge around ARV treatment. Below is the participants' response concerning their knowledge:

This is what they had to say concerning HIV treatment:

“I am on treatment and my child will stop at 6 months, I am not sure if I will continue with treatment.”

“I started with ARV immediately when I found that I was HIV positive because I was thinking if I don’t take I am going to lose my baby and this HIV will pass to my child.”

“I was not fine when I started with treatment, I was not fine when I started, I used to vomit, I realized my body was changing sometimes. I started pills which is in an orange bottle, it’s not easy because I have to take them every day.”

All participants related that they were given treatment, but the majority of them did not know the name of the medication, they only know it is ARV. The study revealed that participants were aware that the implementation of ARVs plays a significant role as a strategy utilized to prevent HIV transmission to unborn babies. Early initiation of ARVs during pregnancy, for an example, at 14 weeks of pregnancy, substantially reduces the chances of transmission of HIV.

WHO (2015:2) states that all infants born to HIV-positive mothers should receive a course of antiretroviral treatment as soon as possible after birth. The treatment should be linked to the mother's course of antiretroviral drugs and the infant feeding method.

- Breastfeeding - the infant should receive once-daily nevirapine from birth for six weeks.
- Replacement feeding - the infant should receive once-daily nevirapine (or twice-daily zidovudine) from birth for four to six weeks.

At four to six weeks old, all infants who are born to HIV-positive mothers should be tested to have an early infant diagnosis. Another HIV test should be done at 18 months and/or when breastfeeding ends to provide the final infant diagnosis.

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).

Simpson and Forsyth (2007:39) for 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 babies when they were born.

According to South African Guidelines on Management of HIV Positive Pregnant Women, the drugs used are tenofovir, emtracitabine and efavirenz, as the first line treatment regimen in SA. 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).

WHO (2013:3) further stated that ARV should be initiated for all HIV-Infected pregnant and breastfeeding women, irrespective of CD4 cell count. This brings benefits to mother's health, prevents the exposed child from becoming infected, and may offer additional benefits for prevention of sexual transmission of HIV.

3.8.2.4.2 Sub-theme 4.2 Experience regarding Health Care Services

The study findings related to this theme suggest that the participants had different views about health care services.

Some participants quote relating to this are:

“Ok, what I use to see actually about health care workers, I didn't know that the health care workers helped the way they did, I thought maybe they do their things for the sake of doing but what I have noticed is that they explain everything even if you don't understand anything you end up

understanding, Actually they were very friendly towards me and they also my reaction and calm me down and always tells me that I am not the only one living with the disease, there are many people living with it, the different is that how we manage the disease. They told me I won't experience any problem and I am not experiencing it at all."

"For me because I am also a nurse it was not that difficult, I was very shy at first to go at collect the pills, I thought everybody was seeing on me, the line of all people waiting to collect medication."

"Health care services were excellent, professional showed to be empathetic, they always work in a professional manner, they are hard workers even though we are many and they apply confidentiality at all times."

Eight participants reported to be very happy about the health care service, however Two said the services were very poor. Those who were happy about the services felt that nurses always applied confidentiality. Immediately when diagnosed with HIV, they were given education on HIV infection and education on ARVs and the side effects. However, they all complained of feeling dizzy after using treatment, but surprisingly they did not know the name of the medication they are using. They just referred to it as ARV.

Two participants complained that they felt that nurses were judging them; they felt that nurses were not empathetic and to be very slow. They felt stigmatized and discriminated. One participant had this to say:

"Health care services was very poor, professionals are very slow when servicing and some of them are judgemental."

"I cannot say that the hospital is short staffed but what I noticed is the way they perform their duties (pause) ... they are slow. I do not know if they (nurses) are responsible for this slow process or it is due to the protocol that they have to follow."

It is clear that some of the participants' experience regarding health care services were not good. Above statements suggested that health professionals need to practice their values when dealing with HIV pregnant women.

Many women living with HIV continue to lack access to HIV prevention, treatment, care and support services and sexual and reproductive health services. Children also continue to become infected prenatally—that is, in utero, during labour or while breastfeeding. Progress in stopping new infections among children and ensuring that mothers are alive and healthy requires reaching the full cross-section of pregnant women with essential health services (UNAIDS, 2014:3).

Maughan-Brown (2007:2) states that HIV/AIDS is stigmatised because it is a transmissible lethal and incurable condition that is typically assumed to be the responsibility of the infected person. It is often overlaid with other stigmas associated with homosexuality, drug use, poverty, prostitution and homelessness. UNAIDS (2015:2) mentioned that achieving the vision of Zero new HIV infections, Zero discrimination and Zero Aids-related deaths, requires that everyone needing HIV treatment has access to life saving medication and access to HIV prevention services. Anti-retroviral therapy is one of the most effective tools available and it is an essential part of an efficient, sustainable Aids response.

The results of this study as presented in this section suggest that HIV positive pregnant women had a mix of negative and positive experiences towards health care services. The negative experiences were expressed in terms of long waiting hours, non-adherence to working hours, and slow delivery of services, and judgement. Multiple duty stations may lead to long waiting hours, while slow delivery of services may be attributed to the huge number of patients in the area or shortage of personnel.

3.8.2.5 Theme 5: Knowledge of mother-to-child transmission

The theme discusses the participants' knowledge on mother-to-child transmission; this is what they have to say concerning their knowledge:

“Mother to child transmission is when one doesn't take treatment and end up affecting her child through birth or breast feeding.”

“I think MTCT is when your child becomes HIV after birth, but you have to breastfeed your child for six months, another participant, when responding to the follow-up question about her understanding with regard to MTCT said “with her smile on the face” “I don’t know.”

3.8.2.5.1 Sub-theme 5.1 Prevention of mother to child transmission (PMTCT)

This sub-theme looks at their knowledge of prevention of mother to child transmission.

The findings from this interview also show that three participants lacked information about PMTCT of HIV infections, for an example following the response of the following participant:

“I am not sure.”

“I guess it’s through breast feeding.”

“I don’t know it but nurses told me that since I tested positive I must take treatment for the sake of my baby.”

The above statements revealed that some participants did not have much information on PMTCT.

The study revealed that although the participants included in the study had different opinions and knowledge of MTCT of HIV infection, they had also different attitudes with regard to the prevention of MTCT of HIV infection. The shared knowledge was related to a lack of understanding of the meaning of MTCT and its importance. On the one hand, existing knowledge about prevention of MTCT was reflected by a participant by outlining that it is when the mother is saving the baby from being infected with HIV.

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/mm³ 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/mm³ 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 three hour intervals and seven 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 seven days post-delivery and infants were tested for HIV at six 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 28 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). WHO (2014:6) announced that the coverage and quality of prevention services have generally improved, and an expanding array of highly effective HIV interventions is available. In addition to the promotion of behavioural changes, several biomedical interventions are being deployed. This included initiating ART regardless of CD4 cell count for serodiscordant couples, pregnant and breastfeeding women.

International efforts to eliminate the mother-to-child transmission of HIV continue to intensify. The number of children newly infected with HIV in low- and middle-income countries declined by 40% to an estimated 240 000 [210 000–280 000] in 2013, down from the estimated 400 000 [370 000–450 000] who acquired HIV infection in 2009, the baseline year for the Global Plan towards the elimination of new HIV infections among children by 2015 and keeping their mothers alive (WHO, 2014:7).

Maputle and Jali (2008:46) further indicated that breastfeeding provides optimal nutrition for infants, as well as protection from diseases and infections. MTCT is a well-established mode of HIV transmission because the human immunodeficiency virus (HIV) is transmitted through breast milk if the mother is infected with the HIV virus.

Sechabe (2011) citing Kumar and St John (2003:11) on the study, conducted in Barberton on the knowledge, attitudes and sexual practice among the HIV-infected women with repeated child birth, revealed that a significant number of mothers did not know that they could transmit HIV to their babies, and further thought that AZT given to them and their babies was to prevent HIV infection in the *baby*.

Some of the participants mentioned:

“I am worried that I will die when my child is still young bust she was tested negative.”

“My child was tested negative, I felt very relieved when the results came negative, I was scared that my child is an innocent blood and can’t die at a young age, my child cannot die for my sins.”

“My child tested negative but was given medication soon after birth, and I am happy for her.”

The above statements show that PMTCT is working efficiently, though some of them showed to be unsure about the treatment, they nevertheless adhered to it and the results appeared through the children’s statuses after birth. All the participants mentioned that their children are HIV negative. Seven participants expressed their happiness with the fact that their child will live longer. Three of the participants who showed lack of knowledge, expressed mixed emotions and they were worried by the fact that they will die and leave the child behind.

Mnyani and McIntyre (2013:64) state that in the past few years, South Africa has made a significant progress in the provision of prevention of mother-to-child transmission (PMTCT) of HIV, both in the delivery of more efficacious PMTCT intervention and also an increase in the proportion of women receiving the intervention. All of the participants mentioned that just after the diagnosis, the health care professionals told them that they need to start the treatment. A short survey by (Zolfo, Delvaux & Tamburrini, 2005:3) assessed the level of HIV/AIDS knowledge amongst pregnant women. The acceptability of a PMTCT programme in rural Zimbabwe showed that although there is a good level of HIV/AIDS knowledge amongst pregnant women, a demand still existed for a more comprehensive PMTCT programme.

South Africa has made significant progress in rapidly expanding access to PMTCT and has produced policies and guidelines supportive of high quality treatment and care for HIV-infected women; however, there are challenges and gaps in translating these policies into action. For the majority of South African HIV-infected women,

despite having good access to therapeutic services, decision making around pregnancy and childbirth is characterised by a number of negative factors including obstacles to pregnancy prevention.

3.8.2.5.2 Sub-theme 5.2: Infant feeding options

The above theme discussed the participants' response about their infants' feeding options, this is what they responded about the feeding options:

“Yes I am feeding my baby, the nurse told me that I have to breastfeed for 6 months and after 6 months I will give my baby formula.”

“After birth I breastfeed my child until 6 months, I will stop after that.”

“I am feeding my baby, but sometimes I am scared that my child may be affected, I still don't understand why they say my child will not be affected because breast milk is coming from me and I am HIV positive.”

“My baby is on treatment; I am breastfeeding her but I don't remember getting training on MTCT.”

From the information provided by the participants, it confirms the recommendation by WHO (2013) that all mothers regardless of their HIV status should practice breast feeding in the first six months proved to be working, this will also decrease infection to the infants and from the biopsychosocial approach, the increase of HIV infections, research and intervention programmes will progressively focus more and more on the psychological aspects of the infection.

All of the participants reported that their children are on treatment, they related that the nurse told them that they must breastfeed until six months.

Ramkissoo et al. (2008:324), confirm that there is evidence to suggest that exclusive feeding, either breast, or with milk alternatives is most effective in preventing mother-to-child transmission of HIV (PMTCT). Several African studies have showed that exclusive breastfeeding resulted in lower HIV transmission rates. HIV-positive mothers who breastfeed should do so exclusively. The better the adherence to exclusive breastfeeding, the lower the risk of MTCT of HIV or infant death.

In March 2013, the PMTCT guidelines which were last reviewed in 2010 were updated in accordance with international good practice. The updated guidelines advocate for a standardised triple-drug regimen including a fixed-dose combination (FDC), to be administered to women, regardless of CD4 count or clinical stage, during pregnancy and breastfeeding. There is continuation of ART after breastfeeding for women with CD4 counts less than 350 (Manyani & McIntyre, 2013:64).

The WHO (2013:26) came up with the consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection. Guidelines include important recommendations for simplifying and further scaling up HIV interventions among pregnant and breastfeeding women living with HIV, their HIV-exposed infants and children living with HIV, including the following:

- ART should be offered to all pregnant and breastfeeding women living with HIV, regardless of CD4 count; and
- ART for pregnant and breastfeeding women should be simplified by using a standardized one-pill-daily, fixed-dose combination of three ARV drugs (TDF + 3TC (or FTC) + EFV), which is the same as for first-line general adult treatment.

ARV drug regimens for adults living with HIV and for pregnant and breastfeeding women living with HIV should be harmonized. Previous WHO ARV guidelines recommended different adult ARV regimens for PMTCT of HIV and for treatment. The 2013 consolidated guidelines recommend the same, fixed-dose, single-pill, triple-drug regimen for all adults and adolescents, including for pregnant women, as first-line therapy. This will simplify the forecasting, supply and delivery of ART and enable pregnant women living with HIV to continue on the same drug regimen for their own health.

- ART delivery should be expanded in antenatal, maternal and child health settings. The 2013 consolidated guidelines recommend that, in many settings, including generalized epidemics, lifelong ART (option B+) be initiated and maintained for all pregnant and postpartum women and infants and for all children younger than five years in maternal, new-born and child health care settings, with linkage and referral to ongoing HIV care and ART clinics where

appropriate. In some settings, ART is to be provided to all pregnant women living with HIV throughout the duration of the mother-to-child transmission risk period (until the end of breastfeeding) and then should be continued lifelong in women who meet other treatment eligibility criteria (for example, CD4 cell counts <500 cells/mm³, option B). Expansion of nurse-initiated ART, decentralization and integration will facilitate access to effective ARV interventions in maternal, newborn and child health services.

- Existing systems need to be strengthened and new technologies should be incorporated to expand infant testing. In addition to further scale-up of dried blood spot polymerase chain reaction testing in central laboratories, point-of-care virological tests, which are expected to become available in late 2014, should help the early identification of HIV-infected infants and promote more rapid linkage to treatment and care. Final diagnosis of infants in settings for PMTCT of HIV, and broader provision of provider-initiated testing and counselling outside settings for PMTCT of HIV to identify HIV-exposed or -infected infants who are not being followed up for PMTCT of HIV, should also continue to be emphasized.
- Immediate, lifelong ART is recommended for all children living with HIV younger than five years of age, regardless of CD4 count. This should facilitate more rapid access to treatment for children diagnosed with HIV infection.

Coutsoudis (2004:47) further discussed strategies that should be employed to minimise risk of transmission include the following:

- Exclusive breast-feeding during the first six months.
- A shorter duration of breast-feeding — about six months.
- Good lactation management must be provided, so that breast-feeding problems such as cracked nipples, engorgement and mastitis are prevented.
- If the mother does develop mastitis or abscesses, she must express milk from the affected side frequently and discard it, and continue feeding from the unaffected side.
- Condoms must be used throughout the lactation period.
- If the infant has oral thrush it must be treated promptly.

From this discussion, it can be pointed out that participants do not have much knowledge on PMTC; the majority related that they got training from the centre, but they could not explain this detail about PMTCT. This is what others had to say:

“Nurses gave me training it’s just I could not grab it because I was depressed throughout.”

“Eish I can’t remember much but I take everything as it comes.”

“I dont have more information on PMTCT but I just know that Nurses gave me education.”

From the response given by the participants about lack of knowledge, the researcher noted that participants were given education when they were still in a shocked state about their diagnosis. It can be said that also showed to be a barrier, health care professionals need to be multilingual to be able to help patients in their own language.

WHO (2015:1) states that effective PMTCT programmes require women and their infants to have access to – and to take up a cascade of interventions including antenatal services and HIV testing during pregnancy, use of antiretroviral treatment (ART) by pregnant women living with HIV, safe childbirth practices and appropriate infant feeding, uptake of infant HIV testing and other post-natal health care services.

The World Health Organization (WHO) promotes a comprehensive approach to PMTCT programmes which includes:

- preventing new HIV infections among women of childbearing age;
- preventing unintended pregnancies among women living with HIV;
- preventing HIV transmission from a woman living with HIV to her baby; and
- providing appropriate treatment, care and support to mothers living with HIV and their children and families.

In the past few years, South Africa (SA) has made significant progress in the provision of prevention of mother-to-child transmission (PMTCT) of HIV services, both in the delivery of more efficacious PMTCT interventions and also an increase

in the proportion of women receiving the interventions (Manyani & McIntyre, 2013:64).

3.8.2.6 Theme 6: Disclosure and support

The theme focused on the participants' disclosure of their HIV status and their relationships and support systems.

3.8.2.6.1 Sub-theme 6.1 Disclosure of HIV status

The following are their responses regarding disclosure:

"I disclosed to my friend as I am not staying with my baby daddy."

"I disclosed to my husband, he was angry at me and he started accusing me and we actually get separated for about two months because we were pointing fingers too each other, he eventually realizes that this is a disease that you can get even in your previous relationship not now, what makes him to think I'm the one infected him whereas I'm not the only person have been in relationship."

"My family and my boyfriend are very supportive."

"I disclosed my statuses to my sisters and mother, they were shocked but later were very supportive, they are always there for me."

"I disclosed to my partner, (paused) he was angry at first but he related realized that I have never cheated on him, He told me that we will get through this together. He is supportive but he was tested negative and we don't know why, but God knows."

The news about HIV/AIDS was generally received with sadness and panic. The disease is perceived to be dreadful and fearful. Besides the stigma still attached to HIV, all of the participants related that they have disclosed their statuses to their husbands, and those who are single have disclosed to their family.

South African AIDS information Dissemination Service (2003:5) states that disclosure means the giving out of information, which might commonly be kept secret, usually voluntarily, or to be in compliance with legal regulations.

Mdlalose (2006:23) citing Makhokha (2000) states at the time of positive test results, women are usually advised to notify their partners about their condition. HIV positive women are also encouraged to obtain regular medical care, to take steps to stay healthy and to make plans about the future of their children as their illness progresses. This can only be attained if they disclose their HIV positive status.

Taylor et al. (2012:135) state that depending on the setting, levels of disclosure of newly diagnosed pregnant women about their HIV status vary, and there are cultural factors that influence the patterns of self-disclosure to partners and other social network members. Disclosure should be encouraged in all cases, but may be viewed as a process that may take some time. There are situations where a newly diagnosed HIV-positive woman refuses to disclose to a current sexual partner, or appears to want to delay disclosure indefinitely. This can give rise to very complex professional, ethical, moral and potentially, legal situations.

Hackl et al. (1997:350) state that sharing an HIV diagnosis with others presents a double bind to most individuals. On the one hand revealing one's status may lead to rejection, isolation and potential loss of self-esteem. Consequently, some individuals avoid disclosing and seeking help to protect themselves from social isolation and discrimination. On the other hand, keeping diagnoses a secret leaves the individuals vulnerable to having to bear the burden alone.

Disclosure of HIV status is a planned and selective behaviour which responds to the person's balance of potential risks and benefits of secrecy and disclosure. It might also be considered to be an expression of responsibility towards a spouse or sex partners. Disclosure to others, lovers, family or friends, has been shown to be a potent stressor, as individuals living with HIV/AIDS might fear negative reactions such as blame, rejection or violence (Titilope, Adediran, Umeh, Akinbami, Unigwe & Akanmu, 2011:14).

Some had to say this concerning their disclosure:

“Disclosing to my family was something which I don’t regret, I felt much lighter after disclosing because they supported me.”

“I felt I can be able to fight this virus after disclosing.”

“I have learnt that family is everything, they didn’t turn their back on me. I am very happy.”

The belief that disclosure of HIV status to sexual partners will lead to rejection and stigmatization appears not to be true, nine participants in the study expressed no regret for disclosing their status. Participants realized family can help them fight the disease and the stigma. One participant mentioned that at first her partner did not trust her thinking and that she is the one who brought the virus at home, but she also mentioned he supported her later.

A study conducted by Kasenga et al. (2008:33), also found out there were positive responses by spouses to women disclosing their HIV positive status. Some women found support and a deeper emotional relationship with their spouses. At the time of positive test results, women are usually advised to notify their partners about their condition. HIV positive women are also encouraged to obtain regular medical care, to take steps to stay healthy and to make plans about the future of their children as their illness progresses. This can only be attained if they disclose their HIV positive status (Mokhoka, 2000:56).

3.8.2.6.2 Sub-theme 6.2 Support system

The following are the participant’s responses in relation to their support system:

“My grandmother, my mother and my boyfriend are very supportive, my mother is also HIV positive, she told me that everything is going to be okay.”

“My family and also my brother are very supportive but they were shocked because I tell them as I do not have a problem because I was already accepting that I am HIV positive.”

“No one knows about my status only my husband and he is very supportive.”

“Honestly my family is the best, they are the one who support me and show me love through dark and night, even my social workers and my nurses more especially when I go to the clinic. Support is the one keeping me going from now.”

All participants related that family and partner are very supportive. They have not disclosed to the community as they are afraid of stigmatization. Their support systems give them hope to continue with life. Psychosocial support addresses the ongoing psychological and social problems of HIV infected individuals, it is important for an HIV pregnant mother to get continuous support.

WHO (2008:18) states that HIV infection affects all dimensions of a person's life: physical, psychological, social and spiritual. Counselling and social support can help people and their carers cope more effectively with each stage of the infection and enhance quality of life. With adequate support, PLWHA are more likely to be able to respond adequately to the stress of being infected and are less likely to develop serious mental health problems. UNAIDS (2005:3) further stated that care and support for people living with HIV can help to protect the health of the public at large by making prevention more effective. This supports the biopsychosocial approach. This differs with what Schuster, Kanouse, Morton, Bozette, Miu, Scot and Shapiro (2000:1074) said, that women who are diagnosed with HIV may have limited financial, social and emotional resources to draw upon while raising their children. Most infected women depend on public and charitable resources that cover such services as income, supplementation, health care, child care and bereavement support.

This theme demonstrated that support is of paramount importance when one is in need. This theme also reflected on the importance of disclosure and maintaining a good relationship to be able deal with the diagnosis. It is therefore concluded that the partner and family support plays a vital role in fighting HIV. Currently there is no cure for HIV and AIDS and it is clearly progressive and always fatal. As it is a life threatening illness, an ill person fears an end to life before his or her life plan can be completed, but with family and society's support, a person's life can be strengthened. This is in line with the biopsychosocial approach as support helps an HIV infected (bio) person who is in fear (psycho) to regain a sense of control and ownership of her life. Once HIV infected people reach the advanced AIDS stage, they can no longer meet their occupational, family and social obligations (social) as fully as they did before they were infected.

3.8.2.7 Theme 7: Recommendations

The following quotes indicate what participants had to say when making recommendations for health care professionals:

“Government should always employ good people, maybe their calling not just walking to get money or to get salary, only just to help people, you know some people works for money, they don’t have patience to help people.”

“Professionals are good to patients who are emotional hurt, they can handle their situation of the patient to emotional done, I can rate the professionals 10 out of 10.”

“Their services are very good at what they are doing, they tell you the truth, is that people they don’t care. They give full support and they don’t judge. What I can say is that it is very difficult to work with someone who is HIV positive but then they have to look forward and work hard to support mothers with HIV, and the only thing I can talk about is the nurses and the social workers to me they are doing a good job, they are working very hard, they are helping us and they keep the secret within themselves.”

Apart from the majority who felt the professional services were excellent the participants as indicated below felt that they were judged by the professionals. Those who felt judged are the ones who also did not have knowledge on PMTCT. This is what those who felt judged by the professionals said:

“I felt one of the nurses was judging me, she kept asking questions that I couldn’t answer and that time I was still in a shock, I felt guilt even though I didn’t know how I got the virus but at the end they treated me very well.”

“You don’t have to judge people yes, I felt that sometimes they were judgemental.”

“Nurses are very knowledgeable but I felt sometimes they were looking down on me because I am sick.”

The study also revealed that three participants felt unhappy about the treatment from the health care professionals. It is therefore recommended that health care professionals must at all times adhere to ethics around the profession.

Manyani and McIntyre (2013:64) state that there is evidence to suggest that the patient-provider relationship may have an effect on decision-making during the antenatal period, and on the uptake of interventions. The health care system and patient factors are important in the scale-up and success of HIV programmes (including PMTCT), as well as the availability of interventions alone is not sufficient to guarantee appropriate implementation and uptake.

Health care facilities need to be well-resourced with competent and motivated staff to provide the services, and there needs to be service uptake and treatment adherence by patients. The providers' and patients' knowledge and attitudes are important (Manyani & McIntyre, 2013:64).

From what the participants said about the professionals, it can therefore be concluded that their services were experienced as excellent, though a few of the participants felt judged by the nurses. From what the researcher gathered from the participants' feedback, it can be concluded that professionals are knowledgeable about HIV. Only a few who related to have felt judged, are the ones who seemed to not have much knowledge on HIV and the treatment and therefore it can be concluded that they were ignorant or in denial throughout the process. They could however, not verbalize their ignorance in the interview. This supports the biopsychosocial approach, in the sense that living with HIV affects the biological, psychological or social spheres of the person. This is understandable and then still needs to be seen in a cultural context, meaning that it needs a multi-disciplinary team to be able to help an HIV infected individual holistically. A positive client/health worker relationship increases the chance of adherence in taking ARV treatment.

3.9 Summary

This chapter was guided by the research methodology herein discussed. Data from semi-structured interviews were transcribed in order to identify themes and sub-themes. Quotes were used to substantiate the themes through direct quotations and with integration of literature where applicable to substantiate.

Seven themes emerged from the data: Knowledge of HIV, Diagnosis, Experiences of living with HIV and pregnancy, Treatment, PMTCT and disclosure and relationships.

The conclusion and recommendations of the study will be presented in the next chapter.

4 CHAPTER FOUR: CONCLUSIONS AND RECOMMENDATIONS

4.1 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.

The chapter seeks to explain how the researcher achieved the goal and objectives of the study. The researcher will explain how the objectives were achieved by highlighting the main findings of the study. Conclusions will be drawn from the study and recommendations will be made on the key findings of the study. Lastly, recommendations will be put forward for practice and future research.

4.2 Summary

The researcher will discuss below, the objectives and goal of the study and how they were met. 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.

4.2.1 Goal and objectives of the study

The goal of this study was: to explore and describe the experiences of women diagnosed with HIV during their pregnancy.

The goal was achieved through the attainment of the following objectives, which will each be discussed and how this was attained.

- **To contextualise HIV during pregnancy**

This objective was realised from chapter 1 in the introduction, whereby the researcher pointed out that HIV infection in pregnancy has become the common complication of pregnancy in some developing countries. This has major implications for the management of pregnancy and birth. Also in chapter 2 in the literature study, where it was discussed how HIV has had a worldwide impact and there are virtually no areas that have not reported cases of infection, and that a number of factors are believed to have influenced the patterns of HIV epidemic

globally. Despite the fact that these biological aspects of HIV are not entirely relevant to the study, but looking at the biopsychosocial approach, it is important to acknowledge them as an important part of HIV and AIDS. The pandemic is affecting the lives of many individuals, families and communities (Kennedy, 2003:15). It was also confirmed by Mswela (2009:173) who said that the burden of HIV/AIDS does not fall evenly or equally. Human immunodeficiency virus (HIV) is the virus that causes acquired immunodeficiency syndrome (AIDS) in humans. The HI-virus is found in blood, semen, vaginal fluids and in breast milk, and is transmitted through sexual contact with an infected person; through mother-to-child-transmission (MTCT) before or during birth, or through breast-feeding; or through contact with infected blood and blood products. From the literature review it is also evident that many women only discover their HIV-positive status once they are pregnant and making the use of antenatal services. Receiving an HIV-positive diagnosis during pregnancy was found to be traumatic, as HIV-positive diagnosis is further complicated by the foetus and health of the pregnant mother. Being diagnosed with HIV during pregnancy is distressing for the newly diagnosed women, as she is concerned about her own and her child's wellbeing. In particular, she may fear transmitting the virus to her infant.

The overwhelming majority of those currently living with HIV/AIDS are young women in the developing countries. Mswela (2009) further stated that the epidemic continues to have a disproportionate impact on women, with a number of premature deaths in South Africa. Many women only find out their status when they are pregnant.

- **To explore and describe the experiences of pregnant women diagnosed with HIV once hearing the diagnosis**

The psychological factors associated with HIV and pregnancy dealt with in this study was discussed at length in chapter 2. 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. The objective was realized in chapter 2, section 2.8.1 where it stated that diagnosis during pregnancy may be a profoundly shocking and life-changing experience for the newly diagnosed HIV-positive women. It was noted that diagnosis may be a complex mix of emotional, psychosocial, relationship,

economic and even legal issues that arise directly out of the HIV diagnosis. The newly diagnosed woman also has a relatively brief time in which she needs to develop trust in her medical service providers and attain sufficient medical knowledge of her situation to be able to make informed decisions that will affect the long-term health of herself, her foetus and her male partner.

This was confirmed by UNAIDS (2002:1) who said that HIV is an illness that is incurable, contagious, disfiguring, and still, somewhat mysterious. Thus from the time of diagnosis, people confront not only the actual and potential physical devastation that their illness can wreck, but also social constructions that encourage blame and dread in themselves and others.

In the present study participants stated that their initial reactions included: shock, denial, sadness, fear of death and leaving their children destitute, self-blame, guilt and anger. Even though these reactions are normal and expected psychological responses, they however, as supported by Tilley (2003:60) negatively affect their future plans.

Women sampled in this study related that the diagnosis shocked them but this did not lead them to lose hope, except few who thought they will die and leave their children. With the support from the family, they were able to accept the situation for the sake of their children and the babies. This was further confirmed by Kalichman (1995:154) who said feelings of sadness, worry, despair and confusion are just a handful of the assorted reactions to HIV that an individual may experience, and these emotions are often compounded by several other affective, cognitive and behavioural responses.

Forsyth (2007:40) 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 blamed their partners for their HIV-positive diagnosis, as they were faithful to the relationship; however very few were blamed by their partners just after disclosure, but later the partner became supportive.

Chapter 2, Section 2.5 also discussed how 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 the pregnancy. Additionally, the present study found that the experience of pregnancy was only felt when women were reassured that their babies could be protected from infection through antiretroviral treatment.

- **To explore and describe how living with HIV during pregnancy influences the maternal needs of pregnant women**

This objective set out to explore how women with HIV during pregnancy are influenced with regard to their maternal needs. The maternal needs of pregnant women were discussed in chapter 2 where it focused on firstly maternal health and PTMTC and its application. In chapter 2, section 2.7 the researcher discussed prevention of transmission of HIV infection from mother-to-child. Many advances have been made in developing effective and affordable interventions that reduce the likelihood that a woman will pass HIV on to her baby. The two most important interventions are the provision of antiretroviral drugs and exclusive breastfeeding for six months, which only applies to HIV-positive women who are on ARVs, was discussed. Both therefore require that a woman know her status.

In chapter 2 the researcher also discussed the maternal health with the focus on the health of women during pregnancy, childbirth, and the postpartum period. It encompasses the health care dimensions of family planning, preconception, prenatal, and postnatal care in order to ensure a positive and fulfilling experience, in most cases and reduce maternal morbidity and mortality in other cases. Chapter 2, section 2.8 discussed the fact that the majority of pregnant women discovered that they were HIV-infected during pregnancy, and although disclosure to partners was high, less than half knew their partner's HIV status. There were important deficiencies in the women's knowledge of the available PMTCT interventions, despite receiving counselling and their perception that the counselling that they received was adequate. There are still several challenges in PMTCT services. Most importantly, knowledge of PMTCT interventions is surprisingly low in both clients and health care providers, and from the discussion it shows there is a need for enhanced interventions to improve the quality of care in PMTCT services. This is

particularly important as PMTCT interventions becomes more complex during the ante- and postnatal periods.

The research revealed that 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. The biopsychosocial approach serves to be the most appropriate for the study as it looks at the medical (bio), psychosocial (emotional) response of pregnant women. The expectation of the patient is that the health professional has the professional competence and motivation to provide support. In practical terms the health professional's tasks are, first to learn how and what the patient is or has been feeling and experiencing.

- **To make recommendations for practice with regards to the needs of pregnant HIV positive women at antenatal clinics**

Recommendations were made in this chapter for practice with regards to the needs of pregnant HIV positive women at antenatal clinics.

The majority of the participants reported that health care professionals made it easy for them to accept their status and move on with their life. The researcher therefore recommends that support and encouragement from health care professionals and reassurance regarding treatment such as ARV to promote well-being, can prolong the life of the HIV positive woman. It was also noted that patient/worker relationship is of paramount concern, so the patient can feel free to ask any questions around HIV and treatment. Health care professionals need to realize that support needs to come from them before they can disclose at home.

This links with the biopsychosocial model which highlighted that the systems-oriented health professional is conscious of responsibilities to the patient and to his family and significant others. At least for the duration of the illness, the two-person system, of doctor and patient, is interposed between the patient and the others constituting his social environment.

4.2.2 Research Question

What are the experiences of women who are diagnosed with HIV during pregnancy?

The research question was demarcated into specific areas which are the main themes of the study. These themes are visually represented in Table 4.1 below:

Table 4.1: Themes and Sub-themes

Themes	Sub-themes
Theme 1: Knowledge of HIV	Understanding of HIV
Theme 2: HIV diagnosis	Reaction to the HIV diagnosis Coping with HIV
Theme 3: Experiences of living with HIV	
Theme 4: Treatment	Experience regarding ARV treatment Experience regarding Health Care services
Theme 5: Knowledge of mother-to-child transmission	PMTCT Infant feeding options
Theme 6: Disclosure and support	Disclosure of HIV status Support system
Theme 7: Recommendations	

4.3 Key findings, conclusions and recommendations

The key findings, conclusions and recommendations will be in three categories, namely key findings and conclusions regarding the appropriateness and value of the research methodology and the literature review, as well as the key findings conclusions and recommendations regarding the research findings.

4.3.1 Key findings and conclusions regarding the appropriateness of the research methodology

The study was qualitative in nature as it seeks to understand and explore the experiences of pregnant women who were diagnosed with HIV during their

antenatal visits, the impact the HIV diagnosis made on their lives, and come up with possible recommendations on how social workers can use these experiences to address the problems women face when diagnosed. The key finding in this regard was that the participants were able to share their experiences regarding their HIV diagnosis in a non-threatening environment. The approach in this study was qualitative, with the focus on the meaning of how people make sense of their life's experiences and how they structure their worlds. It is therefore concluded that the methodology used in the study helped the researcher to gain more insights on the problem

The study adopted phenomenological research as a research design, in which the researcher identifies the essence of human experience about phenomenon as described by participants, understanding the lived experiences marks phenomenology as a philosophy as well as a method. The researcher studied a small number of subjects through extensive and prolonged engagement to develop patterns and relationships of meaning. The key finding is that the phenomenological design was applicable as the researcher was able to gather rich data of a sensitive nature from the participants.

The study adopted applied research as it was designed to offer practical solutions to a concrete problem or address the immediate and specific needs; the key finding is that there are immediate and specific needs which need to be addressed by the government and other policy makers with regard to HIV and pregnant women. It can be concluded that the needs of pregnant HIV women need to be taken into consideration.

The sample of this study consisted of 10 pregnant women who were selected using non-probability purposive sampling. The criteria for selection was: women who were diagnosed with HIV during visits to the antenatal clinic at the Protea Glen Health Centre, Soweto. These are HIV positive women, aged 25-35 years, who gave birth three months prior to the study. These women were due for their 3-month antenatal follow-up visits and they were conversant in English. The methods of data collection included semi-structured interviews that were voice recorded with their permission. It involves direct personal contact with the participant. The method of data analysis included: organising and preparing data for analysis, data collection and preliminary

analysis, managing data, reading and writing memos, generating and coding the data, testing emergent understandings and searching for alternatives, interpreting and developing typologies and presenting the data. Strategies of trustworthiness included: the description of research findings in a way that authentically represents the meaning as described by the participants. The researcher interacted with the participants for a prolonged time and consequently this allowed for rich data collection and for the researcher to gain adequate understanding of the experiences of the participants to make sure that it is credible. The researcher interacted with the participants until data saturation. Ethical considerations were adhered to. All research methodology was found to be appropriate.

4.3.2 Key findings and conclusions regarding literature review

The key literature review findings did not differ much from the actual study findings. Literature reviews shared that HIV diagnosis during pregnancy may be a profoundly shocking and life-changing experience for newly diagnosed HIV-positive women. There may be a complex mix of emotional, psychosocial, relationship, economic and even legal issues that arise directly out of the HIV diagnosis. The newly diagnosed woman also has a relatively brief time in which she needs to develop trust in her medical carers and attain sufficient medical knowledge of her situation, to enable her to make informed decisions that will affect the long-term health of herself, her foetus and her male partner. Another key literature review finding includes feelings of profound grief that are experienced by everyone affected by HIV infection. Most people with HIV infection are concerned about the question of procreation, an issue which often concerns those who face terminal illness. Many of the women affected by HIV will already be in a vulnerable position. Literature findings also discussed the maternal health and needs of the HIV pregnant women.

4.3.3 Key findings, conclusions and recommendations regarding the empirical study

The findings of the empirical study will be discussed according to the themes which were generated throughout the interviews. A discussion on the key findings, conclusions and recommendations of the themes follows.

4.3.3.1 Theme 1: Knowledge of HIV

This theme focused on the participants' general knowledge around HIV.

4.3.3.1.1 Key Findings

Generally participants demonstrated knowledge of the HIV virus, although they mostly only indicated that it is a virus which is incurable that passes through sexual intercourse. Very few indicated all three means of transmission, namely, through sexual intercourse, blood contamination and mother-to-child transmission. The study revealed that majority of the participants viewed HIV as a virus which passes through intercourse which then leads the researcher to conclude that they had minimal knowledge around HIV. The responses of the participants are in line with how the Centre for Disease Control defines HIV, namely as a virus which is spread through certain body fluid that attacks the body's immune system. Unlike some other viruses, the human body cannot get rid of HIV which means that once you have HIV, you have it for life.

4.3.3.1.2 Conclusions

The researcher therefore concludes that HIV and pregnancy continue to be a significant public health problem, despite rapid advances in knowledge about HIV and its mode of transmission and knowledge of HIV/AIDS is of paramount importance to every woman who tested positive.

4.3.3.1.3 Recommendations

- The researcher recommends the strengthening of antenatal classes as a strategy of managing pregnant women diagnosed with HIV.
- The study recommends that women still need to be educated to improve their knowledge of HIV and AIDS.

4.3.3.2 Theme 2: HIV diagnosis

This theme focuses on the participants' HIV diagnosis, receiving HIV results and coping with the virus and pregnancy at the same time.

4.3.3.2.1 Key findings

The study revealed that the respondents became aware of their HIV-status during pregnancy when they underwent testing. All of the participants reported that they were scared when told that they were HIV positive, the majority related that they felt the counsellor was joking when she gave them a positive results. It is important to note that the fear associated with HIV has a general pattern. This fear and anxiety is caused by the stigma and discrimination people experience when they test positive for HIV. It was observed in the study that participants had negative responses when they were told about the HIV positive results. The respondents stated that their initial reactions included; shock, denial, sadness, fear of death and leaving their children destitute, self-blame, guilt and anger. Even though these reactions are normal and expected psychological responses, they however negatively affect their future plans.

4.3.3.2.2 Conclusions

It is concluded that finding out about HIV status while pregnant poses many challenges to a pregnant woman, as they have to focus on being pregnant and the diagnosis as well. The research also concludes that pregnant women diagnosed with HIV are a unique class of HIV/AIDS patients whose numbers are increasing and therefore require special attention as they are carrying another life in them.

4.3.3.2.3 Recommendations

HIV is a sensitive issue and for those women with partners it is recommended that government should review its policy on confidentiality around HIV testing while pregnant. The researcher recommends that for those women who have partners, testing should be done to both of them to avoid stigma and rejection. The researcher is of the view that most of the reactions after the diagnosis manifest because mainly of fear of what the partner will say when finding out about the diagnosis. The study also recommends the immediate enrolment of women who are HIV during pregnancy in a support group. Support groups are a long-term mechanism which could assist them during their journey into the unknown, this can help them to realize that they are not alone, feeling accepted, feeling important, having a safe environment in which to discuss their problems, fears and experiences with similar

others, having the opportunity to support and be supported and experience a sense of belonging.

4.3.3.3 Theme 3: Experiences of living with HIV Status

The above theme concentrated on the women's experiences of living with HIV while pregnant.

4.3.3.3.1 Key findings

Finding out about the HIV diagnosis can propose numerous traumatic reactions including: fear of death, deterioration of interpersonal relations, negative emotions, rejection of the HIV antibody test, stress related to keeping your status a secret, anxiety, depression, guilt, loss of support, isolation, and difficulties with family dynamics. These are feelings experienced by the participants after diagnosis and throughout the pregnancy. The research also found that a HIV diagnosis provides concrete evidence that being HIV positive and pregnant at the same time is not a good experience; one is often filled with mixed emotions and uncertainties. The findings also indicate sadness and fear among HIV positive pregnant women, sadness in response to their HIV-positive status and at the possibility of not seeing their babies grow up. The study further concludes that the reality of an HIV diagnosis in pregnancy remains the same globally and continues to affect women who are diagnosed with HIV during pregnancy.

4.3.3.3.2 Conclusions

It is therefore concluded women who were diagnosed with HIV during pregnancy face many challenges including fear of disclosure, stigma attached to HIV, stress and confusion. It is also concluded that an HIV-positive diagnosis in pregnancy is a stressor that has been found to increase significantly the fear of death and the transmission to the child.

4.3.3.3.3 Recommendations

From what has been gathered from the study, it is therefore recommended that it is important to continue with testing of women during pregnancy for HIV/AIDS, but there should be adequate psycho-social support immediately at the point of awareness. The researcher also recommends combined testing for both pregnant

women and their partner so they can share their feelings. The team for HIV/AIDS at the clinic should include at least a full time clinical psychologist and fulltime social worker to be responsible for the provision of counselling for the patients.

4.3.3.4 Theme 4: Treatment

This theme was about the participant's experience on treatment and health care services.

4.3.3.4.1 Key Findings

The study revealed that participants were aware that the implementation of ARVs plays a significant role as a strategy utilized to prevent HIV transmission to unborn babies. Early initiation of ARVs during pregnancy, for example, at 14 weeks of pregnancy, substantially reduces the chances of transmission of HIV. The study revealed that because of education level some participants had minimal knowledge about the ARVs. Though participants are conversant in English, a language barrier was found to be a problem when receiving education on ARV. The study also revealed that participants had different views about health care services and professionals.

4.3.3.4.2 Conclusions

Even though participants were given education on HIV treatment, they could not master the name of medication because of the language barrier. The study also concludes that health care providers play an important role in clients' lives by rendering direct services to them, educating them on antiretrovirals and providing psychosocial support.

4.3.3.4.3 Recommendations

The study recommends that there is a need for professionals who are multilingual and equipped to give ARV education on treatment to patients in their own language, so that they can understand better. The study also recommends continuous education of health workers to improve their knowledge on treatment as there is always research and changes when it comes to HIV.

4.3.3.5 Theme 5: Knowledge of mother-to-child transmission

This theme pertained to women's knowledge and experiences of mother-to-child transmission.

4.3.3.5.1 Key findings

The study revealed that although the participants included in the study had different opinions and knowledge of MTCT of HIV infection, they also had different attitudes with regard to the prevention of MTCT. The shared knowledge was related to a lack of understanding of the meaning of MTCT and its importance. On the one hand, existing knowledge about prevention of MTCT was reflected by a participant by outlining that it is when the mother is saving the baby from being infected with HIV. The study found that certain participants had minimal knowledge on MTCT. This was confirmed when some could not give names of treatment they are using; it was observed that it was due to the language barrier.

4.3.3.5.2 Conclusions

The study also concludes that health care professionals need to be encouraged to continue to demonstrate positive attitudes towards the programme users as this will increase the utilization of MTCT services. The study further concludes that an effective antenatal mother-to-child transmission (PMTCT) programme reduces perinatal acquired HIV infections. This was confirmed by the fact that all children born of participants tested negative. The study also concludes that early antenatal attendance and knowledge of HIV status allows sufficient time to implement ARV intervention.

4.3.3.5.3 Recommendations

The research recommends that education on MTCT be given to both mother and father so they can help each other with the treatment. It is also recommended that education on reproductive health options (labour, delivery, breastfeeding and PMTCT) should be continuous from the day of diagnosis. Community education about the importance of voluntary antenatal counselling and testing and PMTCT should be strengthened. It will encourage community involvement and the reduction of stigma and discrimination in the society.

4.3.3.6 Theme 6: Disclosure and support

The theme presents findings and recommendations on HIV disclosure, and support systems.

4.3.3.6.1 Key findings

The study revealed that the news about HIV diagnosis was generally received with sadness and panic but with courage it becomes easier to disclose the diagnosis to the family. The study also found that psychosocial support is very critical for women who tested positive; it was evident from the study as all women responded that they were able to cope with the virus because of support they got from the partners and family. The findings can also suggest that government should look into the legislation around testing. The researcher is of the view that pregnant women should attend their first antenatal class with their partners, though some of the participants highlighted shock and disbelief when disclosing to their partner, it later had a positive outcome as they accepted the situation. This shows that family support is of importance.

4.3.3.6.2 Conclusions

It is concluded that the process of acceptance of loss is a painful one for HIV-positive pregnant women, but family relationships play a vital role in accepting the HIV diagnosis. The study also concludes that continuous education and awareness on HIV within the community is needed, so that those who were diagnosed could feel free to disclose. Women grieving about their HIV-positive status need reassurance, counselling and support.

4.4 Recommendations

This section will focus on the recommendations for future research and for practice and future research.

4.4.1 Recommendations for practice

The recommendations may be of interest to social scientists, policy makers as well as health care professionals whose work involves recently diagnosed HIV positive women who were diagnosed during pregnancy.

It is recommended that HIV positive mothers be encouraged to use family support as it is of paramount importance. The study also recommends that psychosocial support should continue to address the ongoing psychological and social problems of HIV infected individuals.

It is recommended that professionals should receive regular refresher courses and psycho-social support, as burnout from work may lead to poor quality services. The study recommends implementation of a peer support group for continuous support for women diagnosed with HIV.

The study also recommends the use of social networks such as WhatsApp social group, in case women are unable to meet in certain places to join support groups. This can help women to educate each other on different topics around HIV, including treatment and the MTCT process; women can remain anonymous to the group.

4.4.2 Recommendation for future research

The researcher recommends that future researchers must focus on the following topics to get a different experience:

- Experiences of men whose partners tested positive during pregnancy and it would also be advisable to evaluate the testing process for pregnant women.
- Experiences of women who gave birth to HIV children.
- It would also be interesting to do a continuous study on communities' knowledge on HIV in general as there are always new developments on the topic.
- Experiences of health care professionals who do HIV testing on a daily basis.
- Mourning process of HIV infected patients.

The study concluded that bio-psychosocial attempts to explain and predict a dualistic view of human experience in which there is a mutual influence of the mind and body. It focuses on the promotion and maintenance of health through socio-environmental and behaviour change. The perspective emphasizes the role of people's behaviour, what they live and their access to health services in determining their health status.

The researcher was of the opinion that the bio-psychosocial model addresses HIV in pregnant women because HIV is a biological factor, as it infects the human body and after the infection the person has to deal with emotions such as anger, denial, frustrations, guilt, and sadness which are the psychosocial factors which will then determine a person's behaviour towards the disease.

The psychological factors associated with HIV dealt with in this study were discussed at length in chapter 2. The literature also discussed how HIV presents a multitude of different sources of depression, such as discrimination, stigma, violence, rejection, fear of infecting others, worrying about blood test results, concern about opportunistic infections, and the fear of death.

HIV/AIDS has been described as the ultimate biopsychosocial phenomenon, as its impact is not only limited to the immune system, but also to the social network, psychological functioning, culture and religion of individuals (Schneider, 1989). Holland and Tross (1985) described a three-phase model illustrating the factors associated with an HIV diagnosis:

- Medical factors (e.g. symptoms, course and complications);
- Psychological factors (e.g. personality, coping and social support); and
- Sociological factors (e.g. stigma, custom, belief and value).

Therefore, the study nestles into the biopsychosocial theory as it provides avenues to the understanding of health behaviours, beliefs, and attitudes and why women diagnosed with HIV during pregnancy behave as they do.

4.5 Concluding remark

HIV remains the leading cause of death among women of reproductive age. HIV testing in South Africa is perceived as compulsory for all women attending ANC at the health care centres and it is beneficial for mothers, especially those who tested HIV positive and their unborn babies. Knowledge of one's status helps one to plan ahead of the baby that is on the way. Pregnant women are encouraged to ask their partners to accompany them to the antenatal clinics so that they can go through the pregnancy process together. Women through the help of the health professionals are encouraged to link with home-based care services and social support groups,

so that they can get to share their experiences with other women who are in the same position. Women are further encouraged to equip themselves with knowledge around HIV and PMTCT. HIV is no longer a death sentence, it is a chronic disease, and one only needs to adhere to treatment, learn to live with this chronic disease and live a healthy life. This research will help women to close the gap around HIV knowledge and coping with the diagnosis during pregnancy.

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6 ANNEXURES

6.1 Annexure 1: Ethics approval, UP



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Research Ethics Committee

31 August 2015

Dear Prof Lombard

Project: Experiences of women diagnosed with HIV during pregnancy
Researcher: PM Netshimbupfe
Supervisor: Dr C Carbonatto
Department: Social Work and Criminology
Reference numbers: 13332423 (GW20150802HS)

Thank you for your response to the Committee's correspondence of 12 August 2015.

The **Research Ethics Committee** notes that the outstanding permission from the *Johannesburg Health District* was submitted as requested and has therefore given **final approval** for the above application at an *ad hoc* meeting on 31 August 2015. Data collection may therefore commence.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should the actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

The Committee requests you to convey this approval to the researcher.

We wish you success with the project.

Sincerely

Prof Karen Harris
Acting Chair: Research Ethics Committee
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail: Karen.harris@up.ac.za

Kindly note that your original signed approval certificate will be sent to your supervisor via the Head of Department. Please liaise with your supervisor.

Research Ethics Committee Members: Dr L Blokland; Prof Prof M-H Coetzee; Dr JEH Grobler; Prof KL Harris (Acting Chair); Ms H Klopper; Dr C Panebianco-Warrens; Dr Charles Puttergill; Prof GM Spies; Dr Y Spies; Prof E Taljard; Dr P Wood



6.2 Annexure 2: Permission letter



GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA



a world class African city

JOHANNESBURG HEALTH DISTRICT

26 August 2015

P.M. Netshimbupfe
Pfarelo.nicro@yahoo.com

Enquiries:
Hillbrow CHC Administration Building, Klein Street
Hillbrow, Johannesburg
E-mail:
CoralF@joburg.org.za
Johannesburg_research@gmail.com

Dear Ms Netshimbupfe

Re: *Experiences of Women diagnosed with HIV during Pregnancy*

Your application dated 1 June 2015 refers. The District Research Committee has reviewed your application. This letter serves as an in-principle approval to access the Districts Health facilities (mentioned below) for the above project subject to following conditions:

- The facility to be visited: Protea Glen Clinic
- The research can only commence after you submit an ethics clearance certificate from a recognized institution.
- You will report to the Facility Manager before initiating the study.
- Participants' rights and confidentiality will be maintained all the time.
- No resources (Financial, material and human resources) from the above facilities will be used for the study. Neither the District nor the facility will incur any additional cost for this study.
- The study will comply with Publicly Financed Research and Development Act, 2008 (Act 51 of 2008) and its related Regulations.
- You will submit a copy (electronic and hard copy) of your final report. In addition, you will submit a six-monthly progress report to the District Research Committee. Your supervisor and University of South Africa will ensure that these reports are being submitted timeously to the District Research Committee.
- The District must be acknowledged in all the reports/publications generated from the research and a copy of these reports/publications must be submitted to the District Research Committee.

We reserve our right to withdraw our approval, if you breach any of the conditions mentioned above.

Please feel free to contact us, if you have any further queries. On behalf of the District Research Committee, we would like to thank you for choosing our District to conduct such an important study.

Regards,

Dr R Bismilla
Executive Director
City of Johannesburg
Date: 26/8/15

6.3 Annexure 3: Letter of informed consent



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Department of Social Work &
Criminology

Letter of informed consent

Research title: Experiences of women diagnosed with HIV during pregnancy

Researcher: Pfarelo Myrah Netshimbupfe

Introduction

My name is Pfarelo Myrah Netshimbupfe and I am currently doing a Masters of Social Work degree in Health Care at the University of Pretoria. I will be conducting a study on the above topic as part of the requirements of my postgraduate studies.

Procedure

The researcher will arrange an interview date and time that suits you. A one-on-one interview will be conducted at the respective health facility you attend. The interview will take approximately 45 minutes and it will be voice recorded with your permission. The researcher will read and explain to you the content of the informed consent letter, to ensure that you understand what the research entails and what is expected of you. Before signing this consent form, the researcher will give you the opportunity to ask questions or seek more clarification to enable you to make an informed decision. Two copies of the consent form will be signed, one will be kept by the researcher and the other by you.

Purpose of the study

Pregnancy brings joy and challenges with responsibilities and therefore the impact of being diagnosed with HIV may pose a challenge to pregnant women; having to focus on the HIV status and pregnancy can be stressful and exhausting. The goal

of this study is to explore and describe the experiences of women diagnosed with HIV during their pregnancy.

Confidentiality

Confidentiality will be kept at all times and the researcher will not use your name, but instead a pseudonym or number will be assigned to you to protect your identity and the data will be stored under this number assigned to you. Only the researcher and supervisor will have access to this data.

Potential Harm

As this is a sensitive topic, there could be possible emotional pain during the interview. The researcher will do debriefing after the interview and if needed, you will be referred to a social worker who works at the clinic for counselling.

Remuneration

The researcher will not remunerate you for partaking in this study. Participation will be voluntary and the researcher will conduct the interview at a time which suits you, at the health facility, which will be accessible to you.

Participation and withdrawal

Even if you agreed to partake in this study, you have the right to withdraw at any time of the research process without any consequences. In addition, if you choose to withdraw, it will not affect the care you receive at the clinic and there will be no consequences.

Potential benefits of the research

You will not benefit directly from partaking in the study. The researcher hopes that the study will give a better understanding of pregnant women and their experiences after an HIV diagnosis, so as to improve health services by making recommendations to staff and management concerning the support needed by HIV pregnant women.

Details of the investigator

If you have any questions or concerns about the study, feel free to contact:

Pfarelo Myrah Netshimbupfe. (**Principal researcher**)

Cell number: 0764148541

Email: pfarelo.nicro@yahoo.com

Signature and consent of participant

I..... (*name of participant*) declare that I have read and understood the above information. I was given adequate time to consider my participation in the study. I was also given the opportunity to ask questions and all of them were answered to my satisfaction. I am hereby consenting voluntarily to participating in this study.

Name:

Signature:..... **Date:**.....

Declaration by the researcher

I declare that I explained the above information to (*participant*)..... who was given ample time to ask any questions.

Name:

Signature:..... **Date:**.....

6.4 Annexure 4: Interview schedule

Theme 1. Biographic information

Age.....

Marital status.....

Number of children.....

Religion.....

Home language.....

Highest qualification.....

2. Knowledge of HIV

- Tell me what you understand by HIV?

3. Experiences of living with HIV during pregnancy

- How did u get to know your HIV status?
- What was your reaction when you were given the diagnosis?
- What were your experiences of living with HIV during pregnancy?
- How did it feel being pregnant and having HIV at the same time?
- Who else knows about your status?

4. Treatment

- What were your experiences regarding health care services?
- Have you started ARV and if so, when?
- How has your experience of the ARV treatment been?
- Any side effects experienced thus far?

5. Baby

- Did the baby receive ARV after birth?
- Do you have knowledge on prevention of mother-to child transmission?
- Tell me how you have fed your baby since birth.
- How is the health of your baby?

6. Coping with the diagnosis

- Have you accepted your HIV diagnosis?
- What do you do to cope with living with this disease every day?
- Who offers support to you?
- How do you experience people's attitude to HIV in general?

- How do people react to your HIV status?

7. Relationships

- Does your partner know of your HIV status?
- Is your partner father of the baby?
- Has your partner tested for HIV?
- What was his reaction to your diagnosis?
- If you have not told him yet when and how do you plan to?

8. Other children

- Do you have other children?
- What is their HIV status?
- Are they aware of your status?

9. Family

- Do family know your status? If so, then who?
- Their reactions to the news?
- Their attitude toward you?
- Their attitude toward baby?

10. Income

- Who provides for you and baby financially?
- Have you ever worked? Provide details.
- Are you returning to your work?
- Employer's reaction to your HIV status – what do you think it will be if disclosed?

11. Future and recommendations

- How do you see the future for you and your baby?
- Any recommendations for professionals working with HIV positive mothers-to-be?

